eHEALTH INITIATIVE 2020 ROADMAP

Part 1: National Priorities, Goals and Areas for Consensus

eHealth Initiative
818 Connecticut Avenue, NW, Suite 500
Washington, DC
www.ehidc.org @ehealthdc

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INTRODUCTION AND MESSAGE FROM THE CEO

Interoperability issues continue to hound the healthcare industry. Impatience is growing. Consumers and providers see technology work in other areas- banking, travel, service industries and don't understand why healthcare lags behind. Over the last two decades, many groups have been working on interoperability issues. We have also seen government action---the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act and the Affordable Care Act (ACA) several years ago. A tremendous amount of money, time and resources has been invested into health information technology efforts. Despite all this time and money, many healthcare leaders question the direction in which the public and private sectors are currently heading and raising concerns about the slow pace of improving the care quality and achieving cost reductions. eHealth Initiative's *2020 Roadmap* was born out of those concerns.

As we look ahead to the next five years, it is critical to reexamine recent policy, innovation and technology efforts and identify the best path forward towards health system delivery transformation. The *2020 Roadmap* is a public-private collaborative, creating a shared vision of the strategies, policies and actions that are required to transform our healthcare system by the year 2020. In collaboration with a wide array of industry thought leaders, organizations and federal agencies, eHealth Initiative is producing a series of recommendations for key federal policymakers and the private sector. The recommendations that follow are only the first in a series of releases.

If you are expecting to find a prescriptive list of answers to mindboggling interoperability dilemmas, you will be greatly disappointed. The *2020 Roadmap* is not a set of answers, but rather a framework for discussion about core technology issues. This document includes the first set of priorities goals and work to be conducted in three focus areas: ***business and clinical motivators; interoperability; and data access and use***. This initial release contains the following:

Our Shared Vision. *2020 Roadmap* participants share a unique vision to transform care delivery with patient-centric care by 2020. In 2020, eHealth Initiative members envision high quality, patient-centered care that reflects a coordinated and collaborative approach between stakeholders. A specific vision was developed for each of the three focus areas.

Strategic Priorities. Esteemed leaders from both the public and private sector helped develop a set of priorities for each area. On September 4, 2014, eHealth Initiative convened 150 executives from across the healthcare ecosystem for three executive roundtable, additional input was sought from experts who contributed feedback through executive roundtables, surveys, webinars and written comments.

Short-Term, Mid-Term, Long-Term Goals. Each focus area includes a set of goals to focus efforts on in the short, mid and long-term. Some of these goals could be addressed by other organizations. Most of these goals require a multi-stakeholder response.

Consensus Groups. As expected, consensus was not reached in many areas and further work is needed. As part of the *2020 Roadmap*, we are creating a framework for the industry to have these discussions. In 2015, eHealth Initiative will launch a series of "Consensus Groups" to dive deeper into these complex areas. These areas are noted within each section.

Next Steps

The recommendations that follow are only the first in a series of releases. We expect to release findings related to several areas of consensus in the spring. Beginning in 2015, eHealth Initiative will convene groups to begin developing a national consensus around key areas identified in each section. As the only neutral, nonpartisan, multi-stakeholder coalition dedicated to improving the quality, safety and efficiency of healthcare through information technology, eHealth Initiative is in a unique position to spearhead this effort. eHealth Initiative represents ALL of the sectors in healthcare: doctors, patients, payers, vendors, hospitals, labs, pharmacies, pharmaceuticals and many others.

eHealth Initiative members will lead many of the activities associated with *2020 Roadmap*, but information gathering opportunities such as surveys, events and roundtables will be open to the public. In addition, we know that many other organizations have efforts which dovetail with much of this work. eHealth Initiative is seeking as much feedback as possible. If your organization is interested in contributing to the roadmap, we want to hear from you.

Role of the Private Sector

There are many priorities, goals and areas of discussion addressed in this release of the *2020 Roadmap*. While different stakeholders and groups did not all share the same agenda or concerns, there was a clear underlying theme. The most prominent finding that while the government has always been a part of the conversation and engine to move things forward, the private sector needs to play a lead and growing role.

We are heading into a world where health care data needs to be exchanged, shared and analyzed- not simply pushed from place to place. Similarly, we are developing a *2020 Roadmap* that requires sharing, analysis and above all collaboration.

To be continued…

Jennifer Covich Bordenick
Chief Executive Officer
eHealth Initiative

ABOUT THE ROADMAP

The primary objective of the *2020 Roadmap* is to craft a multi-stakeholder solution to enable coordinated efforts by public and private sector organizations to transform care delivery through data exchange and health information technology (health IT). The *2020 Roadmap* focuses on the following areas:

- Business and Clinical Motivators
- Interoperability
- Data Access and Use

Purpose of 2020 Roadmap

During eHealth Initiative's first decade, the collective efforts of many stakeholders have improved healthcare through increased use of technology and data. Since the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act and the Affordable Care Act (ACA), a tremendous amount of money, time and resources has been invested into optimizing the healthcare system in the U.S. However, many stakeholder groups are questioning the direction in which the public and private sectors are currently heading and raising concerns about the slow pace of improving the quality of care and achieving cost reductions. As we look ahead to the next five years, it is critical to reexamine recent policy, innovation and technology efforts and identify the best path forward towards health system delivery transformation.

eHealth Initiative Leadership of *2020 Roadmap*

As the only neutral non-profit, multi-stakeholder coalition dedicated to how health information technology can improve the quality, safety and efficiency of healthcare, eHealth Initiative is in a unique position to spearhead this effort. The *2020 Roadmap* is a multi-stakeholder collaborative intended to support current leadership efforts, including those underway within the Administration, Congress, and private sector organizations engaged in health IT and healthcare. eHealth Initiative represents all of the sectors in healthcare. Similar to previous landmark initiatives, including the *Blueprint: Building Consensus for Common Action* (2007) and *National Progress Report on eHealth* (2010), eHealth Initiative will develop a shared vision and set of principles, strategies and actions for improving healthcare through information and technology in today's complex economic and political climate.

