SHARING DATA, SAVING LIVES:

The Hospital Agenda for Interoperability

January 2019

EXECUTIVE SUMMARY:
Sharing Data, Saving Lives

The ability to communicate vital health data is necessary to realize the full potential of our nation's system of health care. This joint statement from seven leading associations representing America's hospitals and health systems, and the physicians and care team members who practice within these systems, sets forth our agenda in support of the urgent need for continued momentum on improving interoperability among health information technology (IT) systems—a goal that holds great promise for lasting improvement in patient care. Together, we seek to enlist and expand public and private stakeholder support around this goal to benefit all individuals, their families and caregivers.

This report reviews the current state of interoperability, which shows promise but is still a patchwork system. It discusses the benefits of fully interoperable data for patients and providers, outlines current challenges and provides suggestions for how all stakeholders can work together to achieve the goal of the best possible health for each individual.

The contributors to this assessment include: America's Essential Hospitals, American Hospital Association, Association of American Medical Colleges, Catholic Health Association of the United States, Children's Hospital Association, Federation of American Hospitals and the National Association for Behavioral Healthcare.

The hospital agenda for interoperability includes the six key elements outlined below as the surest pathways to full interoperability. Each recommendation is presented in more detail later in this document.

Pathways to Interoperability

1. **Security and Privacy.** Stakeholders must be able to trust that shared data is accurate, secure, and used in accordance with best practices and patient expectations. Manufacturers must embed security and privacy requirements into every layer of the infrastructure.

2. **Efficient, Usable Solutions.** Data must be available where and when it is needed, and in a useful format. Systems supporting data exchange also must support accurate patient matching.

3. **Cost Effective, Enhanced Infrastructure.** The infrastructure to connect information sharing networks must be secure, cost-effective, accessible and updated over time. It will require consistent use of standards, semantics and a common set of "rules of the road" for exchange.

4. **Standards that Work.** Connected systems require improved – as well as new – standards used consistently to minimize proprietary solutions and gatekeeping.

5. **Connecting Beyond Electronic Health Records.** To improve health and care, interoperable systems must expand the reach of information sharing to support population health, address social determinants of health and facilitate remote monitoring and patient-generated data.

6. **Shared Best Practices.** Information sharing is happening in pockets but needs to be expanded. All stakeholders should share best practices to build on what works.

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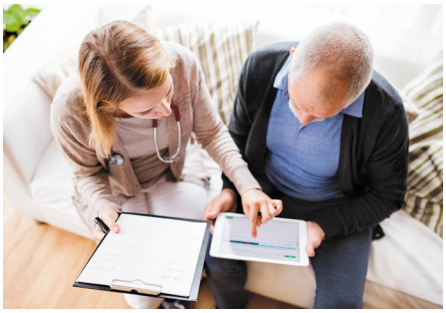

Today, it is common for health care to be delivered across multiple settings. A patient's diagnosis and treatment journey can rapidly take them from a physician's office to an imaging center to the operating room of a hospital. Each stop generates a record, such as doctors' notes, test results, medical device data, discharge summaries or information pertinent to the social determinants of health, which become part of a patient's electronic health record (EHR) in each setting. Key data also are tracked in non-clinical settings, such as schools, and from products such as Fitbit or other devices that capture patient data. For the best outcome, it is imperative that accurate, standardized, accessible and exchangeable health information from all sources accompany patients every step of the way. All this data has the potential to transform our health care system into one that continuously learns and improves through the use of predictive analytics and decision support tools.

We are inching closer to, but still short of, the ideal of seamless interoperability. In health care, this refers to the capacity to send and receive a patient's health information from multiple sources between different systems and locations with its integrity intact. The information communicated must be useful to the receiving care provider, patients and families, and result in the care decisions that are best for them. Today, interoperability is a partially-achieved aim, working well in some but not all settings.

