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OUT OF THE CLINICAL BOX

Interoperability for Whole-Person Care

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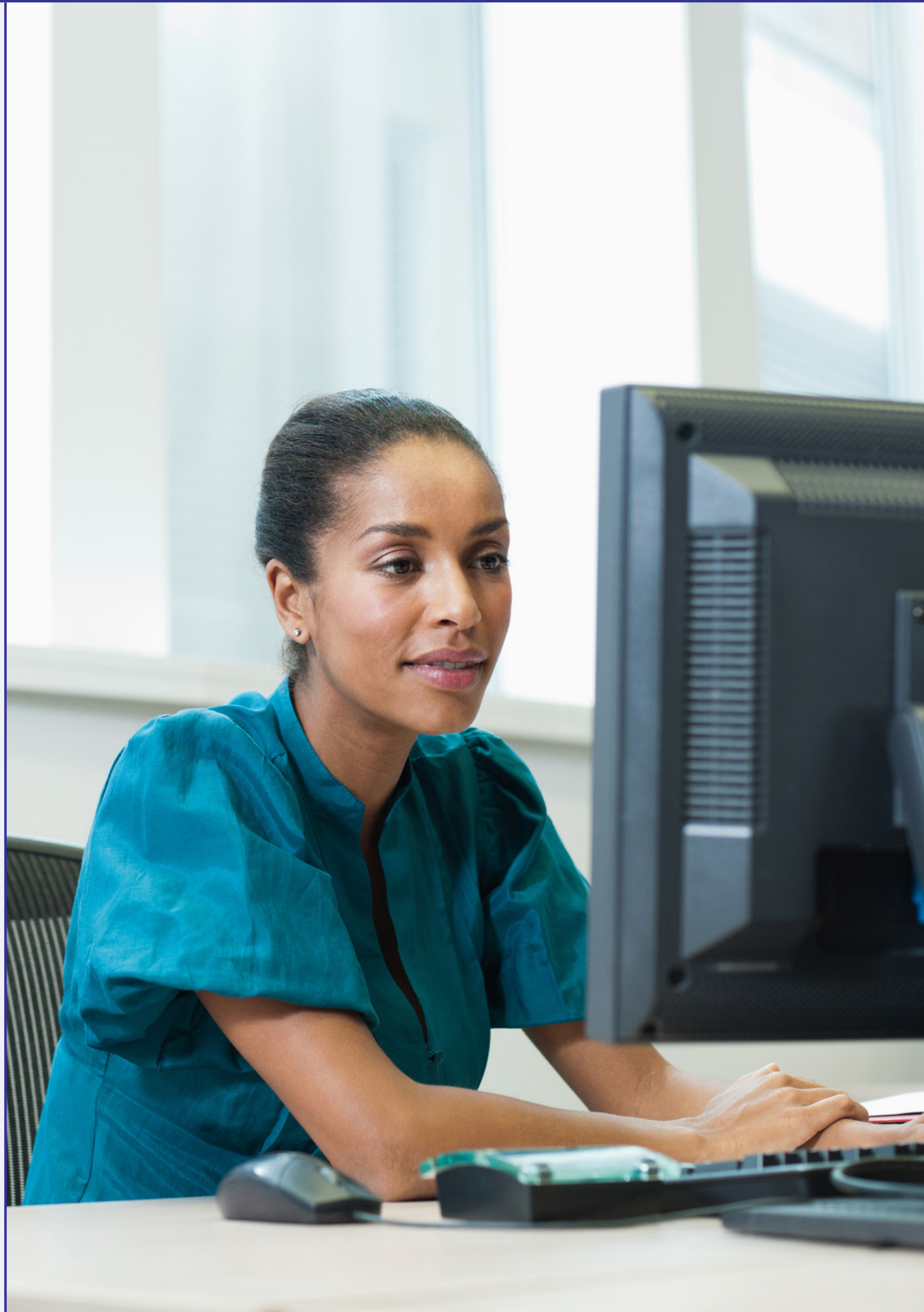

Introduction

We co-founded Luma Health in 2015 with a simple goal: *make it easier for patients to get access to care.*

The last decade of working directly with 650+ healthcare organizations across the U.S. has underscored the importance of standardized operational data, including appointments, intake forms, and financials, to delivering a successful and complete patient care journey. Our mission at Luma Health is to unite all aspects of a patient's healthcare journey – access, clinical, operational, and financial. I'm optimistic that interoperability regulations with the same whole-person view of the patient can positively impact how every stakeholder delivers a great care experience to patients.

