



Joint Initiative Council: Setting the stage for the future

Enabling the digital transformation of healthcare





The world’s healthcare organisations are battling the COVID-19 virus. The entire healthcare industry has come together to defeat a far-reaching, unprecedented danger that has no boundaries. Researchers, manufacturers, government agencies, regulators and especially, healthcare providers are on the frontline of this struggle for global health.

Prior to the pandemic, these same members of the healthcare industry had been working for more than a decade to transform its global system into one that’s digital—making high-quality data available to the right people, at the right place and at the right time, for high-quality decisions and care. The industry aimed to tackle the skyrocketing costs of care, deliver better patient outcomes and safety, and gain efficiencies throughout the supply chain.

Now, the need for accelerating the speed and capacity of this digital transformation has become more important than ever before. Researchers are collaborating to find an effective vaccine, physicians are sharing their observations about treatments, and hospitals are demanding more and more supplies, devices and pharmaceuticals to care for patients.



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Current Chair, Joint Initiative Council
Senior Vice President, GSI Healthcare

Focus on outcomes

In the past, different standards development organisations (SDOs) have created multiple standards that define and guide the uniform identification and labelling of products, the exchange of information and the ways that healthcare providers communicate about patients.



“We are anticipating global problems that we can address now. The theme of this work is, ‘The people that enable the future are the people that are preparing to do it now.’ An important part of our mission is to be ‘those people.’”

– Ed Hammond, HL7 International

Since 2007, leading SDOs have come together as the Joint Initiative Council (JIC) to align and collaborate, as well as connect with other expert organisations, in the delivery of coordinated—not competitive—standards and implementation guides. Today, healthcare researchers, manufacturers and providers can use these JIC outcomes for the successful implementation of digital processes and interoperable systems.

These global (and local) efforts require interoperable systems that provide accurate, real-time information. And the foundation of interoperability is enabled by global standards.

Joint Initiative Council Vision

To foster collaboration between standards and clinical communities worldwide for coordinated—not competitive—standards that address real-world issues



To drive the digital transformation and interoperability of global healthcare systems and processes



To enable game-changing improvements in operational efficiencies, patient outcomes and safety throughout the entire global healthcare industry



Essentially, the Joint Initiative Council:

- Recognises that digital healthcare needs a variety of standards that can be easily brought together in coordinated ways to solve real-world problems.
- Supports digital transformation by driving interoperability of global healthcare systems and processes.
- Enables significant improvements and value in the delivery of individual patient and global health outcomes, leveraging existing investments in global standards.

“At JIC, we recognise the importance of global interoperability across standards and the need to collaborate on their development,” says Ulrike Kreysa, current chair of the JIC and senior vice president of GS1 Healthcare. “We’re concerned not only about standards as ‘outputs,’ but more importantly, how standards impact healthcare ‘outcomes’—their practical value in the delivery of high-quality care.”



“Disease knows no borders, nor should cures. During a pandemic, all healthcare stakeholders must be prepared to act immediately and collaborate, with high efficiency and accuracy. The pandemic has shown us the holes in our health information systems. We need global interoperability—a common global data model.”

– Mike Glickman, ISO TC215



“The JIC acts like an early warning system. We’re developing approaches that can be leveraged when healthcare systems need them. Whether it’s for regulators, government agencies, healthcare providers or manufacturers, our work is focused on enabling solutions today for problems that are just around the corner.”

– Elizabeth Keller, ISO TC215

SDOs in the Joint Initiative Council collaborate on standards-based initiatives that offer practical solutions. Because of their collective experiences, SDOs are also continuously analysing emerging situations that will most likely become the problems of the future. “We are anticipating global problems that we can address now,” explains Ed Hammond with HL7 International. “The theme of this work is, ‘The people that enable the future are the people that are preparing to do it now.’ An important part of our mission is to be ‘those people.’”

One example is the current COVID-19 pandemic. “Disease knows no borders, nor should cures,” says Mike Glickman, ISO TC215. “During a pandemic, all healthcare stakeholders must be prepared to act immediately and collaborate, with high efficiency and accuracy. The pandemic has shown us the holes in our health information systems. We need global interoperability—a common global data model.”