To date, *2020 Roadmap* workgroups have been chaired by Sam Ho, MD, Executive Vice President & Chief Medical Officer, United Healthcare, Chair of eHealth Initiative Board of Directors; John Glaser, PhD, Chief Executive Officer, Health Services, Siemens; Daniel Garrett, Principal & HIT Practice Leader, PwC; Richard Ratliff, Global Managing Director, Connected Health IT Solutions, Accenture; Christopher Ross, Chief Information Officer, Mayo Clinic; and Micky Tripathi, PhD, President & CEO, Massachusetts eHealth Collaborative, Chair of HITPC Interoperability and Health Information Exchange Workgroup; and many other prominent figures.

Who Developed the Priorities?

Initial *2020 Roadmap* recommendations were developed through a series of ongoing eHealth Initiative webinars, executive roundtables and events with key constituencies. On September 4, 2014, eHealth Initiative convened 150 executives from across the healthcare ecosystem for three executive roundtables. Esteemed leaders from both the public and private sectors were in attendance. A complete list of participants is included at the end of this document. In addition, over 200 organizations and hundreds of individuals participated in workgroups, surveys, webinars and other activities.

How Does this Effort Relate to the Federal Government's Interoperability Roadmap?

The Office of the National Coordinator for Health Information Technology (ONC), under the U.S. Department of Health and Human Services (HHS) is in the process of developing a 10-year interoperability roadmap with direction for federal agencies. It is due to be released for public comment in January 2015 after vetting from the Health IT Policy and Standards committees. eHealth Initiative is developing a much broader plan that addresses business and clinical motivators, interoperability and data access and use and delves deep into needed private sector transformation. The *2020 Roadmap* will include recommendations for healthcare providers, payers and other groups in the private sector. eHealth Initiative and ONC are working closely together to ensure the work of both organizations is complementary. There is overlap in thought leadership between the two efforts to ensure they are synchronized. In 2015, eHealth Initiative and ONC will work together to identify effective ways to marry components of the two complementary efforts.

What is in this Document?

This document includes the first set of priorities and recommendations for the three focus areas: business and clinical motivators; interoperability; and data access and use. The priorities were developed by executives who contributed feedback through executive roundtables, webinars and written comments. Discussion around each focus area was led by an expert representative from among the eHealth Initiative membership. Differences in the way priorities are displayed below reflect the different approaches each leader took to their particular focus area. Each focus area also includes a set of short-term goals for collaborative action. As expected, consensus was not reached in many areas and further work is needed. In 2015, eHealth Initiative will launch a series of "Consensus Groups" to dive deeper into these complex areas. The objectives of these groups are noted within each section.

What is Next?

Over the coming months, eHealth Initiative will continue to work with a wide array of industry thought leaders, organizations and key federal agencies. eHealth Initiative will convene national experts from government organizations such as the Food and Drug Administration (FDA), Centers for Medicare & Medicaid Services (CMS) and Office of the National Coordinator for Health Information Technology (ONC), as well as key associations, patient advocacy leaders and many other groups. Executives and decision-makers who directly impact the market are invited to participate. eHealth Initiative members will take a leadership role in developing the *2020 Roadmap*, while information gathering opportunities such as surveys, events and roundtables will be open to the public. eHealth Initiative is seeking as much feedback as possible.

OUR SHARED VISION TO TRANSFORM CARE DELIVERY WITH PATIENT-CENTRIC CARE BY 2020

The healthcare landscape has evolved rapidly over the past few years. With the evolution of technology, the method and manner of how healthcare is delivered has changed. Patient files in folders have been replaced with electronic health records (EHRs) on laptops or tablets. The integration of technology into the changing models of care has brought in a new host issues for consideration. With eHealth Initiative's unique position as a neutral entity that brings together representatives across the entire healthcare continuum, the *2020 Roadmap* was born with the intention to harmonize the new technologies and models of care in a way that brings about meaningful change that improves population health, increases patient-consumer experiences and lowers costs.

2020 Roadmap participants share a unique vision to transform care delivery with patient-centric care by 2020. Participants are working through this project towards a more cohesive vision of health and healthcare that:

- Reflects a coordinated and collaborative approach;
- Includes timely and relevant patient-focused information and health IT tools available to all;
- Supports high quality and efficient patient care through the use of interoperable health IT and secure data exchange between and across all relevant stakeholders.

Participants focused on three areas: Business and Clinical Motivators, Interoperability and Data Access and Use for several months. During these meetings, each group developed a specific vision for each of the three focus areas which are outlined below.

Vision for Aligned Business and Clinical Motivators

- Meaningful incentives promote patient-focused care, so that patient-consumers are fully engaged in their own healthcare, supported by information and tools that enable informed patient-consumer action and decision making, working hand-in-hand with healthcare providers.
- Provider payment and other incentives reward high quality and efficient care delivery and improved care outcomes.
- Incentives for health information technology should evolve from a "feature function" focus to a focus on patient-consumer care outcomes and should address the entire care continuum.
- Financing and incentive programs should take a measured approach to health IT implementation that enables delivery system transformation at an effective and feasible pace.
- Financing and incentive programs involving health IT should ensure that data and data exchange are standardized across care settings.
- A balance is needed between regulatory oversight and innovation, which allows sufficient space and flexibility for entrepreneurial innovation while ensuring that important patient-consumer and healthcare provider needs are addressed.

Vision for Interoperable Systems

- We envision a high-performing healthcare system centered on the patient, where all those engaged in patient care are linked together in a secure and interoperable environment.
- The flow of clinical health information directly enables the most comprehensive, patient-centered, safe, efficient, effective, timely and equitable delivery of care where and when it is needed most – at the point of care.
- Information is utilized to enhance healthcare experiences for individuals, eliminate health disparities, measure and improve healthcare quality and value, expand knowledge about effective improvements in care delivery and access, support public health surveillance and assist researchers

in developing evidence-based advances in areas such as diagnostic testing, illness and injury treatment and disease prevention.