While existing investments in EHR technologies must be preserved, the key to leveraging health data's full potential for improving patient care is the establishment of a framework for compatible technical and linguistic (semantic) standards adopted by all parties that lead us to a generic, vendor-neutral data exchange platform. We currently lack universally agreed upon ways of sharing and using information — "rules-of-the-road" that make possible the uncorrupted transfer of patient data between differing (and often proprietary) health record systems. Consistency is paramount. Just as today's mobile phones can connect with each other regardless of the brand, model or wireless carrier, **America's hospitals are urging all stakeholders to unite and ramp up our ability to securely share patient health information, regardless of where it originates.** The time is now.

What Kind of Interoperable Information Supports the Best Patient-centered Care?

1. **Individual longitudinal health data:** An individual's complete health record, including both provider-generated (e.g., medical visit records) and person-generated (e.g., wellness, fitness and socioeconomic) data.
2. **Within episodes of care:** Data from medical devices, labs, billing, EHRs and quality reporting.
3. **Between care settings:** Episode of care data that seamlessly moves from one care setting to another (e.g., from hospital A to hospital B, or from a hospital to a post-acute care provider).
4. **Marketplace:** Population health and research data that enables: 1) a feedback loop to providers, helping them deliver improved, personalized care; and 2) marketplace innovation.

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The Benefits of Sharing

Achieving the reality of fully interoperable health information offers many benefits for the entire health care ecosystem, including:

- **Strengthened care coordination.** With up-to-date patient data at their fingertips, providers, patients and caregivers can work together to make fully informed care decisions.
- **Improved safety and quality.** Interoperable patient data helps ensure patients receive appropriate tests and medications, while avoiding duplicative or conflicting ones. This translates to a better, safer and more efficient experience — key markers of the current shift to value-based care.
- **Empowered patients and families.** People who have access to their medical records and options can make better informed clinical decisions and can become fuller partners in their own care.
- **Increased efficiency and reduced costs.** Enhanced ability to share relevant information, including patient matching, reduces costs in time and resources for patients and insurers by avoiding duplicative services, as well as for clinical and administrative staff by devoting fewer hours to these tasks.
- **Robust public health registries.** The creation and sharing of aggregated patient health information will support more accurate tracking and prevention efforts for disease and other public health threats.

> **Having access to an interoperable health record is very important to us and to the receiving hospital to provide the best care possible to the patient.**
>
> - Marty Fattig, CEO, Nemaha County Hospital, Auburn, Neb.

The Quest for Interoperability

Investments

Acknowledging their indispensable role in patient care, hospitals and health systems are driving the growing demand for shared health records. They have invested hundreds of billions over the past decade **(more than $62 billion in 2017 alone)** in EHRs and other IT systems that record, store and transfer patient data securely among medical professionals. Significant organizational resources have been devoted to initial implementation, ongoing maintenance, training of all users and work-arounds to create connectivity and address unique patient and family needs. According to the Office of the National Coordinator for Health Information Technology (ONC), the vast majority of hospitals use multiple mechanisms to share health information, and more than half must use four or more. Furthermore, most hospitals devote significant resources to manually matching patient records, since we do not have a national patient identifier.

According to 2010 AHA survey data, only 16 percent of hospitals had a basic EHR system in place. By 2017, 97 percent of surveyed hospitals had adopted a certified EHR system.

Health Information Exchanges

Many of these stand-alone systems have been linked, creating what are referred to as Health Information Exchanges (HIEs), which ONC defines as allowing doctors, nurses, pharmacists, other health care providers and patients to access and securely share a patient's vital medical information electronically — improving the quality, safety, speed and cost of patient care. However, while HIEs do deliver on some of the promises of interoperability, the exchangeable data is often limited to a regional or statewide scale. In addition, some HIEs cannot reliably carry out full data exchange within a health system among different source technologies, or data

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exchange across health systems including ambulatory or post-acute settings. Finally, HIEs may not enable individual patients to access their data. HIEs point in the right direction, but currently fall short of the goal of problem-free interface with systems everywhere.