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Joint Initiative Council



Clinical Data Interchange Standards Consortium



European Committee for Standardisation



Digital Imaging and Communications in Medicine



GS1



Health Level Seven International



Integrating the Healthcare Enterprise



International Organisation for Standardisation



Logical Observation Identifiers Names and Codes



SNOMED International



Better together

Each SDO and its standards bring specific expertise and advantages to the JIC that, when combined in an orchestrated way, produces an ecosystem of digital healthcare practices and systems that are interoperable.

“Each of our SDOs plays a different role in creating healthcare solutions. While our standards are unique, they complement each other,” says Don Sweete, SNOMED International. “At the same time, we have similar missions that focus on the interoperability of information and processes. Likewise, our collective vision is clear: to enable the delivery of efficient healthcare services for safe and effective patient care.”

Kevin O’Donnell with DICOM adds, “When a challenge in the global healthcare community motivates activity in one SDO, it’s not uncommon to motivate activities in others. Healthcare workflows regularly use multiple standards in concert as information flows through the enterprise. JIC helps us communicate to ensure that our efforts are harmonised and complementary.”



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JIC initiatives: Solving real-world problems

SDOs in the Joint Initiative Council have collaborated (and continue to collaborate) on standards’ initiatives that focus on solving some of healthcare’s most pressing challenges.

“We are increasingly working with the clinical community,” says Hammond with HL7 International. “Standards-based processes can only make a difference when clinicians understand and use them for improvements in patient care and outcomes.”

Following are summaries of selected past, present and future initiatives: COVID-19, International Patient Summary, Identification of Medicinal Products and Genomics.



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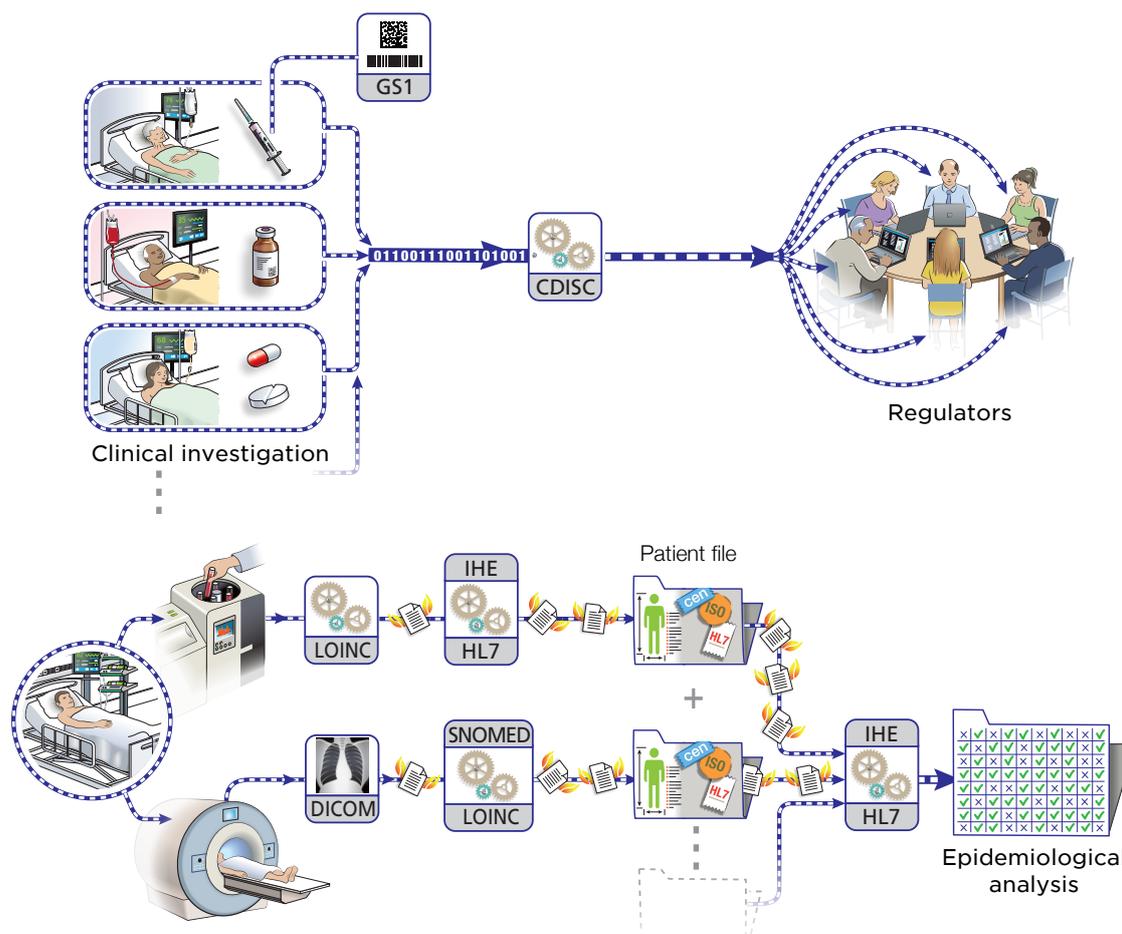


