

August 12, 2014

The Honorable Ron Wyden Chairman Committee on Finance 219 Dirksen Senate Office Building Washington, DC 20510

The Honorable Chuck Grassley Committee on Finance 219 Cannon House Office Building Washington, DC 20510

Dear Senators Wyden and Grassley:

In response to the request for information (RFI) regarding next steps on health care transparency published June 12, 2014, eHealth Initiative (eHI) is pleased to submit these comments and recommendations that addresses the need to enhance the availability and utility of health care data, while maintaining and strictly protecting patient privacy and the quality of care delivered across the healthcare system.

eHI is an independent, non-profit, multi-stakeholder organization. Our mission is to drive improvements in the quality, safety and efficiency of healthcare through information and information technology (IT). eHI advocates for the use of Health IT that is practical, sustainable and meets stakeholder needs, particularly those of patients. Since 2004, eHI has tracked the progress of organizations and initiatives working in health information exchange (HIE) across the country. eHI and its membership support Health IT adoption, implementation, and use of Health IT efforts through advocacy, research, and educational activities. The comments below were developed through our multi-stakeholder consensus process.

From its inception, eHI has emphasized the importance of Health IT, data, and HIE in achieving the goal of a healthcare system that improves the delivery, management and cost of care, and that supports development of therapies, tools, and services for ongoing improvements in the healthcare of patients and populations. Today's health system redesign initiatives underscore the need to accelerate the availability and use of HIE to ensure the availability of health data when and where it is needed. To that end, it is critical for patients, providers, hospitals and other industry stakeholders to have the ability to access and share patient information for care delivery and other secondary uses that inform their individual care but also future health care needs.

### 1. What data sources should be made more broadly available?

Clinical health information must be made more readily available not only to providers at the point of care, but to patients, their families, and other designated caregivers. Giving consumers the ability to access and contribute to their own health information is foundational to enhancing patient engagement and optimizing health outcomes. While patients see the value in easy, online access to their own health information, they also need to be informed of these new avenues to access it. Consumer engagement, partnering with providers and education efforts, will be necessary to fully realize the potential of patient access and use of their electronic health information.

Increasing the availability of mobile, medical device patient data sources for integration into the clinical health record will further enrich the data available for patients and clinicians to monitor care outside traditional settings of care. In doing so, however, consumers must be educated that the privacy protections generally associated with medical information do not apply to entities not covered by the Health Insurance Portability and Accountability Act (HIPAA). Only health care providers, payers, and clearinghouses that support the processing claims are held to the stringent privacy protections in HIPAA.

#### 2. How, in what form, and for what purposes should this data be conveyed?

Patients' health information should be provided and shared in a way that is easily understood and accessible to the recipient, is consistent with their preferences, and applicable privacy and security policies and regulations. Such data, including patients' administrative, lab, and clinical information should be shared in such a way to support and further improve health outcomes throughout the continuum of care. Consistent with patient consent and applicable privacy and security requirements, health care data should also be used for secondary data uses that enable research, population health, quality measurement, patient safety improvement initiatives, cost control initiatives, and other efforts where the goals are to maximize the rich data available to achieve improved health outcomes for all patient populations.

Continued development efforts and focus on defining data standards and deployment of these standards within Health IT will further enable the use of data. In addition, the adoption of new technologies such as Natural Language Processing (NLP) will increase the depth of usable data for health advancements.

# 3. What reforms would help reduce the unnecessary fragmentation of health care data? What reforms would improve the accessibility and usability of health care data for consumers, payers, and providers?

From a care delivery and data analytics perspective, continued focus must be placed upon identifying, prioritizing, and standardizing common data elements used in Health IT to reduce fragmentation in patients' health information and the ability to exchange this data. Such common data elements, with standardize definitions, have been an important part of work conducted by the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Medicare & Medicaid Services (CMS) in the electronic health record (EHR) incentive program as well as standards development organizations. Standardized data elements will further enable the ability to access, use and exchange health information.

Continued work and progress on standards, technologies and infrastructure for HIE and interoperability, including tools and standards to query for needed data, will ensure that data are available in a timely manner for clinical care, management of populations, analytics, patient access, and transparency. Bringing all these initiatives together, there is a need to develop and widely disseminate tools, resources, and guides to support healthcare organizations that collect and share data to inform and explain for patients' understanding, support clinical care, and meet reporting requirements.