Vision for Appropriate Data Access and Use

- In a fully-enabled electronic information environment designed to engage consumers, transform care delivery and improve population health, consumers have confidence that their personal health information is private, secure and used with their consent in appropriate, beneficial ways.
- Technological developments are adopted in harmony with policies and business rules that foster trust and transparency.
- Organizations that store, transmit or use personal health information have internal policies and procedures in place that protect the integrity, security and confidentiality of information.
- Policies and procedures are monitored for compliance and consumers are informed of existing remedies available to them if they are adversely affected by a breach of security.
- Consumers trust and rely upon the secure sharing of healthcare information as a critical component of high quality, safe and efficient healthcare.

FOCUS AREA 1: BUSINESS AND CLINICAL MOTIVATORS

Background

Substantial investments have been made into health IT with the intent to create a more efficient and integrated healthcare delivery system that increases positive outcomes and lowers costs across the healthcare ecosystem. However, adoption and meaningful utilization on both the patient-consumer and healthcare provider sides has been slow due to a variety of reasons. This work is focused on advancing efforts to create a sustainable health IT ecosystem by tackling the systemic issues, within private sector control, that have been hindering adoption and meaningful utilization, while identifying priorities that can be recommended for federal partners to take action on.

Our Vision for Aligned Business and Clinical Motivators

- Meaningful incentives promote patient-focused care, so that patients are fully engaged in their own healthcare, supported by information and tools that enable informed consumer action and decision making, working hand-in-hand with healthcare providers.
- Provider payment and other incentives reward high quality and efficient care delivery and improved care outcomes.
- Incentives for health information technology should evolve from a "feature function" focus to a focus on patient care outcomes and should address the entire care continuum.
- Financing and incentive programs should take a measured approach to health IT implementation that enables delivery system transformation at an effective and feasible pace.
- Financing and incentive programs involving health IT should ensure that data and data exchange are standardized across care settings.
- A balance is needed between regulatory oversight and innovation, which allows sufficient space and flexibility for entrepreneurial innovation while ensuring that important patient and provider needs are addressed.

Strategic Priorities Identified in July

1. **Facilitate advances in consumer-oriented health IT** and information sources that enhance a patient's ability to manage their health and participate as a team member in their care delivery.
2. **Leverage market innovations in developing new care models** which involve direct and indirect incentives to adopt and use health IT**.**
3. **Extend incentives across the continuum** to encompass all care settings and providers**.**
4. **Evaluate the effectiveness of current tactical approaches to implementing incentives** to ensure that incentives are resulting in desired outcomes and not just "compliance."
5. **Reward providers for outcomes.** Allow for flexibility in the component tools providers can use alongside the EHR as long as improved outcomes are achieved.
6. **Leverage industry stakeholder efforts to create additional, complementary incentives.** Explore and demonstrate incentive innovations such as are being developed by medical societies and boards that focus on making the needed fundamental, evidence-based changes to healthcare delivery.
7. **Support provider efforts to leverage health IT to transform the care they deliver by providing process and care delivery transformation support**. Care improvement requires changes in care and operational processes and roles; ensure that providers have the skills and tools needed to leverage their health IT.
8. **Focus technology and standards incentives on data exchange, a rationalized set of quality measures and privacy and security provisions** that are clear, comprehensive and proven to be effective.

Federal Policy Changes

1. **Focus federal policy on advancing interoperability** to ensure that all core data elements for clinical and billing information can be exchanged in a manner that supports care delivery, finance, research and public health needs.
2. **Identify and promote consistent and efficient methods for electronic reporting** of quality and health status measures.
3. **Lower the burden associated with complex quality measurement programs** (Meaningful Use, PQRS, etc…) to focus on truly critical measures.
4. **Require compliance with ICD-10 by October 2015.**
5. **Assess the tactics of the current Meaningful Use (MU) incentive program.** Extend period of time between MU2 and MU3; shift from feature function to outcome; allow time for providers to implement HIT and leverage the technology to begin to transform care delivery.
6. **Promote consistency in policy and enforcement.** Create a coordinated effort that ensures that all HIT regulations are assessed for consistency across regulations and that the aggregate regulatory demand is not over burdensome.
7. **Provide incentives across the continuum.**
8. **Broaden and diversify the Meaningful Use incentive program**. Leverage other innovative incentive models created by medical societies, boards and other groups.
9. **Broaden and diversify the incentive programs to leverage innovative market approaches** and support the ability of providers to leverage technology to improve care.

Additional Priorities Collected on September 4

- Federal policy should focus on the standards and the minimum data requirements necessary to improve individual and population health and manage healthcare costs while promoting adaptability and innovation.
- Standardization of measures for quality, cost efficiency, patient satisfaction and value.
- Incentives should be designed to help reduce inappropriate variation and reward innovation in population health management and cost control.
- Outcome measures should migrate from point-of-care and processes to population health and the entire care continuum.
- Share the value of integrating health IT into workflow with both patient-consumers and healthcare providers.
- Capitalize on the experience and collaboration of the public and private sectors to create a social laboratory for all.

Short-Term Goals

1. **Utilize an expert panel of patient-consumers, healthcare providers, payers and vendors to identify key lessons and best practices in healthcare provider and payer organizations where incentives are effectively engaging patient-consumers.** Identify private sector best practices, as well as innovation opportunities enabled by the federal government through waiver programs and Center for Medicare and Medicaid Innovation (CMMI). Focus on multi-stakeholder partnerships in key projects that include patient-consumers, healthcare providers, public and private payers and vendors to ensure closed loop accountability.
2. **Identify standards and the minimum data requirements necessary to improve population health and manage healthcare costs while promoting adaptability and innovation.** Identification of programs should also recognize differences in healthcare providers, types of clinical information systems (EHR vs. radiology vs. laboratory information system, etc.) and expected relationships with patient-consumers. Draft proposed policy recommendations on minimum data requirements with collaboration from ONC.
3. **Work with patient-consumers, healthcare providers, payers and vendors on a toolkit of existing useful resources available** to assist in their efforts to integrate health IT into daily workflow and processes.