Congress and the Administration

Interoperability that allows users to find, understand and act on information when they need it holds the promise of significant improvement in patient outcomes and is a priority for policymakers. In 2009, Congress passed The Health Information Technology for Economic and Clinical Health (HITECH) Act to incentivize the transferability of health IT through the Medicare and Medicaid Promoting Interoperability Programs. Lawmakers followed up in 2016 with the 21st Century Cures Act, which authorizes further advances in interoperability. The Act requires the Department of Health and Human Services (HHS) to recognize or create a trusted exchange framework and common agreement to support information sharing (see box below), develop voluntary pediatric EHR standards, and encourage the exchange of information among registries and patient safety organizations. Through ONC, HHS also identifies technical standards for health IT and has a program to certify that EHRs and other products adhere to standards.

TEFCA

The "Trusted Exchange Framework and Common Agreement" (TEFCA) draft specifications, released by HHS in January 2018, proposed the standards for interoperability across HIEs as required by the 21st Century Cures Act.

TEFCA would:

- Establish a single "on-ramp" for HIEs enabling providers, hospitals and other health care stakeholders using EHRs to join any health information network, as well as automatically connect and participate in a nationwide HIE.
- Create "Qualified Health Information Networks" (QHINs) as a vehicle to help facilitate a standardized methodology for HIE inter-connectivity.
- Create a new administrative organization to administer TEFCA and operationalize the Trusted Exchange Framework.

HHS is expected to release a second TEFCA draft proposal in 2019. While TEFCA is voluntary, ONC encourages providers, insurers and states to adopt it. We support the intent of TEFCA, particularly the goal of establishing a non-proprietary, vendor-neutral data exchange platform with hospitals playing a key governance role. We also favor private sector efforts to address interoperability outside of HIE-level exchanges.

Progress to Date

The nation's hospitals and health systems have forged ahead to create the most interoperable systems possible to date. The task is incomplete, but their effort has produced measurable results (Figure 1):

- 93 percent of hospitals nationally give patients the ability to view their health records online, up from 27 percent in 2012. This validates the significant expansion of patient-friendly portals created and supported by care providers.
- 88 percent of hospitals now send records to ambulatory care providers outside their system, up from 37 percent in 2012.

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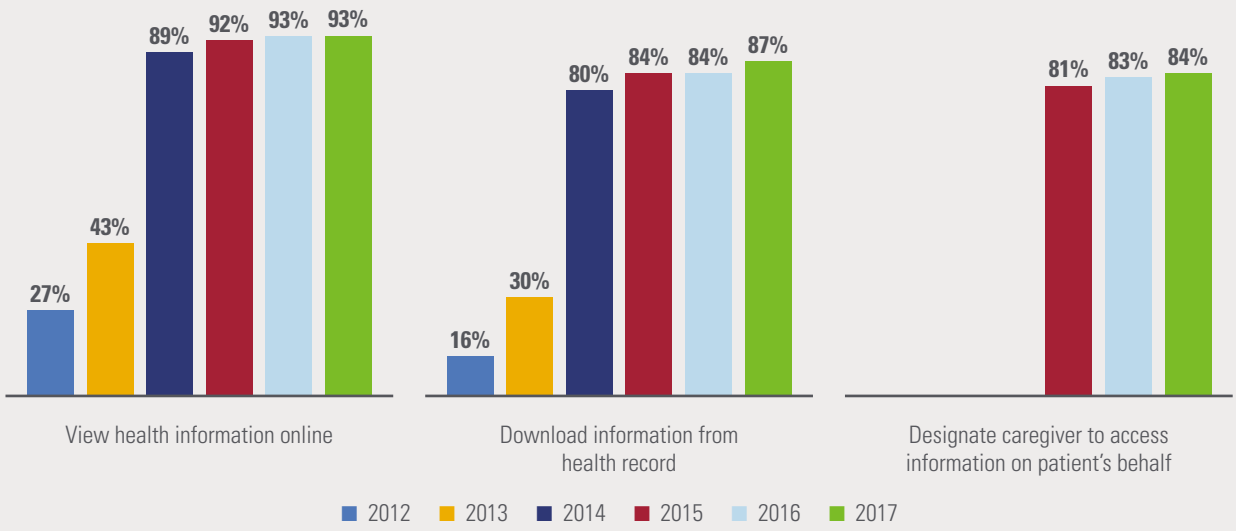
These capabilities are important, but do not yet reach our goals. Hospitals and health systems also are pursuing public-private collaborations to establish national information structures for transferable health information. One prominent example is The Center for Medical Interoperability, a cooperative research and development lab founded by health systems to simplify and advance data sharing among medical technologies and systems, including medical devices.

