

White Paper

Medical Specialty Societies Have a Key Role in Driving Clinical Data Content Standardization, Especially for Reducing Reporting Burden

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Note: This article focuses on content-focused data standards (e.g., developing and using a common set of data elements, terminology, definitions, and structure). Data standardization more broadly also encompasses standards methods, protocols, and specifications for the collection, exchange, storage, and retrieval of information. These more technical subjects are of critical importance but are outside of the scope of this piece.

Introduction

The growing demand for EHR data has revealed fundamental limitations in usability for benchmarking clinical quality, understanding patient populations, and conducting research studies. Medical specialty societies are ideally positioned to drive the development and adoption of new data standards for their specialty areas.

GROWING DEMAND FOR EHR DATA REVEALS FUNDAMENTAL LIMITATIONS

Widespread adoption and interoperability of EHRs have been key US policy priorities since 2009 (Henry et al., 2016),¹ and billions of dollars have been spent by providers and the federal government towards achieving these aims (Glaser, 2020).²

In some ways, these efforts have been a success. The secondary use of EHR clinical data outside of direct care delivery has increased in demand, due to its utility in quality measurement, public health, research, and enriching the understanding of the effectiveness and efficiency of health care systems. However, this growing demand for EHR data has also revealed fundamental limitations in downstream usability, such as benchmarking clinical quality, understanding patient populations, and conducting research studies.

Much of this lack of usable and interoperable data can be attributed to limitations and slow adoption of agreed upon common data elements and current standards for structured collection of disease- and

specialty-specific variables. Where there is either a lack of options for structured data entry, or a lack of consensus and commitment to capturing information in a particular way, physicians are likely to document much of the clinical information in free text rather than discrete data fields. Thus, the information captured will be highly variable and difficult to access and leverage by users beyond that particular physician or practice. This creates many issues for care coordination as there is little immediate impetus for documenting patient data in a particular way if it will not be used to follow an established treatment pathway.

It is possible to convert unstructured data to a structured format for use in both clinical care and downstream research through methods such as chart reviews or natural language processing (NLP), however, both chart reviews and NLP algorithm development can be costly, time-intensive processes. To achieve true, sustainable health data interoperability, it is necessary to standardize and structure clinical data at the point of collection.

The problem: EHR data is generated by providers, however input of data can vary significantly between EHR systems, and even between individual providers in the same department. Therefore, even though EHR data may contain highly valuable and detailed clinical data, the data may be nearly impossible to access without significant time and effort.

MANY ORGANIZATIONS HAVE TRIED TO TACKLE DATA CAPTURE STANDARDS, EACH WITH VARYING SUCCESS

The Office of the National Coordinator for Health Information Technology (ONC) has set data standards and requirements that must be followed by entities looking to certify their health information technology systems. These standards can be found in the [ONC's USCDI \(United States Core Data for Interoperability\)](#). The USCDI is a standardized set of health data classes and constituent data elements meant to promote nationwide data interoperability. Having data standards included in the USCDI will be key to promoting widespread adoption and achieving true interoperability, by capitalizing on the regulatory requirement for EHR vendors to include these standard elements in their platforms. However, USCDI standards do not yet encompass all relevant disease-specific metrics. Thus, there is still significant work to be done in alignment with USCDI to improve overall content standardization.

Possibly the most successful data standard in the U.S. thus far is the International Classification of Disease (ICD)-10 codes for disease and condition diagnoses. The ICD-10 coding system is a good example of standardized health data, however these codes represent limited clinical information that is needed by physicians, payers, patients, or researchers. As such, there have been multiple additional efforts to introduce data standards for other clinical data types. These efforts have been led by various stakeholders, including academic medical centers, EHR vendors, and independent societies.

Academic hospital systems are often at the forefront of clinical data standards. They often develop their own general and disease-specific documentation standards to be used throughout the system, consulting their own experts, and customizing the implementation to meet the needs of their own patients and clinicians. While these standards are certainly valuable, there is rarely a concerted effort to drive adoption of these thoughtful standards at other sites. Therefore, data generated at these sites is still not comparable with data generated at other hospitals and health systems.