COVID-19

To help manage and contain this global public health emergency, two global health standards organisations, SNOMED International and Regenstrief Institute (which maintains the LOINC terminology) worked together to help global care teams code and track SARS-CoV-2 testing and COVID-19 cases, supporting clinicians and researchers in their efforts to address its containment.

“With our subject matter experts in coding and structuring clinical information, we (LOINC and SNOMED International) were able to quickly introduce new content into our respective terminologies,” says Swapna Abhyankar, LOINC.

To provide this new content, a SNOMED CT International Edition Interim COVID-19 data file was released, and LOINC pre-release content was updated on an ongoing basis as new concepts were created, sometimes several times a week.



Today, JIC members are contributing to the COVID-19 public health need, either by addressing immediate gaps or by providing their existing standards, to include:

- CDISC released the *Interim User Guide for COVID-19*.
- DICOM provides existing imaging standards.
- GS1 enables the tracking and tracing of supplies.
- HL7 International is developing several new implementation guides and projects to address new COVID-19 use cases, and define and incorporate essential new data elements and terminologies into its Fast Healthcare Interoperability Resources (FHIR) standard.
- IHE International provides profiles to ease the adoption of standards, as well as assessment procedures for strong conformity, (e.g., Connectathon).
- ISO TC215 and CEN TC251 are integrating the new need into their standards for implementation.
- SNOMED International and LOINC provide electronic health data elements.



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Due to the timely and effective work between LOINC and SNOMED International, important electronic health data elements were rapidly made available for use. With the high rate of global adoption for both LOINC and SNOMED CT standards, the ability to digitally encode laboratory and clinical information will help to support those on the ground facing the virus.

In April 2020, CDISC released the *Interim User Guide for COVID-19* that describes the most common biomedical concepts relevant to COVID-19, and the necessary metadata to represent such data consistently with terminology; the Clinical Data Acquisition Standards Harmonization (CDASH) used for data collection; and the Study Data Tabulation Model (SDTM) used for tabulation of data for submission.

“The CDISC standards specify how to structure research data for regulatory submissions. The COVID-19 guide addresses how to represent research data in COVID-19 studies,” says Rhonda Facile, CDISC.

International Patient Summary

More and more, patients are receiving treatment at locations other than their traditional points of care. For those patients, the holy grail of interoperability suggests that their relevant medical information must be available to those caregivers who need it, when they need it and wherever they need it.

With an increasingly mobile population, information also needs to cross jurisdictional borders (local, regional or national) as well as a myriad of health systems. Consider a physician treating a patient who has shortness of breath in a regional COVID-19 centre, a spectator who sustains an injury when attending an event far from home or a child taken ill whilst on holiday.

Leading clinical practices prescribe that an initial overview of a patient’s relevant clinical information will improve outcomes, while dramatically reducing time-to-treatment and costs. For decades, clinicians have relied on the patient summary to capture demographics, allergies, medical conditions, diagnoses, and essential diagnostic and treatment data. Yet, these documents—whether paper or electronic—were not standardised beyond their local use.

The JIC’s informative set of documents, *Patient Summary Standards Set*, complements the International Patient Summary (IPS), which standardises a clinical dataset for use on a global basis, thereby facilitating the movement of this clinical information anywhere it is needed.



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“The IPS is essential data about a patient’s healthcare, that can be made available whenever and wherever it is needed for their treatment,” explains Stephen Kay with CEN TC251. “It will effectively provide an information bridge from their home healthcare system to another, thereby, supporting continuity of care.”

IPS specifications and implementation guides were originally developed as a joint initiative of CEN TC251 and HL7 International. This successful collaboration was further extended to include additional SDOs, including ISO TC215, IHE International and SNOMED International.