Figure 1: Patient Access to Health Data, 2012-2017



Note: The question about hospitals providing the ability to patients to designate a caregiver was added in 2015.
Source: American Hospital Association Annual Survey Information Technology Supplement data, 2012-2017.

In late 2018, two large national data exchange initiatives, CommonWell and Carequality, successfully established connectivity, paving the way for more than 15,000 hospitals, clinics, pharmacies, and other health care organizations to connect with each other in a consistent way. This allows clients of the two largest EHR vendors, Epic and Cerner, to access data from outside their own systems. Patients and providers at these care sites now have access to more complete data on which to base health care decisions.

Technology is also keeping pace. New phone apps are available that can link patient data sources, whether from clinics, hospitals or wearable devices. In addition, many hospitals and health systems are contributing to the development of more modern approaches, such as Fast Healthcare Interoperability Resources (FHIR). This draft standard for describing data formats supports application programming interfaces (APIs) for exchanging EHRs. Innovation like this helps propel society toward the goal of full interoperability, but requires the collaboration of all stakeholders.

Action in the Field

Exactly how is transferable health information being shared in ways that benefit patients, care providers, regulators and insurers? Consider some current examples:

- **Nemaha County Hospital**, a small rural hospital in Auburn, Neb., has reduced area readmissions by sharing continuity of care documents that help all local care providers, affiliated with the hospital or not, stay informed with complete and up-to-date patient health records.

- A network launched by the **Tennessee Hospital Association** has put 88 percent of the state's hospitals in touch with each other, exchanging real-time admission, discharge and transfer (ADT) alerts that help providers track a patient's

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progress through the system and produce more informed and better coordinated care decisions. The network tool is also accessible by facilities without EHRs.

- 2017 Hurricane Harvey's death toll might have been even higher without the intervention of **Greater Houston Healthconnect.** The regional HIE responded to the emergency by assisting doctors treating evacuees in area shelters. Healthconnect's staff used their portal to look up medication, diagnosis, allergy and other critical data to keep people's chronic conditions under control and better treat emergent issues.

- **Ochsner Health System** in New Orleans now receives 10 records and sends out another 20 for every patient it sees, building from many connection points, including the recent ability to query records through the link between Commonwell and Carequality. The technical bridge between Epic and Cerner helped Ochsner (an Epic client) exchange vital patient data with more than 209 out-of-system providers – in December 2018 alone.

- **HCA Healthcare** has automated a process for closing the surgical referral loop. A surgeon referring a patient to an HCA hospital for surgery sends the relevant patient records in advance of admission. Upon patient discharge, HCA automatically sends updated information back to the referring surgeon, who can provide informed follow up care.

- **UMass Memorial Heath Care** has partnered with **Reliant Medical Group** to aggregate community organization information on a website that allows providers to connect patients to many kinds of social services by ZIP code. This initiative concentrates on identifying the social determinants of health to connect individuals to needed community organizations and providers. Website data provides a window into the primary population health needs for the community by ZIP code.

- **Boston Children's Hospital** developed and uses a chronic and acute care management system called TriVox Health to improve patient care. The web-based platform enables children's hospital clinics to employ electronic surveys to gather data remotely from multiple responders including patients, parents, school personnel and ancillary physicians, and view the responses in multiple formats.