EHR vendors, such as Epic and Cerner, are also developing their data standards to improve the usability of their

products and to support their own internal analytics. For example, Epic has formed multi-specialty task forces that support the creation of forms and tools that can aid data capture for specific disease areas. However, these standards and tools are not shared between companies. Additionally, there can still be significant variation in how these standards are implemented across provider organizations, even if they have the same EHR vendor.

Finally, independent societies, such as medical specialty societies and independent standard development organizations (SDOs), are also driving efforts to standardize health data. Two well-known examples of medical specialty society-driven standardization efforts have been led by the American Society of Clinical Oncology (ASCO), and the Radiology Society of North America (RSNA).

ASCO convened a work group of oncologists, informaticians, researchers, and standards experts to create mCODE, a set of open-source structured data elements for oncology (Osterman et al., 2020).³ Their goal is to support multiple stakeholders, including clinicians, patients, and researchers, by improving the overall quality and consistency of cancer data (Confluence).

Similarly, RadLex, a comprehensive set of radiology terms, was created by RSNA to create a single source of medical imaging terminology that could be used by humans as well as computers, as the previous index, created by the American College of Radiology, was established well before the advent of digital images and the widespread use of EHR systems. The RadLex project brought together working groups of radiologists of all specialties for a series of meetings to deliberate over the appropriate terms that should be used to appropriately describe anatomy, pathology, devices, procedures, and imaging sequences (Langlotz, 2006).⁴

Other independent SDOs include LOINC and SNOMED International, which create international standards for health measurements and terminology. Although they are separate initiatives, SNOMED, LOINC, and ICD-10 are complimentary content standards which have been adopted by USCDI.

KEY PROVIDER-CENTRIC CHALLENGES LIMIT THE ABILITY OF SPECIALTY SOCIETIES TO BENEFIT FROM INTEROPERABILITY TODAY

A common source of frustration is that, despite widespread adoption of content standards such as LOINC, SNOMED, and ICD-10 at provider organizations, there are still significant barriers to accessing that information in a seamless fashion. Specifically, medical specialty societies may have considerable trouble getting valuable data from the EHR into their quality registries, despite their provider partners having taken many steps towards improving interoperability. This difficulty usually occurs for two main reasons: technical challenges with mapping data to standards, and/or limitations in the standards themselves.

True interoperability will only be achieved when both the technical and semantic hurdles have been reached. However, it is the journey towards semantic interoperability where medical specialty societies have the greatest role to play.

On the technical front, it's important to remember that just because information is captured in the EHR, there is no guarantee that it is available in a FHIR API, or that it is mapped to a standard code system. A lack of mapping can happen in a few ways. First, as discussed previously, if clinical information is entered as a narrative, specifically into unstructured 'free text notes', then there is generally no automated process at provider organizations for extracting that information and mapping it to an API such as FHIR that would allow the information to be accessed elsewhere and/or incorporated into a registry.

However, it is also possible for this crucial mapping step to be missing even if the information is entered in a structured or semi-structured form. For example, a form may guide a provider to use 'smart phrases' that are linked to ICD-10 codes for billing or for internal quality reporting, however, that does not necessarily mean the information is being mapped to the FHIR API. Similarly, clinical information captured in flow sheets (frequently used to document nursing workflows), while technically structured, is often not easily mappable to existing code standards (Johnson et al., 2019),⁵ and even if the mapping has been implemented, EHR vendors typically do not make flowsheet data available in the FHIR resource.

Even if information is technically accessible through the FHIR API, there may still be challenges to incorporating that information into a registry (or using it for any number of other purposes) because of a lack of semantic interoperability. Many standards as they exist today are intentionally somewhat loose to enable them to support multiple use cases and be implemented across multiple geographies and sites of care. However, this flexibility can also lead to unwanted ambiguity when trying to integrate information from two different providers or EHR systems.