Each of the participating SDOs contributes its specific expertise and standards capabilities, to include:

- CEN TC251 provides the reference standard for conformant implementation guides.
- GS1 and DICOM provide their existing standards and solutions.
- HL7 International delivers FHIR and CDA implementation guides.
- IHE International provides profiles and conformance testing.
- ISO TC215 is transitioning the European-focused IPS to become a truly global standard.
- SNOMED International provides access to clinical terminologies to support IPS.

“This unprecedented JIC collaboration has demonstrated how, when working together, standards can be produced that have broad clinical and industry support, and more global opportunities for implementation,” explains Michael Nusbaum with IHE International.



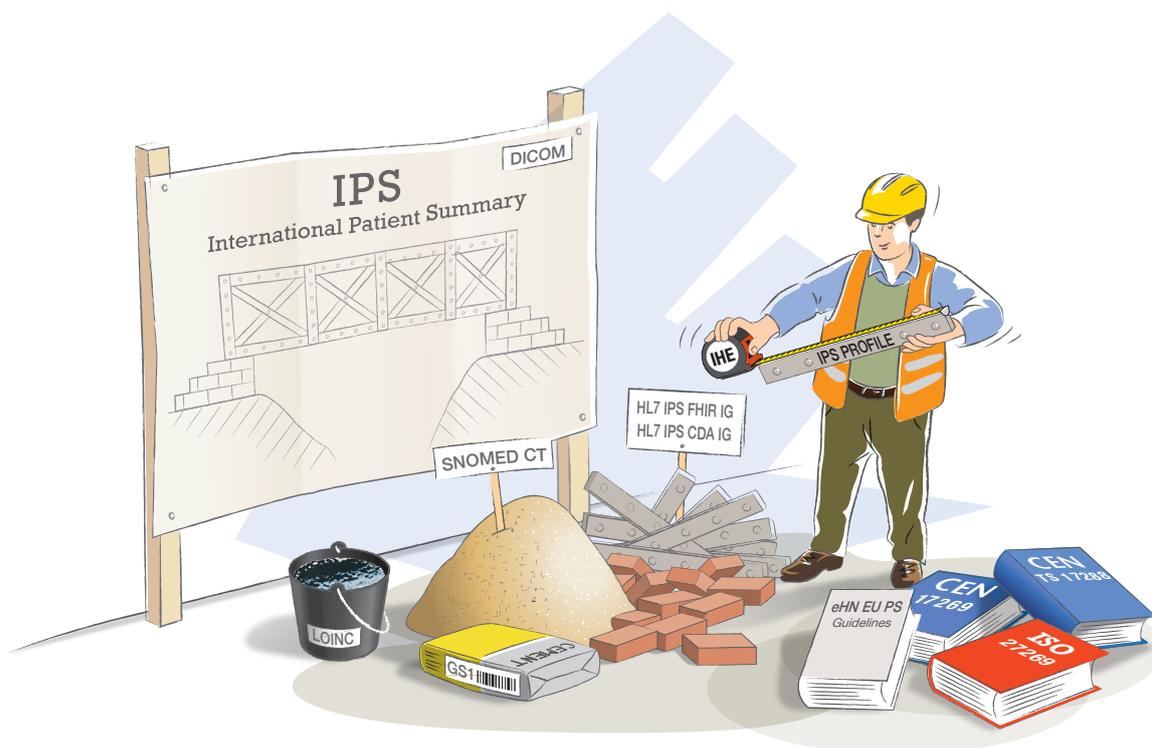
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Identification of Medicinal Products

In the global pharmaceutical industry where a medicine could have an adverse effect on patients, it is vital to quickly pinpoint and resolve the root cause and/or substance, as well as enable an efficient alert system between countries. Yet, the medicine's product name, how it is administered and measured—may all differ from country to country, causing confusion and costing valuable time, pain and lives.

In response, the IDMP project was initiated by members of the global healthcare industry and regulators, and implemented by CEN TC251, ISO TC215, HL7 International, CDISC, SNOMED International and GSI.

Working together, the SDOs produced the IDMP suite of standards that uniquely identify and describe medicinal products for the consistent documentation, coding and exchange of product information between global regulators, manufacturers, suppliers and distributors.

Each SDO contributes an element of the IDMP solution, to include:

- CDISC integrates IDMP in its standards for clinical studies.
- CEN TC251 and ISO TC215 deliver the information architecture.
- GSI provides the link to the physical products and supply chains.
- HL7 International provides the standards to communicate and store information.
- SNOMED International maps its terminologies to bridge regulatory and clinical needs.