- San Francisco-based **Dignity Health** leverages open standards and a novel deployment of packaged technologies to allow providers to find, retrieve and use clinical information from non-Dignity Health providers across the communities it serves within providers' workflow to make a positive impact on care delivery. Being an anchor participant in the eHealth Exchange since 2012 has allowed Dignity Health to accelerate connectivity with other health systems, government agencies and national retail clinics. Utilization shows an average of 100,000 care summaries sent and received per day.

- **Kaiser Permanente** (KP) exchanged medical records with other providers via HIE networks more than 100 million times in 2018, averaging more than one inbound and about one outbound exchange for every patient encounter. Individual health information is accessible through KP's online presence and mobile apps, which offer patients easy and convenient access to personal health records including clinical visits, test results, immunizations, scheduling appointments and medication refills.

As demonstrated through these examples, hospitals and health systems have identified ways to exchange patient health information in a secure and timely manner that serves the interest of both the patient and provider. But achieving this consistently on a national scale remains an unmet goal.

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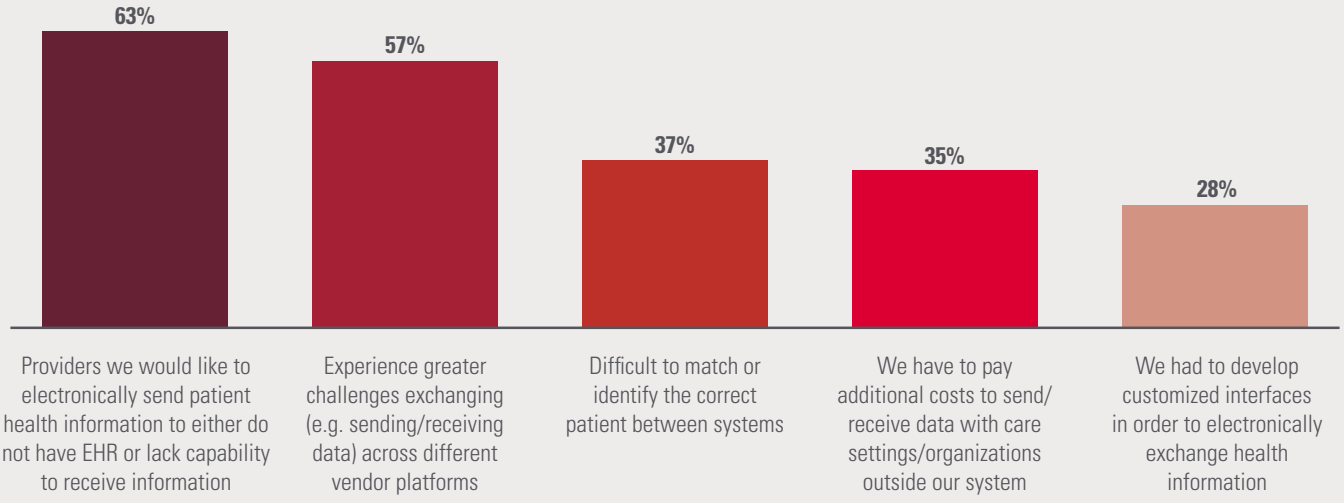
Challenges to Comprehensive Interoperability

United Nations diplomats speak a multitude of languages that require translators to make everyone understood. Similarly, the technical and data incompatibilities between HIE platforms created by different vendors, and for different user types, necessitate their own "translation" mechanisms to ensure, for example, that patient health data coming from different sources correlates correctly. But these solutions often are budget-busting, ineffective workarounds that can compromise patient care. They require expensive technical patches that may connect a few systems but lack general applicability. Such limited fixes require a disproportionate amount of staff time to use and manage – time that comes at the expense of patient care. And, current approaches can lead to clinicians receiving too much, and sometimes duplicate information, presented without tools to find the data relevant to a care decision. In addition, technical band-aids do not address the potential lack of a commonly understood vocabulary (semantics) between platforms. A human doctor will know that "dropsy" equates to congestive heart failure, but a computer is unlikely to make that distinction. Yet another drawback to short-term solutions are their high vulnerability to cybersecurity threats. These challenges are even greater when sharing across vendor platforms (Figure 2).