True interoperability will only be achieved when both the technical and semantic hurdles have been reached. However, it is the journey towards semantic interoperability where medical specialty societies have the greatest role to play, both in defining new standards to capture information relevant for their specialty, and in helping to refine existing standards to reduce ambiguity and increase usability for the providers they serve and the researchers who will use this data to track quality and advocate for better patient care.

How does data standardization work?

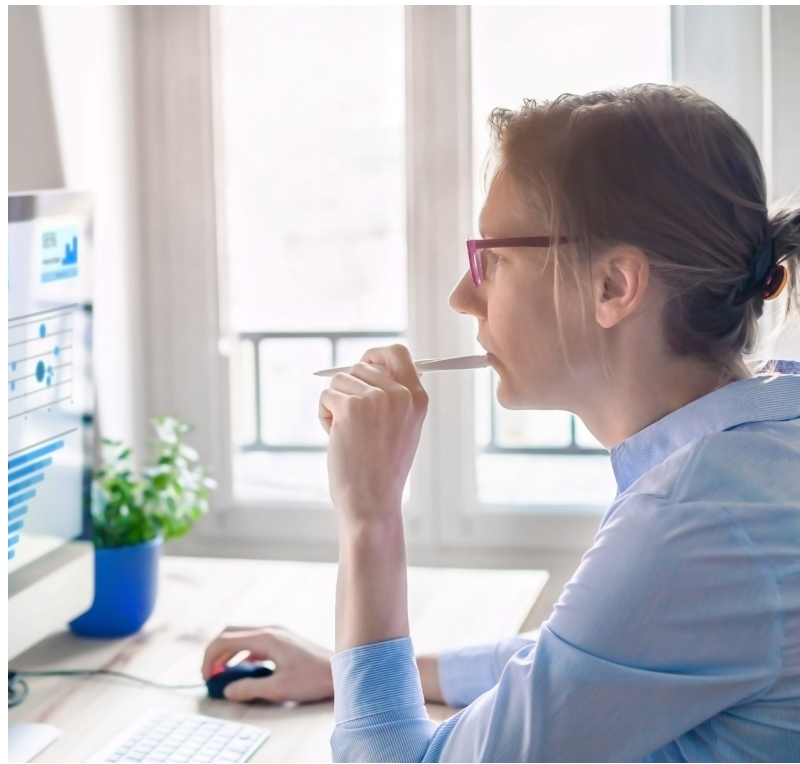
There are two key stages to clinical data standardization: developing the standards and disseminating the standards to drive adoption. Please note that there can be quite a bit of back and forth between these two phases, as standards development is a highly iterative process.

DEVELOPING DATA STANDARDS

Data standard development is a multi-stakeholder process where important variables to support key use cases (such as patient management) for a particular specialty or disease area are identified, public comments are solicited, and consensus is driven regarding the most appropriate ways to capture those variables in a usable and user-friendly way. Stakeholders who use the data, such as clinicians, patients, or researchers, are often the best positioned to identify appropriate variables needed in a particular data set. IT experts are also critical in translating these variables into technical data standards that can be incorporated into a common data model for collection and re-use.

DISSEMINATING DATA STANDARDS

Once the standard data elements are developed, they then need to be shared and adopted if they are to drive meaningful change. Eventually, the goal and gold standard is to have new elements adopted into future versions of the USCDI guidelines to drive widespread adoption and use. However, for a new data element to be accepted by USCDI, there needs to be a certain level of existing adoption in the community already. Thus, dissemination and real-world use is still an important goal for new standard clinical elements.



Disseminating the standards prior to USCDI adoption can be done in a few ways. One is through a top-down approach with the selection of a few key EHR vendors or key health systems with a robust population of the patients in the target disease area to adopt and integrate the standard data elements into their EHR data and user interfaces. The other is a more grassroots, or bottom up, approach, where awareness and value of the use of common data elements is driven by physician champions. In either case, disseminating the standard data elements involves getting buy-in from the providers and provider organizations who will adopt and use the standards. Messaging needs to be customized for different types and levels of stakeholders who will need to support the logistics and implementation of the new standards and help incorporate them into existing clinical workflows (e.g., leadership to sign off on funding, IT teams to manage technical build and integration).