4. **Outline an education campaign, highlighting best practices to assist patient-consumers and healthcare providers in effective ways to integrate health IT into daily workflow and provide guidelines for data provenance for all sources of data**, including patient-consumer generated data. Develop timeline and specific action steps for member organizations and government agencies to disseminate information.
5. **Reaffirm inclusion of patient-consumers and families in health IT recommendations**, by convening a group of patient-consumer experts to harmonize efforts around patient-consumer tools and mobile apps to better engage and empower patient-consumers to take a more active role in their healthcare management.

Mid-Term Goals

1. **Based on best practices**, recommend new regulations, guidelines and/or incentives to state and federal agencies that relate to the adoption and meaningful utilization of health IT.
2. **Advance standards needed to support new clinical and administrative workflows** using public-private collaboration. Target medical colleges and other educational facilities to advance the use of standards to their students and members and gather their feedback.
3. **Identify other goals and objectives** as the marketplace evolves.

Long-Term Goals

1. **Monitor innovation and strategies** in the private sector.
2. **Monitor federal regulations and incentives**, including new grants that relate to the adoption and meaningful utilization of health IT.
3. **Identify other goals and objectives** as the marketplace evolves.

Consensus Groups for Business and Clinical Motivators

As expected, consensus was not reached in many areas and further work is needed. As part of the *2020 Roadmap*, we are creating a framework for the industry to have these discussions. In 2015, eHealth Initiative will launch a series of "Consensus Groups" to dive deeper into these complex areas and tackle the goals listed above.

- **Best Practices Subgroup:** This group will identify best practices in the private sector in payer, provider and patient-consumer organizations.
- **Minimum Requirements Subgroup:** This group will work to identify standards and the minimum data requirements necessary to improve population health and manage healthcare costs while promoting adaptability and innovation.
- **Resource Development Subgroup:** This group will identify existing resources and opportunities for new tools to ease the integration of health IT into the daily lives of patient-consumers and healthcare providers.
- **Education Subgroup:** This group will work to identify the best ways to educate patient-consumers and healthcare providers on best practices and existing resources—helping spread the word about successful efforts.
- **Tracking Incentives Subgroup:** This will be an ongoing group that will focus on maintaining a catalogue of public and private sector incentives that promote adoption and utilization of health IT and can be dispersed to eHI members via eHI's website.

FOCUS AREA 2: INTEROPERABILITY

VISION & PRINCIPLES

Background

Interoperability involves information and technology systems working together within and across organizational boundaries to advance effective delivery of healthcare for individuals and communities. Today, interoperability is not only a common buzzword, but a concept deeply embedded in Meaningful Use efforts and national-level initiatives in both the developed and developing world. Consensus continues to grow around commonly accepted interoperability rules and standards for healthcare information systems, but many questions remain about how to achieve true interoperability in the U.S. and across the world. Collaborative, capacity, technical, training, legal, policy and other interoperability barriers are well recognized and increasingly being addressed on a global scale.

The *2020 Roadmap* Interoperability Workgroup, comprised of over 60 well-recognized experts, is examining these issues and discussing how to better incentivize and attain interoperability across communities, while facilitating coordination and cooperation among key stakeholders.

Vision for Interoperable Systems

- We envision a high-performing healthcare system centered around the patient, where all those engaged in patient care are linked together in a secure and interoperable environment.
- The flow of clinical health information directly enables the most comprehensive, patient-centered, safe, efficient, effective, timely and equitable delivery of care where and when it is needed most – whether in-person at the point of care or remotely.
- Information is utilized to enhance healthcare experiences for individuals, eliminate health disparities, empower care management and self monitoring, measure and improve healthcare quality and value, expand knowledge about effective improvements in care delivery and access, support public health surveillance and assist researchers in developing evidence-based advances in areas such as diagnostic testing, illness and injury treatment and disease prevention.

Principles

eHI has developed a set of interoperability principles that remain as appropriate today as they were when originally articulated in the *eHealth Initiative Blueprint: Building Consensus for Common Action* (2007) and the *National Progress Report on eHealth* (2010). The following five core principles for health information exchange were derived from these reports and are affirmed by the *2020 Roadmap* as important considerations when developing interoperable systems:

1. **Health IT interoperability is essential to care improvement.** Efficient and high quality patient-centered care will require secure, interoperable health IT systems that facilitate collaboration and coordination among providers in different clinical settings.
2. **There are compound benefits from broader and deeper interoperability.** The benefits of health information exchange for patient-centered care will be compounded as interoperability diffuses across the care continuum.
3. **By necessity, interoperability will develop at different rates and in different ways across the market.** Both interoperability and healthcare delivery overall are highly complex and multi-layered. Therefore, health information exchange will mature incrementally and non-uniformly across disparate communities.
4. **Approaches to health information exchange must be flexible to accommodate varying market conditions.** The heterogeneous and dynamic care delivery market requires diverse

approaches to sharing healthcare data, which consequently must be founded on open architectures and consensus-based standards and policies.

5. **Interoperability solutions will not be valuable if they are not usable.** Health information exchange should assure genuine interoperability by focusing on policies, processes and technology that are highly usable by patients and clinicians.

The Interoperability Workgroup added the following principles to those above as part of the *2020 Roadmap* process:

6. **Both the government and private sector have critical roles to play in interoperability.** The private sector needs to be heavily engaged in solving interoperability challenges, particularly in the area of standards development and testing to ensure that data follows the provider and patient for clinical and health purposes. The government needs to continue to be active in providing guidance and benchmarks that raise the bar in almost all building block areas of healthcare. Standards development should be a primarily private sector effort managed by Standards Development Organizations (SDO) and other related organizations. Key government agencies should participate in the SDO process as they historically have, rather than lead the effort.
7. **Nationwide interoperability goals should be defined in terms of the interoperability functions that should be universally available**. This includes automation of key exchange processes.
8. **Patients' control of their data can help to overcome some existing barriers to interoperability**. This includes privacy issues.

Strategic Priorities Identified in July and September 2014

1. **Establish a usable and efficient infrastructure for exchange across the spectrum of health care.**
    a. Promote constrained standards that allow for efficient connections between all networks that require exchange services.
    b. Encourage all HISPs to enable connections will all other HISPs by making their provider directories freely available to anyone wanting to exchange data.