One-off solutions are not the only challenge standing in the way of achieving interoperability. Others, not indicated in the chart below, include:

- Uneven adoption of technology across care settings, with many clinics and post-acute settings unable to receive or send data in standard formats.
- Shifting regulatory requirements and unclear timetables.
- Health plans that do not or cannot share claims data.
- Vendor protocols that fail to transfer full data sets.
- Differing standards for patient privacy across states and types of data. For example, hospitals, health systems and other providers are covered under one set of rules – the Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations – while data brokers and health IT companies may not be, creating confusion for patients and health care providers over privacy expectations.
- Inappropriate or inapplicable clinical content for unique patient populations, such as children, in some vendor products.
- Behavioral health providers are not included in – and do not benefit from – the provisions of the HITECH Act.

Figure 2: Barriers to Exchange and Interoperability, 2017



Source: AHA analysis of American Hospital Association Annual Survey Information Technology Supplement data, 2017.

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Our Agenda: Pathways to Interoperability

For every health care patient in the nation, the interoperability of health information is a foundational issue, now and in the future. The ability to access, match, reconcile and use patient data generated by different systems enables better patient care and engagement. The following set of goals will accelerate the transition to having relevant health data available where, when and in the form needed to support the best possible health outcomes for patients, families and caregivers, as well as assist in keeping pace with evolving technology and standards.

1. **Security and Privacy.** Individuals expect their sensitive health information to be kept private and secure. Hospitals and health systems, clinicians and patients must be able to trust that the data being shared is accurate, secure and being used in accordance with best practices and patient expectations. Security and privacy requirements must be embedded into every layer of the infrastructure. This includes mechanisms to validate the practices and standards of third-party apps and APIs that allow more flexible sharing of data. The infrastructure also must include a mechanism for health care providers to verify that a request for information is authorized, and each entity with access to individuals' data must be responsible for appropriately securing and using that data. Medical device manufacturers must do more to confront the privacy challenges that unsecurable devices may pose to hospitals and health systems.

2. **Efficient, Usable Solutions.** In today's health care environment, data must be available where and when it is needed, and in a format that is useful to clinicians and individuals. The systems supporting data exchange must be efficient and functional, limiting the effort, time and level of expertise required of clinicians and health care provider organizations to use them. They must support accurate patient matching – the comparison of health data from different IT systems to confirm that the data belongs to the same patient – and obtain a complete record of the patient's health history and medical care. In the absence of a national patient identifier system, the ability to perform patient matching is a critical issue. Finally, users of data exchange systems must be able to easily locate other providers in order to share pertinent data about patients in a timely way.

3. **Cost-Effective, Enhanced Infrastructure.** Consistent use of standards, common vocabulary and "rules of the road" to connect information-sharing networks will improve the ability to distribute information within and across settings, between providers of care, with individuals and within the marketplace. This infrastructure must be secure and accessible – both in terms of time and costs – and be updated as needed to keep pace with rapidly-evolving technology. The end goal is complete data sharing via a non-proprietary, vendor-neutral data exchange platform, similar to how the country is served by cable technology.

4. **Standards that Work.** The current standards supporting our information-sharing infrastructure are incomplete, implemented inconsistently, and may differ between systems. They may not be up to the task of seamless sharing of information. There is an urgent need to coalesce around improved standards that overcome the significant gaps making communication difficult between systems. New standards also show promise. For example, APIs, including those based on the FHIR standard, allow for more nimble approaches to accessing needed data. Health care will benefit most from use of standard, secure, non-proprietary APIs that minimize the added costs associated with proprietary solutions and gatekeeping. API access should support both patient access to

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information from providers and other stakeholders, and the use of trusted third-party tools to support clinical care. A secure app ecosystem will enable trust in these promising tools. The roadmap for future standards development should be built on priority needs for information sharing (use cases). These should include how best to share information across clinical and social service settings.