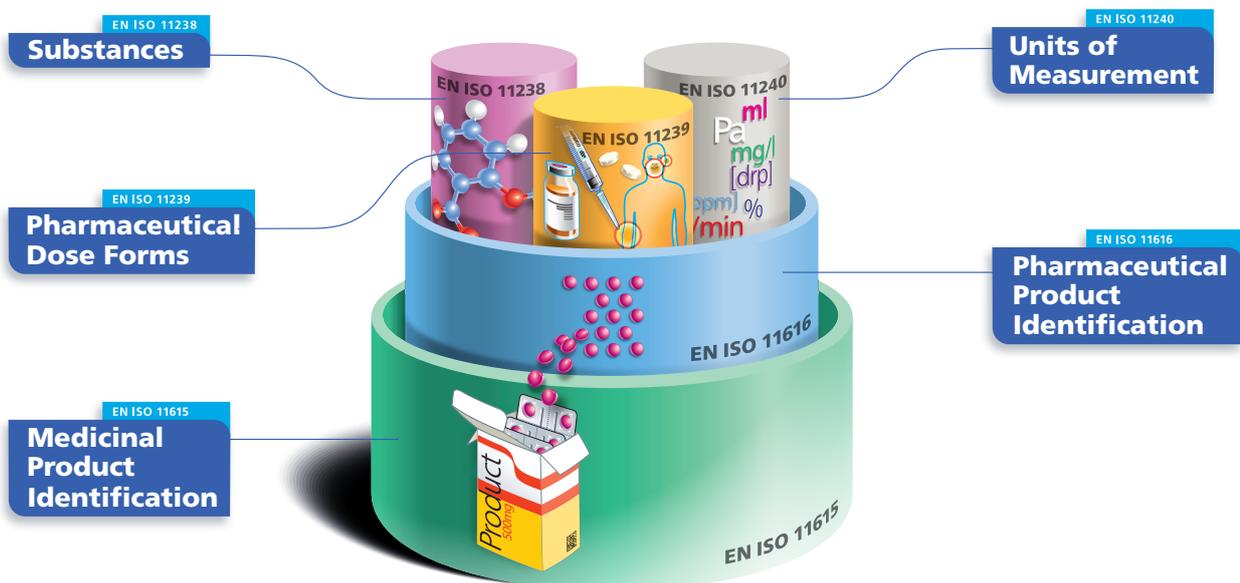
The standards deliver a uniform way for computerising and sharing medicinal information about pharmaceuticals—their substances, units of measurements, forms of dosage, routes of administration and packaging.

"IDMP standards help facilitate regulatory activities such as pharmaceutical development and registration, life cycle management of medicinal products, pharmacovigilance and risk management," advises Christian Hay with GSI Healthcare. "The standards can also be applied to clinical needs, such as for prescriptions, medicinal product comparisons in case of shortages, and much more."



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Genomics

Since 2015, there has been significant interest and growth in genomics research and data. With the COVID-19 pandemic, infectious disease is becoming a critical area for the use of genomics data, leading to increased genomic sequencing. From raw sequencing of a virus to sharing phenotypic (e.g., disease signs, symptoms) information for every outbreak patient, vast amounts of genomic data—beyond gigabytes to petabytes and eventually exabytes of data—are providing key resources for researchers and clinicians alike. In response, JIC members started to explore existing research and knowledge in this field a few years ago.

“As the field of genomics continues to grow, the use of reliable, high-quality global data standards is imperative,” says Bron Kislser, chair of the ISO Genomics Sub-Committee (SC) with ISO TC215. “Various genomics standards are needed in genomics data processes and workflow—from data production to clinical application.”

Data sharing within and between organisations is another important factor, as well as integrating genomics data from many different sources, such as the US National Cancer Institute Genomics Data Commons.

To address this growing need and build on genomics standards already under development, JIC members and other SDO representatives, experts and organisations are contributing to this collaborative effort, including:

- CDISC has a set of pharmacogenomics standards and seeks to expand these in collaboration with other SDOs.