2. **Develop a public education campaign to encourage increased provider and patient understanding of a nationwide interoperability ecosystem**.
    a. Needs to be realistic and achievable

3. **Encourage the market to adopt standards and open architecture**
    a. Leverage open architecture (e.g. public APIs) and consensus-based standards to support core medical functions.
    b. Encourage development of a portfolio of data exchange capabilities focused on specific use cases and emphasizing actionable, context-specific information available at the point of care.
        i. Include push- and query-based transactions to support continuity-of-care
        ii. Facilitate data aggregation, consumption and reporting, including for tools for research and population health in the longer term
        iii. Recognize that one exchange model cannot meet the needs of the entire healthcare system
    c. Facilitate more rapid maturation and alignment of Direct-based capabilities and increase awareness and education about its availability, utility and usability. Emphasize testing and open exchange across all Direct platforms.
    d. Use collaborative and consensus-based approaches to motivate the market's use of standards for query capability

        i. Do not penalize or discourage use of existing approaches that perform functionally (e.g., IHE profiles, HL7 2.x)
        ii. Facilitate adoption and maturation of approaches reflecting cross-industry IT trends (e.g., currently REST, FHIR, OAUTH, etc.)
    e. Promulgate standards and create rigorous, publicly available test harnesses that can be used during development, for certification, and during/after implementation. Testing should include creation, transmission and consumption of data to be exchanged.
    f. Continue certifying health IT systems, but shift the focus of certification to be market-based and oriented around priority capabilities such as interoperability, safety and security
    g. Promote continued growth in vendor-neutral apps and APIs for data access and aggregation.
    h. Promote the development and use of patient-controlled applications that allow patients to aggregate, access, use, and contribute to their health records.

4. **Identify the needs of post-acute care and behavioral health providers (as well as others not participating in Meaningful Use)** to determine how they can also meaningfully exchange healthcare data.

5. **ONC and CMS need to help define the elements of a nationwide interoperability ecosystem and the way data is exchanged.**
    a. Unlikely to be a single true “system” due to the highly fragmented nature of the industry
    b. Rather, should focus on defining key elements of an ecosystem (e.g., constrained standards, implementation guides, exchanges networks, and mechanisms to uniquely identify patients and providers).
    c. When appropriate, the government should use its purchasing power, certification requirements and other levers of support to facilitate development of the interoperability ecosystem.
    d. Set expectations that interoperability can and will happen, but recognize that it takes a long time for elements to converge to make it happen.
    e. Federal government will likely need to be involved in creating consistently applied privacy and security rules that address challenges with variations across state lines.

6. **Focus on aligning existing regulatory approaches with non-regulatory approaches to influence creation of a health information exchange/interoperable healthcare ecosystem** (e.g. by convening stakeholders or educating on use of standards)
    a. Although the Meaningful Use program is a real and important tool, it is not a sufficient lever to entirely guide the creation of an interoperable healthcare ecosystem.
    b. Need to align and orchestrate Meaningful Use with other Federal government efforts, focusing on non-prescriptive higher-level incentives for HIE and interoperability, including:
        i. Purchasing of health IT systems (DoD, VA, IHS, other)
        ii. Creation of publicly accessible HIE infrastructure components (e.g., nationwide provider directory with required elements to identify exchanging partner)
        iii. NIH intramural and extramural research
        iv. FDA and pharmaceutical and medical device regulation
        v. CDC and public health surveillance work

7. **Align MU and interoperability plans with other regulatory and industry initiatives**
    a. Too many simultaneous, disparate requirements
    b. Align privacy regulations and reporting requirements across programs and across the care continuum

c. Address non-clinical interoperability and associated standards
d. Need to sequence these initiatives to acknowledge bandwidth and consider appropriate timelines for level of change that is anticipated.

Short-Term Goals

1. **Better define the costs and benefits of information sharing and interoperability** in the context of widespread data exchange and existing/emerging business drivers for sharing information (starting with meaningful use requirements, but also including ACOs, PCMHs, readmission penalties, etc.).
2. **Identify and prioritize needed interoperability use cases***,* champions and the private sector's role in driving development.
3. **Evaluate the existing infrastructure for exchanging health information** to determine gaps and inefficiencies.
4. **Compile resources** on state consent models and privacy laws to identify areas of commonality and discord.

Mid-Term Goals

1. **Specify the steps that must be taken to share information** to better understand what is working and where there are challenges. Steps may include achieving consensus on standards to identifying exchange partners, matching patient identities, establishing and connecting to a network, connecting across networks, and using data received from others within a provider system.
2. **Outline a public education campaign** around the value of interoperability.
3. **Examine tactical approaches to resolving state variation in privacy laws** as it relates to interoperability.
4. **Identify ways of aligning existing regulatory approaches with non-regulatory approaches** to influence creation of a health information exchange/interoperable healthcare ecosystem.

Long-Term Goals

1. **Drive industry-wide consensus** on how to measure and quantify current and future interoperability progress.
2. **Explore step-wise process to establish innovative private sector operational test processes, tools and harnesses**.
3. **Build consensus around what data elements should be universally available**. Regardless of where the patient is, what data is necessary to understand their medical needs? Which of these elements still need standard clinical definitions? How are these elements already incorporated into programs and levers for driving interoperability, and which need to be added? Recognize that many data elements are collected during patient care and primarily used to support that care, but may also be used for secondary purposes, as allowed under existing business, privacy, and legal constructs.
4. **Encourage development of a portfolio of data exchange capabilities focused on specific use cases** and emphasizing actionable, context-specific information available at the point of care.
5. **Facilitate more rapid maturation and alignment of Direct-based capabilities and increase awareness and education** about its availability, utility and usability. Emphasize testing and open exchange across all Direct platforms.

Consensus Groups for Interoperability

As expected, consensus was not reached in many areas and further work is needed. As part of the *2020 Roadmap*, we are creating a framework for the industry to have these discussions. In 2015, eHealth Initiative will launch a series of "Consensus Groups" to dive deeper into these complex areas and tackle the goals listed above.