Medical specialty societies are ideally positioned to overcome data standardization challenges

Medical specialty societies are often the best candidates to lead specialty-centric data standardization efforts and drive the development and adoption of new data standards for their specialty areas because of their access to deep clinical expertise, physician-centricity, and strong convening power across institutions and geographies. Additionally, as experts in their specialty areas, medical specialty societies are in an ideal position to coordinate the thoughtful addition of new clinical content standards needed for physicians in their specialty, and to ensure these standards are developed with “formal, explicit, reproducible methods for recognizing and filling gaps in content” (Cinimo, 1998).⁶ Finally, Medical specialty societies can use their clinical knowledge and broad stakeholder relationships to develop custom messaging needed to bring everyone together in support of this common goal.

Medical specialty societies also stand to benefit significantly from the downstream use cases that are enabled when clinical data is captured in a more structured and consistent format. These benefits can include:

- Capture of novel quality measures through a more granular view of patient pathway
- Decreased burden on physicians to input data into registry and registry coordinators in cleaning and structuring information
- Broader data capture from existing EHR inputs, enabling broader data and registry use cases. For example:
 - » Ability to benchmark clinical outcomes by provider, care site, and treatment pathway
 - » Identifying new clinical endpoints for treatment guidelines and regulatory use
 - » Improve the ability to support value-based contracting agreements through ability to access structured clinical outcomes data

Developing and disseminating health data standards present significant challenges

It is also important to note that developing clinical data standards is not a “build it and they will come” scenario. There is no such thing as a perfect standard. All standards development processes dance between the design elements such as the amount of detail, the generalizability of its use and with what other standards or systems it is compatible. Therefore, the most important factor in the adoption and dissemination of a data standard is the level of support a standard. The ONC has created the Interoperability Standards Advisory (ISA), a repository of all the data standards known to them and the maturity level of the standard. The ONC strongly encourages MSSs and other stakeholders to consult the ISA and consider partnering with other stakeholders who have already begun developing standards in your area of interest. The most advanced organizations will continue to work proactively with government regulators to shape downstream standards development around their specialties.

Additionally, after standards are developed, adopting them requires physicians to change the way they currently document information, requiring awareness of the new data elements that can be used, in addition to willingness to utilize these new elements as part of standard practice. Adoption may also require providers to commit resources to upgrading EHR systems and/or funding new roles (e.g., a ‘data standards officer’) to promote the value and use of data standards throughout their organization (Richesson, 2020).⁷

FOR MORE DETAILS ON HOW ORGANIZATIONS CAN SUBMIT DATA STANDARDS FOR INCLUSION IN USCDI, SEE:

[Getting Your Data Into The U.S. Interoperability Machine: Making The Most Of The USCDI](#)

Strategies to maximize your chances of success

Driving clinical documentation standardization is a complicated and resource-intensive process. However, it is also critical for the advancement of research and patient care. A review of early successes from organizations who are leading the way in data standardization yielded several important learnings.

These learnings and strategies include:

FOUR DATA STANDARD DEVELOPMENT STRATEGIES

1. Don't reinvent the wheel

In many disease areas, there are several concurrent efforts to develop data standards, often led by specialty clinics, academic medical centers, or expert committees within commercial EHR vendors. To effectively drive consensus around disease-specific data standards, organizations should seek out and familiarize themselves with existing efforts and use them as a starting place where appropriate. The [ONC's Interoperability Standards Advisory \(ISA\)](#) is a great starting point to investigate existing efforts in your specialty or disease area. Taking advantage of existing expertise will help raise the quality of data standards and increase the likelihood of downstream adoption, while avoiding unnecessarily duplicating efforts.