5. **Connection Beyond EHRs.** To date, health IT investments have focused on the sharing of information across EHRs. Achieving true interoperability and improving health care will require tools that expand the reach of information sharing to support population health, address social determinants of health, and facilitate remote monitoring of patient and family-generated data, including the intake of information from personal medical devices with other sources of data. The integration of data from a wider number of sources will allow providers to become more nuanced in their care of individuals. For example, in pediatrics, interoperability tools can enable sharing of important physical and mental health information between clinicians and schools.

6. **Shared Best Practices.** Many current examples demonstrate the benefit to patients when health records and data are successfully shared between providers, although often as the result of great effort in terms of time and cost. Every stakeholder in the health care delivery system should understand the obligation to disseminate such useful and instructive case illustrations of interoperability that serves the needs of patients, caregivers and providers. It is important to build on what is working and identify what needs improvement.

Stakeholder Collaboration

True interoperability that advances improved health care and outcomes is within reach with effective federal policies and key stakeholders doing their part. By aligning around goals that encompass privacy, security, standards and infrastructure, hearing all voices, and committing to share best practices and lessons learned, we will make progress.

Stakeholder	Role
Hospitals and health systems	• Continue to invest in systems that facilitate interoperability. • Use procurement power to drive vendors toward compatibility in systems design. • Identify highest priority use case(s). • Lend a voice to the development process.
Consumers	• Engage with online health records and understand what the data represent. • Be familiar with privacy rules, such as what health information is or isn't protected by HIPAA.
Clinicians and other care settings	• Commit to continued investment in systems and connecting to others. • Provide feedback as to what works for clinical care and specific care settings. • Encourage patient and family/caregiver engagement through health IT. • Share perspectives in the interoperability development process.

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Stakeholder	Role
EHR Vendors and other IT companies	• Commit to more field testing and consistent use of standards; document adherence to standards. • Avoid pricing models that create a "toll" for information sharing. • Increase transparency about realistic expectations for technical solutions. • Offer alternatives to expensive, labor-intensive workarounds that drain providers' time and energy. • Avoid user interfaces that make information sharing complicated and/or time consuming. • Commit to meeting regulatory requirements and individuals' expectations for data security, privacy and use.
Insurers	• Commit to sharing claims data with patients and care providers, using standard approaches. • Ensure privacy and security of their information sharing activities.
Health Information Exchanges	• Regional HIEs should accelerate the effort to coordinate and connect to national networks and to each other.
Medical device companies	• Expand "plug and play" approach in design and function. • Enhance security of data. • Add lifecycle support for devices.
Government	• Support more robust testing, within and outside of certification. • Support standards development and consistent use of standards. • Maintain regulatory relief on use of technology; focus on growing interoperability of technology, including support for connection to settings and providers that did not receive EHR incentive payments. • Commit to use of best practices by government agencies and contractors. • Educate consumers on privacy rules. • Collaborate with private sector to vet APIs and applications for data security and usage.

Conclusion

Full interoperability of patients' electronic health information and related data is a logical extension of the way Americans already live. We carry detailed personal records and information with us everywhere, embedded in smart chips in our cars, credit cards and mobile phones. While we have made much progress, at present, we have the incomplete outline of a national data-sharing system in place, one that lacks the agreed upon rules of the road, conformance, technical standards and standardized implementations to ensure that all HIE platforms can communicate correctly with each other.

The movement toward true, national interoperability has been underway for some time. As national hospital associations, we are united in our conviction that it is time to finish the job and grant all patients the peace of mind that comes from knowing that their health care decisions are based on the best and most complete information possible.

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