- **Private Sector Innovation Subgroup**: This subgroup will focus on initiating needed private sector activities to move interoperability forward in alignment with the eHI Interoperability Workgroup's goals.
- **Policy and Communications Influence Subgroup:** This subgroup will gather input from multiple stakeholder entities to develop detailed policy recommendations on interoperability and an accompanying advocacy and communications plan.
- **Patient and Provider Utility Subgroup:** This subgroup will highlight unmet interoperability needs for patients and providers in the current healthcare ecosystem and develop strategies for closing the gap.
- **Infrastructure Evaluation and Use Cases Subgroup:** This subgroup will produce issue briefs and industry reports that better define the costs and benefits of information sharing and interoperability, identify and prioritize needed interoperability use cases and evaluates the existing infrastructure for exchanging health information to determine gaps and inefficiencies.

FOCUS AREA 3: DATA ACCESS AND USE

Background

With nearly 6 in 10 hospitals using at least a basic electronic health record (EHR)[1], the growing ability to collect and share data offers a plethora of opportunities to improve the delivery and cost of healthcare. However, industry leaders have to overcome a number of organizational and process challenges preventing them from fully participating in proper data access and use. This work focuses on solving five key challenges facing today's healthcare information privacy and security officials – data security, appropriate data sharing, granular data control, data provenance, and data matching – to increase appropriate data access and use by patients and providers.

Vision for Appropriate Data Access and Use

- In a fully-enabled electronic information environment designed to engage consumers, transform care delivery and improve population health, consumers have confidence that their personal health information is private, secure and used with their consent in appropriate, beneficial ways.
- Technological developments are adopted in harmony with policies and business rules that foster trust and transparency.
- Organizations that store, transmit or use personal health information have internal policies and procedures in place that protect the integrity, security and confidentiality of information.
- Policies and procedures are monitored for compliance and consumers are informed of existing remedies available to them if they are adversely affected by a breach of security.
- Consumers trust and rely upon the secure sharing of healthcare information as a critical component of high quality, safe and efficient healthcare.

Strategic Priorities

1. **Emphasizing Data Security to Leadership** – Given growing rates of healthcare data breaches, organization leaders must understand how to take effective security measures to prevent and manage breaches. Privacy and security officials need to be armed with effective ways to represent the importance of data security and explain what they are doing to ensure security throughout an organization, from the point of care to senior leadership.
2. **Appropriate Data Sharing** – Individual organizations struggle to manage the diversity of patient information they are obligated to share with others (e.g. government departments, public health entities, vendors, etc.). In addition, privacy and security officials frequently receive requests to share data with other 3rd parties for non-clinical purposes. However, decisions around who to share data with and for what purposes are typically made on an individual organization level. As interoperability matures, these decisions will have ramifications for patients and other organizations, even though that decision remains out of their control. The industry needs to develop consensus on policies for obtaining consent, sharing data across organizations, and using protected health information while maintaining the privacy and security of that information.
3. **Granular Data Control** – Given the importance of data access to patient engagement, the healthcare industry will need to develop a common framework for determining the appropriate level of data management capabilities for patients. For example, to what extent should patients be able to control which data is shared with their providers? The framework will need to balance the opportunities for patient choice with the capability of providers and technology to realistically allow for different levels of consent. With respect to granular data control, it should assess the strengths and weaknesses of today's "all or nothing approach" in which patients can either share all of their data or must choose not participate in information exchange.
4. **Data Provenance** – When healthcare organizations share data with third-parties, they often forgo control over what is done with the data. Currently, electronic health records collect metadata on

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[1] ONC Data Brief No. 16; May 2014

the origins of data elements, which can be used to track a dataset. However, this information is easily and frequently removed from datasets being used by third-parties. The industry must develop controls to prevent the unknown proliferation of data through a standard process for keeping the origins of data points known when sharing personal health information.

5. **Accurate Data Matching** - Interoperability and health information exchange are contingent on properly identifying patients and matching them with the correct data. The industry needs a better understanding of the different data matching practices of organizations in order to work towards developing the best process to guarantee accurate patient matches and promote interoperability.

Short-Term Goals

1. **Utilize a collaborative process to produce best practice resources and guides** for chief privacy and security officials to emphasize the importance of data security at all levels within an organization, including the point of care and executive leadership.
2. **Develop an industry report on the costs and benefits of giving patients granular consent to control how their data is shared.** The report should cover the strengths and weakness of the current "all or nothing" approach while considering the existing technical capabilities of current tools for information sharing (e.g. the Consolidated Clinical Data Architecture (C-CDA)) and whether they can support more granular consent controls.
3. **Work with providers, clinicians, payers, and vendors to develop an issue brief describing current best practices in patient matching efforts**, including efforts undertaken by the federal government.
4. **Collect and review industry accreditation, certification, and testing tools and processes** to determine how they are leveraging the criteria and standards work that has been developed and continues to evolve.
5. **Develop a report that explores the current best practices for sharing data with 3rd parties** and build consensus around appropriate secondary data uses.
6. **Evaluate the frameworks and guidance published by federal agencies from an industry perspective**. Provide stakeholders with information on how these publications affect their current activities.

Mid-Term Goals

1. **Work with industry leaders to create a standard *Data Breach Policy Guidebook* aimed at aligning Health Insurance Portability and Accountability Act (HIPAA) guidelines and existing best practices** to enable organizations to better protect patient health information, handle data breaches to minimize damage, and share lessons learned.
2. **Develop a *Trust Framework* for healthcare entities and 3rd parties to collaboratively** protect against the unintended proliferation of healthcare data during the process of data sharing.
3. **Disseminate accreditation and certification tools** to health IT adopters and utilizers for education purposes.

Long-Term Goals

1. **Develop national stakeholder support for the *Data Breach Policy Guidebook, Trust Framework,* and data security materials** and disseminate across eHI membership and other industry partners.