For example, when the ASCO work groups came together to identify the data elements that for mCODE, they conducted a review and mapping of the elements to existing coding systems, including RxNorm, the American Joint Committee on Cancer, ClinVar, Human Genome Variation Society, Human Genomic Organization Gene Nomenclature Committee, International Classification of Diseases (ICD), LOINC, and Systemized Nomenclature of Medicine (Osterman et al., 2020).

2. Define the use cases that will drive variable selection

While improving patient care and management is arguably the most important goal of standardizing clinical data collection, it is not the only use case that to consider when developing standards. Structured clinical data can also be used to measure quality, compare treatment outcomes, discover new clinical endpoints, and answer other disease-specific research questions. Identifying the uses cases for the data standards up front is essential to affirm the resultant data can drive as much value as possible. Tying data elements to specific use cases can also help drive real-world adoption, which is critical to demonstrate when advocating for the inclusion of new standard data elements in subsequent versions of the USCDI.

To build upon the standards established in mCODE, ASCO is supporting CodeX, an HL7 FHIR accelerator program that is working to build upon mCODE to support data capture aligned to specific use cases of interest. The CodeX community began by prioritizing use cases based on interest and expected impact, then determining where new data models and implementation guides would be needed to augment the existing mCODE standards (Confluence).⁸ Current use cases that CodeX is working to support include cancer registry reporting, prior authorization in oncology, patient recruitment, and risk evaluation and mitigation strategies (Confluence, 2022).



3. Balance granularity and usability

Simply developing standards does not guarantee they will work well in the real world. Providers have significant demands on their time, and it can be difficult to change existing behaviors. Therefore, despite the theoretical value of perfect and highly detailed data, it is important to balance the effort required to collect the data with the downstream value and other practical constraints.

When a group of researchers (supported in part by the Epilepsy Foundation) set out to define common data elements (CDEs) for pediatric epilepsy, they began by surveying existing documents with standardized epilepsy clinical data, including clinical notes and templates from pediatric epilepsy centers, existing sources of CDEs for research, and data dictionaries of three pediatric epilepsy registries. Once the working group had identified their initial set of CDEs to standardize, they then solicited comments on their pilot CDEs from 10 different specialty centers. They used the commentary to clarify the questions themselves, but also to optimize the number of questions included, as well as what information would pull through from previous visit entries such as diagnosis and epilepsy history, and which would require new entry each time, such as seizure frequency and treatments (Grinspan et al., 2021).⁹ Such refinements allowed them to find an appropriate balance between data quality and ease of entry.

It's important to note that the optimal balance between effort and detail will depend on the intended downstream use cases for the data. There is a higher bar for quality and specificity of data that is intended to be reused for regulatory submissions, as opposed to quality improvement or clinical care follow up.

4. Ensure standards are aligned with evolving interoperability guidelines

Emerging regulatory standards are shifting how data is captured, stored, and shared. While USCDI and HL7 guidelines are not yet comprehensive enough to cover critical data elements for all diseases and conditions, it is still important to be aware of existing and upcoming rules to ensure that your standards will align with evolving interoperability requirements. The ONC, in conjunction with CMS, have published multiple regulations that set interoperability standards for health IT systems. Much of these interoperability standards rely on the data elements and classes outlined in the USCDI. In addition, the FDA has recently released several guidance documents for the use of real-world data for FDA submission. The good news: by being proactive in driving adoption of your disease-specific elements, you will have an easier path forward to align with new guidelines as they are released.

For the past 10+ years, the ASCO has driven multi-stakeholder engagements to support the development and adoption of multidisciplinary, interoperable data standards for oncology research and care. This work has culminated in the mCODE project, started in 2018, which focused specifically on ensuring that cancer data would be sharable across providers and across different EHR platforms (Osterman et al., 2020).

This initiative has also spurred further collaboration between related specialty societies. For example, the American Society for Radiation Oncology (ASTRO) joined mCODE's executive council in 2019 (Christodouleas et al., 2021).¹⁰ The two groups have been collaborating on CodeX, an HL7 FHIR accelerator that is working to expand the number of standard oncology data elements.

