HIMSS Call to Action: Achieve Nationwide, Ubiquitous, Secure Electronic Exchange of Health

INTRODUCTION
Patients’ lives, the health and security of our nation’s citizens, and the health of the US economy are – in part – reliant on ensuring the right people have the right access to the right health information at the right time. While we have made great strides over the past generation, seamless, secure, nationwide interoperable health information exchange continues to elude us.

For many years, HIMSS and our valued collaborators have worked relentlessly on ensuring individuals and organizations routinely use secure, trust-worthy, interoperable technologies and work flows to promote wellness, as well as protect and improve the health status of patients and populations. While we’ve made much progress, and entire careers have been spent creating the building blocks and putting them in-place, our work is not complete. HIMSS asserts that we must achieve secure, appropriate, and ubiquitous data access and electronic exchange of health information: Now is the time for bold action. HIMSS publishes this Call to Action, guiding principles to inform health policy and spur our nation’s health sector to action. We welcome all who share our commitment to join us in achieving better health through the best use of information and technology.

HIMSS CALL TO ACTION
HIMSS calls on the Department of Health and Human Services and the broader health information and technology community to demonstrate the following leadership:

1) Demand Integration between the Interoperability Approaches and Trusted Exchange Frameworks for the Public Good;
2) Educate the Community to Appropriately Implement Existing and Emerging Standards, Data Formats, and Use Cases to Ensure a Comprehensive, Integrated Approach to Care;
3) Ensure Stakeholder Participation from Across the Care Continuum, Including Patients and Caregivers;
4) Identify the “Minimum Necessary” Business Rules for Trusted Exchange to Enhance Care Coordination;
5) Standardize and Adopt Identity Management Approaches; and,
6) Improve Usability for Data Use to Support Direct Care and Research.

Note: The order of these six themes does not reflect any prioritization regarding their role in achieving the goals outlined in this Call. HIMSS believes efforts to address these themes should occur concurrently to achieve seamless, secure, interoperable health information exchange.
DETAILED INFORMATION on HIMSS’s CALL TO ACTION

1) Demand Integration between the Interoperability Approaches and Trusted Exchange Frameworks for the Public Good

HIMSS Call to Action: HIMSS strongly encourages HHS to demand integration between the interoperability approaches and trusted exchange frameworks with the objective of achieving semantic interoperability and data access that improves the quality and cost effectiveness of care delivery for the public good.

Background: A common misperception exists that these interoperability approaches and trusted frameworks operate in silos. Several examples of collaboration across these efforts are currently underway and more opportunities are in the pipeline for the future. For example, many of the existing interoperability approaches leverage DirectTrust and Carequality. Efforts that originally focused on provider-driven exchange are exploring conversations with patient-directed exchange solutions. However, it is important to consider exchange from the provider’s perspective and understand that many currently have to implement a multi-pronged exchange approach to care for their patient population in a comprehensive manner. Used together or independently, these approaches can solve the unique needs of the individual and the provider.

2) Educate the Community to Appropriately Implement Existing and Emerging Standards, Data Formats, and Use Cases to Ensure a Comprehensive Integrated Approach to Care

HIMSS Call to Action:

Education: Existing standards, data formats, and use cases must be leveraged. A comprehensive integrated approach to care can recognize and build upon the many mature, consensus-based standards and profiles already in place, while allowing innovation to pilot and incorporate new and emerging standards. An important component of driving implementation of interoperable systems is the proper education about the existing standards and use cases. HHS and the Office of the National Coordinator (ONC) should support and encourage efforts and convening opportunities for the health information and technology community, specifically Standards Development Organizations (SDOs), to provide such education. The health community increasingly includes non-traditional data sources (e.g. social determinants of health gathered from public health registries, social services agencies, genomic information, immunization information, quality reporting, environmental science, payer and billing components and other non-traditional stakeholders). As a result, education is pivotal to ensuring that these data are based on known and adopted standards; standards that will continue to drive semantic interoperation and value for the broader healthcare community.

Implementation: Beyond education, HHS should lead efforts to ensure appropriate standards are implemented, and used, consistently. Three of the biggest challenges limiting standards implementation revolve around quality, the level of consistency in the use of the standards, and the complexity of versioning (e.g. C-CDA Release 1.1 vs 2.0 vs 2.1). HIMSS supports continued efforts to develop a Measurement Framework to understand and drive consistency in standards implementation and use.

HHS should also work with community stakeholders to articulate the value proposition and outcomes related to the use of these standards in how they improve aspects of care (e.g. preventing duplicative tests, medication errors, adverse events, incorporation/reconciliation of data, and data access). HHS should facilitate development of, or identify, existing clear and
comprehensive implementation guides (i.e. IHE technical frameworks) aligned with the standards for all healthcare domains; these guides should align with setting and clinical domain, and must address information exchange between entities that may have different levels of health information and technology sophistication.

**Background:** Currently the work to achieve ubiquitous, interoperable health information exchange has led to the creation and use of numerous standards, data formats and use cases. These vary greatly in their scope of implementation and use. Understanding of the adoption and use of these standards is limited at best, and inconsistency in the implementation of these standards has created challenges in producing interoperable exchange. As the US health system continues its push toward value-based care and the use of patient-generated health data, more data sources must integrate into the patient record, including but not limited to, social determinants of health, behavioral health data, genomic information, immunization data, and quality reporting metrics.