Consensus Groups for Data Access and Use

As expected, consensus was not reached in many areas and further work is needed. As part of the *2020 Roadmap*, we are creating a framework for the industry to have these discussions. In 2015, eHealth Initiative will launch a series of "Consensus Groups" to dive deeper into these complex areas and tackle the goals listed above.

- **Organizational Strategies Subgroup**: This subgroup will focus on the importance of initiating and maintaining a culture of security and commitment to data security. Deliverables include an organizational strategy guidance document for how CIOs, CISOs, CPOs should address data security within an organization.
- **Policy Influence Subgroup:** This subgroup will gather input from multiple stakeholder entities to develop an industry *Data Breach Policy Guidebook,* make recommendations and provide feedback on emerging federal policies and initiatives relating to data access and use.
- **Appropriate Data Sharing Subgroup:** This subgroup will develop a national *Trust Framework* to help the industry understand the appropriate use of data as it's shared.
- **Data Provenance Subgroup:** This subgroup will produce deliverables in the form of guidelines, issue briefs, and industry reports on data provenance. Deliverables include, but are not limited to developing methods for consistently representing, managing, and communicating privacy preferences and consent across the ecosystem.
- **Data Sharing Toolkit Subgroup:** This subgroup will produce deliverables in the form of guidelines, issue briefs, and industry reports on data sharing topics including granular data control and patient matching.

MOVING FORWARD

This document is the first in a series of releases, further work is currently underway. Areas where consensus is still needed were identified. The *2020 Roadmap* creates a framework for the industry to have these discussions. eHealth Initiative will launch a series of "Consensus Groups" to dive deeper into these complex areas. Beginning in 2015, eHealth Initiative will convene multi-stakeholder groups to begin developing a national consensus around key areas. We expect to release findings related to several areas of consensus in the spring.

There are many other efforts under development by government agencies and other associations. eHealth Initiative has invited numerous organizations to participate in the *2020 Roadmap*. The *2020 Roadmap* will help link and coordinate many of these efforts. Executives and decision-makers who can directly impact the market should participate in *2020 Roadmap* activities.

eHeeHealth Initiative and Office of the National Coordinator for Health Information Technology (ONC) will work closely to ensure the work of both organizations is complementary. In 2015, eHealth Initiative will identify effective ways to marry components of the two complementary efforts.

eHealth Initiative members will lead many of the activities associated with *2020 Roadmap*, but many information gathering opportunities such as surveys, events and roundtables will be open to the public. eHealth Initiative is seeking as much feedback as possible. If your organization is interested in participating in the roadmap, we want to hear from you.

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- Daniel Garrett, Principal & HIT Practice Leader, PwC
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SEPTEMBER 4 EXECUTIVE SUMMIT PARTICIPANTS

- Anne Adams, Emory Healthcare, Inc, Chief Compliance & Chief Privacy Officer
- NeelKamal Agarwal, PwC, Director, Health Industries
- Brian Ahier, Medicity, Director, Standards and Government Affairs
- Tim Alcorn, Johnson & Johnson
- Peter Alterman, SAFE-BioPharma Association, Chief Operating Officer
- Kristine Anderson, Booz Allen Hamilton, Senior Vice President
- Steve Aylward, Microsoft, General Manager for Commercial Health & Life Sciences (HLS)
- Linda Bailey-Woods, himagine solutions, Managing Director
- Michael Barr, NCQA, Executive Vice President
- Lee Barrett, EHNAC, Executive Director
- Deepak Bhatnagar, CareFirst BCBS, Planner - Lead Strategic Architecture
- Gina Bianco, Advances In Management (AIM), President & CEO
- Patricia Bickley, Updox, Chief Product Officer
- Chris Bradley, Mana Health, CEO
- Hans Buitendijk, Siemens
- Adam Bullian, QIP Solutions, Director
- Leigh Burchell, Allscripts, VP, Policy & Govt Affairs
- Steffani Burd, Ansec Group,
- Blair Butterfield, VitalHealth Software,
- Julie Cantor-Weinberg, College of American Pathologists, Director Economic-Regulatory Affairs
- Mary Ann Chaffee, Surescripts, SVP
- Imran Chaudhri, Imran Tech - PRESS,
- Krishnan Chellakarai, Gilead Sciences, Associate Director, IT Security & Privacy
- Nikolay Chernavsky, Amgen, Director of Information Security
- Lauren Choi, JD, Premier, Inc., Senior Director, Federal & International Affairs
- Gary Christensen, InterSystems, General Manager States, Public Sector
- Brian Cincera, Pfizer, Senior Director of Worldwide Technology Infrastructure
- Sarah Corley, NextGen Healthcare, Chief Medical Officer
- Linda Cramer, Healthcare Financing,
- Kelly Cronin, Office of the National Coordinator
- Monica Cunningham
- Bill Cushing, Blue Cross and Blue Shield of Massachusetts, Chief Information Officer
- Frances Dare, Accenture
- Anuj Desai, New York eHealth Collaborative (NYeC), Vice President, Market Development
- Karen DeSalvo, MD, MPH, MSc, U.S. Department of Health and Human Services, National Coordinator for Health Information Technology (ONC)
- Doug Dietzman, Great Lakes Health Connect, Executive Director
- Ayame Dinkler, U.S. Department of Health and Human Services, Special Assistant to the National Coordinator
- John Donnelly, HSX of Southeast Pennsylvania, Health IT Architect
- Paul Eddy, Walgreens, GVP, CIO
- Gai Elhanan, Halfpenny Technologies, Inc., CMIO
- Ty Faulkner, QIP Solutions, Professor of Health Technology Management
- Kim Fleurquin, Banner Health, Chief Risk Officer
- Ali Foti, National Partnership for Women & Families, Health IT Policy and Outreach Assistant
- Thomas Fritz, Inland Northwest Health Services, Chief Executive Officer
- Jonathan Fuchs, SRG Technology,
- Barbara Gabriel, PwC, Lead Editor
- Daniel Garrett, PwC, Principal and Health Information Technology Practice Leader
- Hugh Gilenson, DataMotion,
- Aaron Goldmuntz, Center for Medical Interoperability, Director
- Miya Gray, Surescripts, VP, Customer Integration and Activities
- Joe Greene, PwC, Partner, Advisory Services
- Sharon Gruttadauria, CVS pharmacy, Director Industry Standards
- Sarah Haflett, PwC, Senior Manager, Health Research Institute, PwC
- Peter Harries, PwC, Principal
- Jennie Harvell, HHS/ASPE, Sr. Analyst
- Sam Ho, UnitedHealthcare, Chief Medical Officer
- Cherie Holmes-Henry, NextGen Healthcare, VP Government & Industry Affairs
- David Horrocks, CRISP, President
- Mario Hyland, AEGIS.net, Inc, Sr Vice President
- Charles Jaffe, HL7, CEO
- Kathleen Jobes, Sentara Healthcare, CISO
- Erik Johnson, Avalere Health LLC, Senior Vice President
- Stacie Jones, American College of Emergency Physicians (ACEP), Quality & Health IT Director
- Sara Juster, Surescripts, Associate General Counsel & Privacy Officer
- Christyn Keeling, UPMC
- David Kendrick, U.S. Department of Health and Human Services, Senior Advisor, Interoperability
- Hima Kher, Bristol-Myers Squibb, Director HIT
- David Kibbe, Direct Trust, President and CEO