Aditya Bansod

Co-founder and CTO

Luma Health

EXECUTIVE SUMMARY

Interoperability has exploded in the past five years, with advancements like the Office of the National Coordinator for Health Information Technology (ONC)'s 21st Century Cures Act Final Rule and the establishment of the United States Core Data for Interoperability (USCDI). Today, healthcare providers and health IT vendors have clear definitions for what and how to exchange patient data – and an important next step is ensuring that the data being exchanged forms an accurate and holistic picture of a patient's care. While interoperability regulation has made enormous progress in recent years, the exclusion of operational and financial data from USCDI and other relevant regulatory frameworks represents a key blind spot that impacts patient care.

Consider the experience that we're accustomed to at an airline. If an important flight is canceled, it's possible – though perhaps not typical – for Airline A to book a replacement flight on Airline B. The consumer can continue their journey with as little disruption as possible, because the airlines share important information like their schedules and destinations. This coordination didn't happen overnight. It took regulations, oversight, funding, and time. Ultimately, though, the effort paid off – resulting in a coordinated effort by private airlines to help consumers complete their journeys efficiently.

Introduction

Meanwhile, major healthcare providers within the same 10-mile area often don't share enough information to create true continuity of care. A specialist might have very little idea what care 15-month-old Ellie is receiving at her nearby pediatrician, and likewise the pediatrician relies on updates from Ellie's parents for a complete picture of her care. But knowing what was scheduled, didn't occur, is canceled frequently, or might be influenced by social determinants of health is just as important to the picture of Ellie's overall care as what happens in the visit room. Without this information, her providers have only a clinical view of her care – not a whole-person view.

The healthcare experience could be much more seamless with improved data exchange as a starting point. Imagine that instead of waiting for an update on the specialty care at Ellie's next well child visit, her pediatrician could proactively see that Ellie hadn't yet received the care and offer additional resources or specialists – even outside their system – who could see her sooner.

This whole-person, consumer-focused care delivery model is possible – we see it in other industries today. It's a future that will require regulation, oversight, funding and time. But the next step, and one that's possible given positive trends in interoperability, is improved data exchange beyond clinical information.

Challenges and Opportunities

CURRENT LANDSCAPE & CHALLENGES

In the short time following the Cures Act Final Rule, ONC has rapidly expanded USCDI to cover not just immunizations, problems, procedures, and similar data, but also broader clinical data such as social determinants of health goals and expanded demographics, including sexual orientation and gender identity. These expansions are critical to standardizing how patients get care across providers and care settings. The 2024-2030 Federal Health IT Strategic Plan released through ONC pledges to support "expan[sion], improv[ment], adopt[ion], and "implement[ation]"[1] of federal data exchange and certification standards, and ONC's USCDI+ initiative provides an agile framework for expanding the USCDI data set.[2]

However, in the meantime, data exchange standards lack a key portion of patient data. **Interoperability today is largely defined as the exchange of clinical data, including medications, allergies, social determinants of health, and more.** But the full patient journey includes more than just what happens in the exam room or hospital encounter. It includes scheduling and appointment data, insurance details, invoicing and payment data, intake forms, and other administrative data that does not necessarily contain PHI but forms a significant piece of a patient's healthcare information. Without exchange of this key data, the provider's understanding of the patient's care journey could be incomplete – ultimately impacting clinical care.

Challenges and Opportunities

THE OPPORTUNITY

State-level regulations have begun building on federal exchange standards. For example, California bill AB-133 Health (2021-2022) established the California Health and Human Services Data Exchange Framework (DxF). The DxF's policies encourage (though don't require) sharing of data including social determinants of health, and explicitly require compliance with federal data sharing requirements.[3] More recently, California bill AB-1331 California Health and Human Services Data Exchange Framework (2023-2024) proposes tasking a multidisciplinary stakeholder group with "Identify[ing] gaps, and propos[ing] solutions to gaps, in the life cycle of health information, including gaps in... sharing, exchanging, and providing access to health information," as well as with "develop[ing] definitions of complete clinical, administrative, and claims data consistent with federal policies and national standards."[4]

While these initiatives show promising progress toward advancing interoperability, their scope remains limited. Even with expanded required data sets to exchange at the state level, patients receiving care across state lines would not necessarily receive the benefits of that regulation. To continue to advance interoperability and data exchange throughout the period outlined in the 2024-2030 Federal Health IT Strategic Plan, we recommend that USCDI and other relevant data sets be expanded to include not just clinical data, but administrative data that providers need to understand a patient's care journey and take next steps.