The HIPAA privacy and security rules, enhanced through HITECH, provide a rigorous set of protections to be followed by HIPAA-covered entities and their business associates. More work, however, must be accomplished to achieve alignment among policies, business rules, and technological developments to support the exchange of health data across multiple entities and by HIE organizations. One consideration is an opportunity to leverage the testing and certification programs through ONC to validate and ensure adherence to meeting these requirements.

## 4. What barriers stand in the way of stakeholders using existing data sources more effectively and what reforms should be made to overcome those barriers?

#### Interoperability as an Essential Building Block

Continued implementation of existing and emerging standards for interoperability and data exchange is essential. Stage 2 of the EHR Incentive Program and associated EHR certification criteria have positioned us to move ahead, with greater access to data by clinicians, health care organizations, and patients. We have been learning that the roll-out of this stage has been more challenging than expected, because of very tight regulatory timeframes and other challenges faced by the industry. There is a great opportunity to solidify and then build on this progress as Stage 2 implementation continues and as we look to Stage 3, but it is essential that providers and vendors have sufficient time and flexibility to develop, implement, and test the technology needed to meet standards and certification, as well as reporting requirements.

Overall, continued emphasis should be placed upon building the infrastructure and tools to achieve interoperability among Health IT systems and applications to sustain seamless data exchange. At the same time, beyond technical issues and capabilities, the more challenging aspects of developing interoperable systems are the infrastructure for exchange outside of EHRs, the needed business cases for exchange, and the clinical and business processes surrounding the health information capture, use, and exchange for patient care. To leverage data sources more effectively, it is essential to design Health IT and HIE processes and supporting applications to collect data at all points of care as part of the normal workflow in a way that enables utilization for multiple purposes, such as healthcare quality improvement, care management, billing, decision support, performance data reporting, and research and population health initiatives, including disparities reduction efforts.

We believe that an increased focus on value-based payment, care integration, accountable care and most broadly, a focus on caring for populations will drive greater demand for true data access and exchange. We encourage Congress, and by extension the Administration, to place its emphasis on the desired quality of care or other specific outcomes desired and enable industry stakeholders to work together and discover what works best to achieve the stated goals without a prescriptive approach to how we should accomplish the goals.

#### Patient Identification and Matching

The ability to accurately identify and match patients within and among Health IT systems continues to serve as an obstacle as more and more patients' health records become electronic. This also creates a potential patient safety issue whereby duplicate records are unknowingly created thus records may not provide a full representation of a patient's clinical history or patients are incorrectly matched with another patient causing a patient "overlay" with each other. We believe placing attention on this issue is critical and ONC has begun efforts to address the challenges associated with patient identification and matching. The challenges create a severe impact on a provider's ability to treat patients across the care continuum. We encourage Congress, and by extension the Administration, to place emphasis on resources needed to reduce barriers and improve the ability to accurately identify and match patients.

#### Leverage the use of Standards

eHI recommends support for the development and use of standards in a manner that advances seamless data exchange. In general, many of the needed standards are available but others are now entering or on the midst of refinement, testing, and pilot usage. We note, however, that standards use requires considerable planning to ensure adequate testing of systems, education, and training for successful adoption and real interoperability. The use of data and technical standards will only be achieved if implementation steps are clear, timelines are adequate, and vendors and providers have the needed time and

incentives to implement mature standards into technology and operations. We urge accomplishment of this goal within a public-private framework.

#### Prevent Additional Burden and Leverage Existing Programs and Policies

The Department of Health and Human Services (HHS) has several diverse programs in place to facilitate the acceleration of health information exchange and improved interoperability efforts for the exchange and use of health care data. Health IT and HIEs continue to enter the market and evolve to meet the needs of providers and patients and we believe that this process should progress and mature without undue regulatory burden that would inhibit further development. eHI recommends considering approaches that utilize public-private partnerships that complements and aligns with the federal regulatory processes.

#### Conclusion

eHI appreciates the opportunity to comment on the RFI regarding next steps on health care transparency. Through Congress' continued engagement and outreach with Health IT stakeholders to inform, develop and mature the adoption, implementation, and use of technology, we anticipate continued improvements with EHR interoperability and exchange of health information. This would also include the improvement of quality measurement initiatives, program flexibility, patient engagement and evaluation, and alignment of technology with policy to advance high quality patient care.

We look forward to providing further information in support of your efforts. If you have any questions, please contact me at <a href="mailto:lengths.covich@ehealthinitiative.org">lengths.covich@ehealthinitiative.org</a>.

Sincerely,

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eHealth Initiative