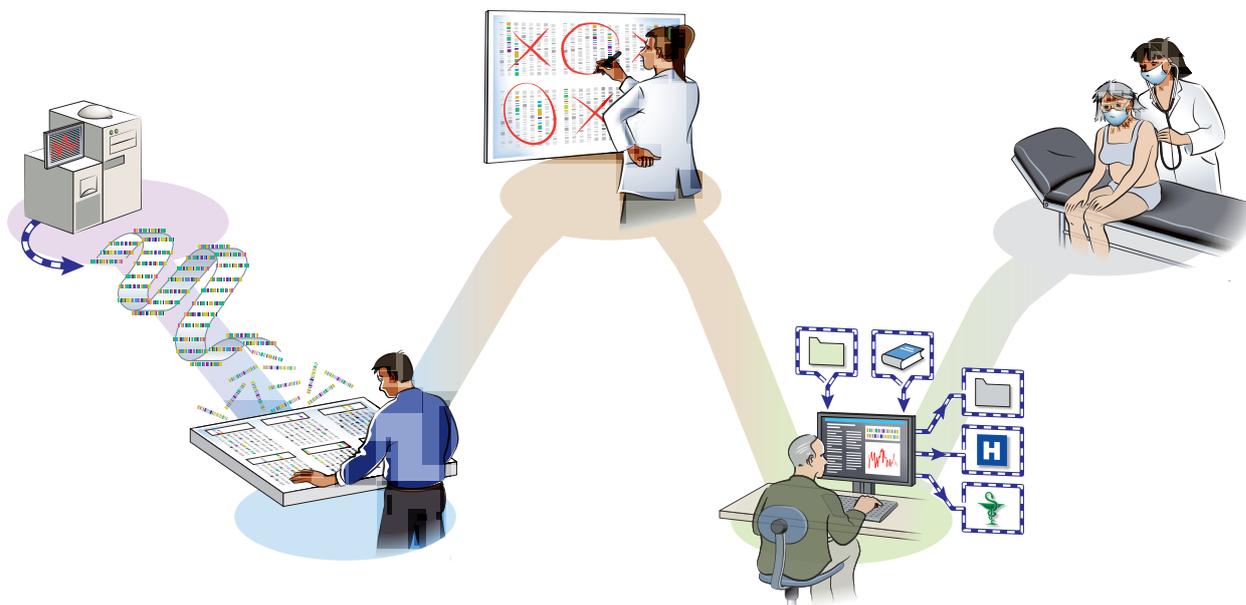
- The Global Alliance for Genomics & Health (GA4GH), a liaison to the ISO Genomics Sub-Committee, is contributing with subject matter experts.
- HL7 International is developing standard tools to structure and communicate genomics information.
- ISO TC 215 has formed the Genomics Informatics Sub-Committee and other liaison committees are contributing expertise—ISO/TC 276, ISO/IEC, JTC1/SC29 and IHE International.
- LOINC is providing laboratory terminologies.
- SNOMED International is offering clinical terminologies.



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To avoid the duplication of data standards being developed across different SDOs, proactive collaboration will be essential. The ISO Genomics SC is further working on a strategic roadmap to identify existing standards and gaps along the genomics data process as well as data sharing.





More than this

These four initiatives and resulting standards provide examples of JIC's ground-breaking work efforts to realise a digital healthcare system that's highly efficient, effective and safe.

"COVID-19 is not the first global pandemic, and it won't be the last," says Kreysa. "Global healthcare will continue to be an ever-changing environment where we must anticipate and address the next seismic shift. We're prepared to ensure our standards are there to support these changes."

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For more information about the Joint Initiative Council, visit www.jointinitiativecouncil.org.



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About the organisations



About Joint Initiative Council

The Joint Initiative Council for Global Health Informatics Standardisation (JIC) is formed to further the important role of health informatics standards to enable interoperability of information and processes across health domains. Health informatics standardisation is supported by a community of experts that works within and across various health informatics standards development organisations (SDOs). The JIC supports the timely, efficient delivery of safe, coordinated, accountable, high-quality health services to individuals, communities and populations. www.jointinitiativecouncil.org



About Clinical Data Interchange Standards Consortium (CDISC)

The CDISC is a global, non-profit standards development organisation. CDISC's community of volunteers has created a suite of standards for Exchange of Nonclinical Data (SEND), data collection (CDASH) aggregation and tabulation (SDTM), analysis (ADaM), (ODM-XML, Dataset-XML and others), standards description (Define.xml) and archiving (ODM-XML) translational research data. In collaboration with the National Cancer Institute's Enterprise Vocabulary Services (NCI-EVS) program, CDISC has developed rich controlled terminology that are linked to other common research semantics through NCI-EVS tools. www.cdisc.org



About Digital Imaging and Communications in Medicine (DICOM)