This white paper will detail the impacts of operational and financial data on a patient's care, summarize the challenges and opportunities of requiring this data to be exchanged, and offer next steps for healthcare organizations, providers, and vendors looking to advocate for this next evolution of healthcare data exchange.

> Interoperability is all about getting the right data to the right people at the right time. The industry has made a lot of progress, and it would be really helpful to be able to expand some of those data elements that we collect as value-based care continues to advance."
>
> **Kathleen Snyder**
> Senior Counsel at Husch Blackwell
> and Healthcare Strategy Advisor

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1. U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. (2024). 2024-2030 Federal Health IT Strategic Plan.
2. U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. (2024). Interoperability: Standards and Technology: USCDI+
3. CalHHS Data Exchange Framework Policy and Procedure, Subject: Data Elements to Be Exchanged. (2023)
4. California Health and Human Services Data Exchange Framework, Cal. Assemb. AB-1331 (2023-2024).

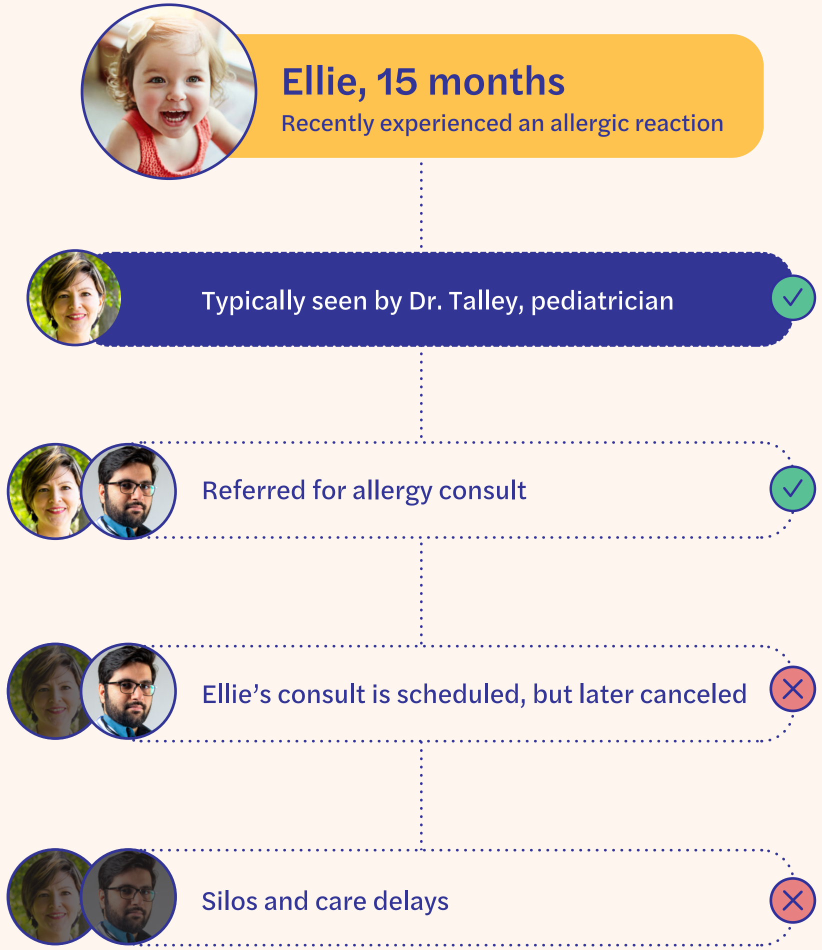
The Impact on Patient Journeys

By defining the required USDCI data set as solely clinical information, ONC misses the opportunity to require administrative information that could also impact patient care – and sets the standard for other regulatory frameworks that do the same. Namely, this administrative information might include:

- Insurance details, including insurance provider, insurance card upload status, and insurance eligibility
- Intake forms and patient questionnaires
- Invoicing and payment data
- Scheduling and appointment data

Without inclusion in USCDI and other regulatory frameworks that leverage it, this information is exchanged inconsistently. Open APIs might not exchange this information, or vendors' documentation on accessing the APIs might not be readily available.