FOUR DATA STANDARD DISSEMINATION STRATEGIES

1. Adoption strategies are not one-size fits all; different approaches may be needed for common conditions versus rare diseases

The most appropriate strategies for driving adoption will differ depending on the specifics of your disease specialty area and the associate provider environment. For example, data standards for more common diseases require a more widespread implementation plan is needed than for rare disease, where it may be sufficient to target a small number of specialty centers when lobbying for standard adoption and use.

For example, the Clinical Data Interchange Standards Consortium (CDISC) and the National Organization for Rare Diseases (NORD) recently announced a partnership to develop data standards for rare diseases. Data standards and associated user guides when developed will be posted on CDISCs website, where they can be accessed for free by any interested parties. This strategy is appropriate for rare diseases, where resources and data standards may be limited, and interested clinicians are more likely to seek out support. However, for a common disease such as diabetes, simply making data standards available on a website is unlikely to drive adoption by enough stakeholders to make a meaningful difference in interoperability.

2. Engage health IT vendors directly to drive widespread access to new standards

Prior to USCDI adoption, getting buy-in on new standards on a site-by-site basis is a long and difficult process. Unless you are targeting standards for rare diseases, the sheer number of sites where patients are managed is likely going to be too overwhelming for a successful grassroots effort.

In these cases, it can be beneficial to work directly with health IT vendors to build the standards directly into their platforms, rather than asking each site for the IT resources needed to build in the standards. If you implement site by site, it's important to know that the process for implementing the standards will vary across sites, and will require collaboration with clinical, IT, and EHR vendor stakeholders (RSNA, 2022).¹¹

To implement radiology standards, RadLex worked with Epic to incorporate their playbook directly into Epic's Foundation system. That way, not only do all Epic users have access to RadLex, they also automatically receive any updated features and content (RSNA, 2022).

To maximize the usefulness of this strategy, identify which vendor systems serve the most patients in your disease area, and start by engaging with them first before expanding to other platforms.

3. Provide resources to support adoption

Even the most thoughtfully curated data standards will still require some level of explanation if they are to be adopted properly. Providing resources to support staff training about the appropriate use and definitions of your standards (in keeping with Cimino's desiderata of formal definitions for controlled clinical vocabularies) can help reduce the burden of change on providers.

The PhenX Toolkit for Sickle Cell Disease Research is an excellent example of an initiative designed to promote the adoption and use of CDEs. The PhenX toolkit provides an explanation of each standard measure, the rationale for that measure, as well as a protocol for how that measure should be collected (Eckman et al., 2017).¹² It's worth noting that the PhenX toolkit focuses on CDEs for research, rather than clinical use, however it is still a valuable example of providing clinicians and researchers with the support and information they would need to successfully adopt CDEs into their work.

Beyond explanations of the purpose and proper use of new standards, additional resources may also be needed in instances where providers are asked to transition from old standards to new ones. For example, researchers have noted significant challenges when asking radiologists to transition from using the old ACR Index to the new radiology lexicon, RadLex. In response, RadLex created a web-based tool to allow radiologists to look up ‘translations’ from the old index to the new to make it easier for them to translate their academic and clinical work to the current standard (RSNA, 2008). Ideally, medical specialty societies should be prepared to offer this type of support throughout the lifecycle of the content standards they champion, particularly given the need for standards to “evolve gracefully” over time (Cimino, 1998).

4. Integrate standards seamlessly into clinical workflows, and provide real-time data back wherever possible

Adopting new standards is always challenging. Providers are often reluctant to add tasks to their already full schedules, especially if it’s not apparent that there is any clear benefit to changing their behavior. New standards can also manifest in several different ways, such as through the collection of specific data on each visit, new discrete data fields, or the modification or creation of note templates. To promote adoption, therefore, there should be a careful consideration of how best to integrate these standards into provider workflows (including who will capture the information, and how the capture will change from previous methods), and how to demonstrate real-time utility of the new methods to motivate uptake and continued adherence.