- Paul Kleeberg, Stratis Health, Chief Medical Informatics Officer
- Laura Kolkman, Mosaica Partners, President
- Madeleine Konig, American Heart Association, Sr. Policy Analyst
- Andrew Kraus, Cardiovascular Research Foundation, COO & Treasurer
- Thomson Kuhn, ACP, Sr. Systems Architect
- Thien Lam, BayCare, Director, IS Security and ISO
- Mark Lantzy, WellCare, Chief Information Officer
- Matthew Lawson, PwC, Healthcare Security and Privacy Consultant
- Russell Leftwich, Tennessee Office of eHealth Initiatives, Chief Medical Informatics Officer
- Len Lichtenfeld, American Cancer Society, Inc., Deputy Chief Medical Officer
- Karin Lindgren, Availity, SVP, Legal and Regulatory Affairs and General Counsel
- Rebecca Little, Medicity, Inc., SVP of Sales
- Richard Loomis, MD, Practice Fusino, Senior Medical Director
- Patricia MacTaggart, George Washington University, Lead Research Scientist/Lecturer
- Kathryn Marchesini, Office of the National Coordinator for Health IT,
- Rakesh Mathew, HealthShare Exchange of Southeastern Pennsylvania, Inc., Program Manager
- Jeremy Maxwell, Allscripts, Application Security Architect
- David McCallie, Cerner, Vice President
- Laura McCrary, Kansas Health Information Network, Inc., Executive Director
- M. Ellen Milantoni, UPMC, Sr. Product Manager
- Ryan Miller, Availity, Senior Vice President of Strategy and Corporate Development
- David Moore, Sonora Quest Laboratories, CIO
- Jill Mulligan, Surescripts
- Rohit Nayak, Quest Diagnostics, Executive Director, Strategy and Business Development
- Mitchell Parker, Temple Health, CISO
- Emilie Paternoster, Just Associates, Inc., VP Data Integrity Services and Sales
- David Pittman, POLITICOPro, eHealth Reporter - PRESS
- Derek Plansky, Sandlot Solutions, Vice President, Product Development
- Robert Porr, Sandlot Solutions, Executive Vice President, Sales & Marketing
- Marc Probst, Intermountain Healthcare, Chief Information Officer and Vice President
- Karen Proffitt, Just Associates, VP Consulting
- Shawn Ramer, Bristol-Myers Squibb, Sr. VP, Information Technology
- Rick Ratliff, Accenture, Connected Health Global Managing Director
- Alisa Ray, CCHIT, Executive Director
- David Rebey, Johnson and Johnson, US Team Leader
- Morgan Reed, ACT/The App Association, Executive Director
- Kenia Rincon, PwC, Manager Health Information Privacy & Security Practice
- Ivonne Rivera, Puerto Rico Health Insurance Administration
- Robert Robke, Cerner Corporation, Vice President
- Ken Rosenfeld, eHealth Technologies, CEO & President
- Cris Ross, Mayo Clinic, Chief Information Officer
- Lynda Rowe, Booz Allen Hamilton, Sr. Associate
- Anahi Santiago, Einstein Healthcare Network, Chief Information Security and Privacy Officer
- Mark Savage, National Partnership for Women & Families, Director, Health IT Policy and Programs
- Lucia Savage, UnitedHealthcare, Senior Associate General Counsel
- Steve Schiefen, ICA, Director of Business Development - Technology Integration
- Mark Segal, GE Healthcare,
- Nandini Selvam, HealthCore, Inc., Senior Director
- Jeffery Smith, M.P.P., CHIME, Vice President of Public Policy
- Max Sow, Surescripts, VP, Business Intelligence
- Steven Stack, AMA, President-Elect
- Sally Stansfield, Deloitte Consulting, Director
- Jonathan Teich, Elsevier / Brigham & Women's, CMIO
- Russ Thomas, Availity, CEO
- Lynne Thomas-Gordon, AHIMA, CEO
- Tim Thompson, BayCare, Senior Vice President and CIO
- Michael Tobin, Janssen Diagnostics, LLC,
- Joe Touey, GlaxoSmithKline, SVP, North America Pharmaceuticals Information Technology
- Andy Truscott, Accenture,
- Rachel Urban, UL,
- Paul Wallace, MD, Optum Labs, Chief Medical Officer & SVP Clinical Translation
- David Ward, Two Labs Marketing,
- L. Kendall Webb, University of Florida/ACEP, CMIO
- Marcy Wilder, Hogan Lovells US LLP, Partner
- Daniel Wilt, HealthShare Exchange of Southeastern Pennsylvania, Senior Director of IT
- Chantal Worzala, AHA, Director of Policy
- Gretchen Wyatt, Office of the National Coordinator for Health IT,
- Victoria Zagaria, Intel Federal Healthcare Intel Enterprise Solutions, Director