PATIENT JOURNEY



Ellie, 15 months
Recently experienced an allergic reaction

Typically seen by Dr. Talley, pediatrician ✓

Referred for allergy consult ✓

Ellie's consult is scheduled, but later canceled ✗

Silos and care delays ✗

The Impact on Patient Journeys

Consider the impact on patient Ellie's journey when scheduling and appointment information is not readily available:

✗

1. Ellie is typically seen at a pediatrician using EHR A.
2. Ellie is referred to an allergist using EHR B.
3. Ellie's pediatrician, Dr. Talley, would like to schedule a follow-up visit after Ellie receives allergy testing. However, he lacks information about whether and when the allergist referral was scheduled.
4. Dr. Talley's office and Ellie's parents must manually coordinate and share information during Ellie's well child visits, creating additional burden and delaying Ellie's follow-up.
5. With the combined impact of transportation challenges, a provider shortage at the allergy group, and the manual coordination by Ellie's parents, Ellie waits for months to be seen – time during which she risked exposure to allergens at daycare.

By contrast, Ellie's journey when this information is exchanged is much smoother:

✓

1. Ellie is typically seen at a pediatrician using EHR A.
2. Ellie is referred to an allergist using EHR B. Dr. Talley would like to schedule a follow-up visit after Ellie receives allergy testing.
3. The week after Ellie's visit, Dr. Talley sees that she is scheduled with an allergist for the following week.
4. When Ellie doesn't receive the scheduled appointment, Dr. Talley follows up and learns that Ellie's parents have transportation challenges during the hours that the allergist's office is open. He reaches out to discuss changing Ellie's allergist appointment to a nearby pediatric allergist that offers weekend visits, when Ellie's parents have more flexible transportation.
5. Ellie receives her allergy testing and follow-up with Dr. Talley within a month, rather than waiting several months.

Headwinds and Tailwinds

TAILWINDS

1. **The establishment of USCDI represents a huge step forward for interoperability.** Now, the industry shares a framework for exchanging a core set of data with standardized definitions, and USCDI forms the basis of other regulatory frameworks for data exchange. With this common framework, expanding to further data types is simpler and more standardized. USCDI includes other information necessary for whole-person care, including social determinants of health concerns and goals. This sets a positive precedent for adding more data points that can paint the full picture of a patient's care. For example, a provider might see that an appointment is frequently canceled and intervene with support for social determinants, such as transportation assistance.
2. **The continued expansion of USCDI and other relevant regulatory frameworks with USCDI+, an initiative to iteratively extend the USCDI data set.** The USCDI+ initiative and the regular expansion of USCDI, with the latest proposed version of USCDI released in January 2025, show encouraging progress toward broadening the data set and could easily include additional operational data in further versions.

HEADWINDS

1. **The change of presidential administration creates a transition period in policies and priorities.** ONC under the Biden administration focused on interoperability as a priority, establishing the Trusted Exchange Framework and Common Agreement (TEFCA). It's unclear if interoperability regulation will remain a priority in the new Trump administration, or how the administration might make changes.
2. **Reticence from EHRs and other data holders to fully exchange patient data creates a challenge for interoperability.** To continue to move forward, health systems and providers must encourage all vendors to openly exchange as much patient data as possible.

HOW YOU CAN HELP

- Encourage your vendors to exchange "above and beyond." Many vendors today are already exchanging more than the required data set! Encourage all of your vendors to look at the big picture when exchanging data, and continue to go beyond the required data set.
- Keep an eye out for state and federal regulatory public comment periods where you can add your input. For federal regulations with open comment periods, search regulations.gov.

Conclusion

To support whole-person care, interoperability regulations must encompass more than just clinical data. An expanded required data set across regulatory frameworks would create more actionable opportunities for providers to intervene in their patients' care, ultimately getting patients to the desired outcome faster. The good news is, recent advancements in interoperability have made this more attainable than ever. But there's still work to be done to move beyond clinical-only data exchange.

You can help make an impact on the future of interoperability by making your voice heard – both as regulations are being developed, and as your health IT vendors respond to their communities' feedback. By advocating for a fuller data set – clinical, operational, and financial – for exchange, you can help advance the ways that providers use patient data to provide holistic, proactive care.

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