Organizations who are successful in setting and driving adoption of clinical data standards will have to ensure that those standards can be seamlessly integrated into existing EHRs and clinical workflows. In fact, data standard adoption in specialty clinics also

affords an opportunity for existing EHR interfaces to be customized to unique specialty provider workflows, a process that has been shown to reduce clinician burnout (Jason, 2021).¹³

Researchers at Nemours Children’s Health System set out to implement data standards for Sickle Cell Disease (SCD) that would enable real-time insights to guide patient care. They integrated their standards into clinical practice by encoding them in Epic SmartForms, and providing training to SCD providers, including nurse practitioners and hematologists. The researchers found that, 6 months after introducing the new system, the SmartForm was used to capture patient information about 50% of the time, a high level of compliance for a new procedure. They found that the providers were generally willing to take the time to enter standardized, detailed patient information at the bedside because the resulting data was fed into a dashboard that allowed them to easily view “individual patient reports that include baseline comorbidities, AEs, a health maintenance dashboard with annotated delinquencies, and information on medication dosing and adherence. This dashboard decreases the amount of time required to review a patient chart prior to an outpatient visit, as these data elements are scattered throughout the EHR” (Miller et al., 2020).¹⁴

Please note that these strategies are focused on driving adoption and real-world use prior to USCDI adoption, given that successful USCDI adoption requires a strong level of existing adoption and use. Please see [Getting your data into the US interoperability machine: Making the most of USCDI](#) for a detailed overview of the process of USCDI submission.

Conclusion

It's a long road to develop and deploy clinical data standards but there are many lessons to be learnt from organizations who have come before you to help along this journey.

Every step toward interoperability yields incremental gains, which can build upon one another as more organizations and providers start to see the benefits of more usable data and better insight into patient care.

Nevertheless, it should be recognized that even the best approaches to clinical data standardization are unlikely to yield perfect, universal adoption, as it's still likely that one or more providers or health systems will choose to modify your work at least slightly to meet their own needs or preferences. However, even partial adoption of data standards is still a major victory.

Organizations who are successful in setting and driving adoption of clinical data standards will have to ensure that those standards can be seamlessly integrated into existing EHRs and clinical workflows.

GETTING STARTED

The first step is the hardest part and our IQVIA data standard experts can help. We will have a confidential conversation with you to determine the best way to develop and disseminate your health data standards while mitigating any challenges. With a simple engagement, you will have a true understanding of what you have, what you need, how long it will take, and what it might cost. Contact us today to get started.

For more info, email PR-contact@IQVIA.com

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Jessica joined the IQVIA Healthcare Solutions team in 2021 to support patient advocacy organizations and medical specialty societies in developing registry and data strategies that support their core mission while also contributing to organizational sustainability. Previously, Jessica worked as a research analyst supporting health systems and their partners with topics such as medical group medication management, specialty pharmacy, and health system service allocation.

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In his current role, Harvey leverages his scientific background and healthcare consulting experience to assist medical specialty societies and patient advocacy organizations to enhance their data-driven capabilities, provide sustainable registry value, develop research offerings, and navigate the complex data governance of multiple registries.

Harvey has been with IQVIA for 7 years, managing large, global projects for pharmaceutical companies, providers, and other healthcare organizations. Prior roles include data and evidence strategy and implementation roles in Real World Analytics Solutions. He has a BSc in Biology from Imperial College London. Harvey is based in San Francisco, California.



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Lead the IQVIA nonprofit team that focuses on medical specialty and patient advocacy markets; Lead client engagement and strategy to develop innovative registry solutions for medical specialty societies.

15 years of experience working at various medical specialty societies developing clinical data registries, accreditation programs, measures, guidelines; analyzing and strategizing health policy changes; and technology and data strategy and development. Leverages experience and deep knowledge in medical specialty society quality programs to strategize and implement solutions to enable the specialty society's mission-driven capabilities while maximizing value to members.



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