DICOM® is the international standard for medical images and related information. It defines the formats for medical images that can be exchanged with the data and quality necessary for clinical use. DICOM is implemented in almost every radiology, cardiology imaging, and radiotherapy device (X-ray, CT, MRI, ultrasound, etc.), and increasingly in devices in other medical domains such as ophthalmology and dentistry. With hundreds of thousands of medical imaging devices in use, DICOM is one of the most widely deployed healthcare messaging standards in the world. There are literally billions of DICOM images currently in use for clinical care. www.dicomstandard.org



About European Committee for Standardisation (CEN)

CEN TC 251 delivers and maintains health informatics standards for Europe, preferably by producing them in co-operation with other SDOs at a global level and by adopting standards from other SDOs. CEN TC 251 will seek to further increase engagement with other standards development organisations, consortia and fora to enhance efforts to coordinate its work with other organisations that have similar goals, such that stakeholder wishes for fewer, but more universal, global standards for health informatics are recognised and delivered in Europe. www.ehealth-standards.eu



About GS1 Healthcare

GS1 Healthcare is a neutral and open community bringing together all related healthcare stakeholders to lead the successful development and implementation of global GS1 standards, enhancing patient safety, and operational and supply chain efficiencies. The development and implementation of GS1 standards is led by the experts who use them: pharmaceutical and medical device manufacturers, wholesalers, distributors, group purchasing organisations, hospitals, pharmacies, logistics providers, solution providers, governmental and regulatory bodies, and trade associations. Evidence available from industry implementations shows that GS1 identification, data capture and data sharing standards in healthcare deliver tangible benefit to all stakeholders. Global members of GS1 Healthcare include more than 100 leading healthcare organisations worldwide. www.gs1.org/healthcare



About Health Level Seven® (HL7) International

HL7 International is an ANSI-accredited, not-for-profit organisation that develops standards with the mission of empowering global health interoperability. With affiliates in nearly 40 countries, HL7's global membership envisions a world in which everyone can securely access and use the right data when and where they need it. Widely implemented by vendor and healthcare systems, and required by governing bodies around the world, HL7 standards deliver solutions for health information technology, including HL7® Fast Healthcare Interoperability Resources (FHIR®), Version 2 (V2) and Clinical Document Architecture (CDA®). www.hl7.org



About IHE International

Since 1998, IHE International has improved healthcare by providing specifications, tools and services for interoperability. IHE International engages clinicians, health authorities, industry, and users to develop, test, and implement standards-based solutions to vital health information needs. www.ihe.net



About International Organisation for Standardisation (ISO)

ISO is the world's largest developer of international standards. Working as a global federation, ISO brings together public and private sectors in more than 160 countries to create consensus standards. To date, nearly 20,000 ISO standards have been published representing the work of more than 250 ISO Technical Committees and thousands of subject matter experts providing standard-based solutions and meaningful benefits for global development. www.iso.org

Established in 1998, ISO Technical Committee 215, Health Informatics (ISO/TC215) has 60 member countries and liaisons representing millions of healthcare stakeholders worldwide. The ISO/TC215 mission is standardisation in the field of health informatics to facilitate the capture, interchange, and use of health-related data, information, and knowledge to support and enable all aspects of the health system. www.iso.org/committee/54960.html



About LOINC®

LOINC, which stands for Logical Observation Identifiers Names and Codes, was initiated in 1994 by Clem McDonald, then an investigator at Regenstrief Institute, a non-profit medical research organization associated with Indiana University. Indianapolis-based Regenstrief organized the LOINC Committee to develop a common terminology for laboratory and clinical observations because there was a growing trend to send clinical data electronically from laboratories and other data producers to hospitals, physician's offices, and payers who use the data for clinical care and management purposes. www.loinc.org



About SNOMED International

SNOMED International is a not-for-profit, member-owned and driven international organisation, which owns and maintains SNOMED CT, the world's largest clinical terminology. The international organisation works to ensure that SNOMED CT can be routinely integrated into healthcare information systems. With SNOMED CT, users can record patient data more accurately and comprehensively - and use tools and analytics to provide better patient care and health management. The safe, accurate and effective exchange of health information is an essential part of the foundation to improve healthcare around the world. With 39 Members and use of SNOMED CT in over 80 countries, SNOMED International strives to determine the best global standards for health terminology, and to engage with the global healthcare community to improve SNOMED CT, ensuring it is clinically relevant and supports patient safety. www.snomed.org