3) **Ensure Stakeholder Participation from Across the Care Continuum, Including Patients and Caregivers**

**HIMSS Call to Action:** The frameworks and approaches that currently exist include a wide range of stakeholder groups. While the majority of these entities focus currently on provider-directed exchange within the acute and ambulatory settings, many also discuss current and future plans to engage individuals to enable access to their own health information. HIMSS recognizes this as a critical step towards empowering patient-mediated exchange. HHS should include consumers, patients, caregivers, payers, public health and non-traditional provider groups (i.e., community-based providers, long-term/post-acute care), in these interoperability approaches and trusted exchange frameworks. Unfortunately, existing frameworks mainly focus on acute and ambulatory information exchange; gaps remain in Long Term Post-Acute Care, Long-Term Service and Support, and Behavioral Health. These gaps must be addressed.

Emphasize the importance of engaging patients through patient-mediated exchange. In our 2017-2018 Public Policy Principles, HIMSS states that all individuals, their families, and healthcare providers should be able to send, receive, find, and use electronic health information in a manner that is appropriate, secure, timely, and reliable to support their health and wellness.

**Background:** There is a tremendous need to better understand how all healthcare stakeholders can participate in these efforts, the value of the actors in these models, and identify the business and legal exchange agreements needed to further advance ubiquitous semantic interoperability. Some current approaches, such as DirectTrust, NATE, and the CARIN Alliance, are driving efforts to place the patient at the center of data access and exchange.

4) **Identify the “Minimum Necessary” Business Rules for Trusted Exchange to Enhance Care Coordination**

**HIMSS Call to Action:** Across all interoperability approaches, HIMSS endorses the creation of a “minimum necessary” set of business, legal, privacy and technical protocols that identify and leverage a baseline framework for trusted exchange. This baseline, which may be similar to the Common Clinical Data Set, can simplify onboarding for participants, allowing for greater involvement across the disparate exchange solutions and lead to better care coordination. In addition, standards and protocols should be developed to address the information needs of
those users that need them the most — those rules include addressing the needs of high-risk, complex and costly populations. These populations highly value the business case for semantic interoperability. Improved measurement and real-world testing are necessary to ensure the identified and implemented standards, and existing testing and certification programs, are leveraged to deliver value and serve their intended purpose for clinical use.

HIMSS urges the use of the Health Information Technology Advisory Committee to facilitate this work, allowing for and obtaining public comment and feedback throughout the process. Once identified, these approaches could add further “clearances” for those wanting to exchange in those networks; this could be analogous to security clearances that occur within the federal government.

**Background:** The current healthcare ecosystem consists of a variety of care settings, use cases and stakeholders. There is no existing one-size-fits-all interoperability solution. With the diversity across the ecosystem and the variety of interoperability initiatives that exist, it is not feasible at this time to put forth one “interoperability framework” that could accommodate each of these unique scenarios and user needs.

### 5) Standardize and Adopt Identity Management Approaches

**HIMSS Call to Action:** Streamlining identity management to address the foundational needs for interoperability is critical to achieving ubiquitous and secure data integration. Establishing a common framework for patient identity matching is an important element to ensure further consistency across disparate trusted exchange solutions. We advocate for the community to identify, test, adopt and implement standards and their respective algorithms for matching patients to their data across and between clinical and claims data sets.

**Background:** The ability to quickly and accurately identify and match patient records remains a critical challenge across the health community. Standards to support specific activities regarding patient identity matching are well established, yet one solution does not fully address the standardization needed at the attribute level to sufficiently match patient records. This lack of a solution remains one of the barriers to true interoperability. For three years, HIMSS has funded an Innovator-in-Residence at HHS to advance the national dialogue on algorithm attributes and approaches to strengthen algorithm accuracy. The resulting algorithm challenge has given the healthcare community great insight into areas for improvement, which will help with adoption.

### 6) Improve Usability for Data Use to Support Direct Care and Research

**HIMSS Call to Action:** The health information and technology community, with HHS’s support, must make improving usability a priority to ensure active engagement by individuals and providers. Improved usability would ensure that data are consumed discretely, incorporated seamlessly into workflow, help enable clinical decision-making, allow secondary use of data for research, and limit the burden on the end-user. This enhanced exchange is fundamental to promoting patient safety, achieving quality outcomes, facilitating care coordination as well as transitions of care, and controlling costs. To achieve this end, semantic interoperability is essential. Efforts to date have focused on syntactic aspects of exchange, i.e. the framework or message format. Renewed focus on implementation and use of relevant terminology standards and protocols is critical to improving usability.
**Background:** The inability to achieve semantic interoperability continues to be a barrier to seamless exchange and data access. Often when data are shared, they are of low quality and not useful in informing the delivery of care or improving patient outcomes. Each of the existing frameworks and approaches offers solutions that improve the transportation and access to documents and discrete data related to a variety of use cases. Any trusted exchange framework needs to provide high quality, usable content in order for an end user to reap full participation benefits.

HIMSS commits to activating this Call in real and practical ways. Leadership is needed at many levels – local, regional, and national. HIMSS applauds and honors the many individuals who have literally dedicated their careers to building the foundations of a learning health system, and the interdependencies of multiple networks, consortia, and trust frameworks. We thank the tireless volunteers and subject matter experts from all areas of the health sector who collaborated on our Call to Action. And, we welcome all collaborators to join us in our Call to Action.

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