Closing the Data Divide in Healthcare

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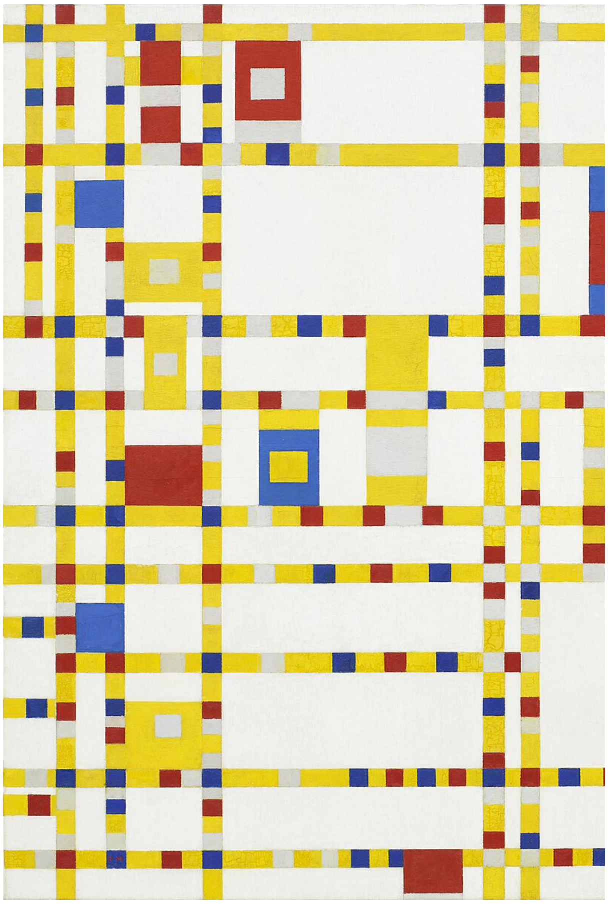
Starting clinical rotations in medical school is a very unique experience. You see diseases you may have never learned about, you are expected to understand a language you don't yet speak, and you are being constantly evaluated. I expected all of these things. What I did not expect was that learning the electronic medical record (EMR) would be one of the biggest challenges of the year.

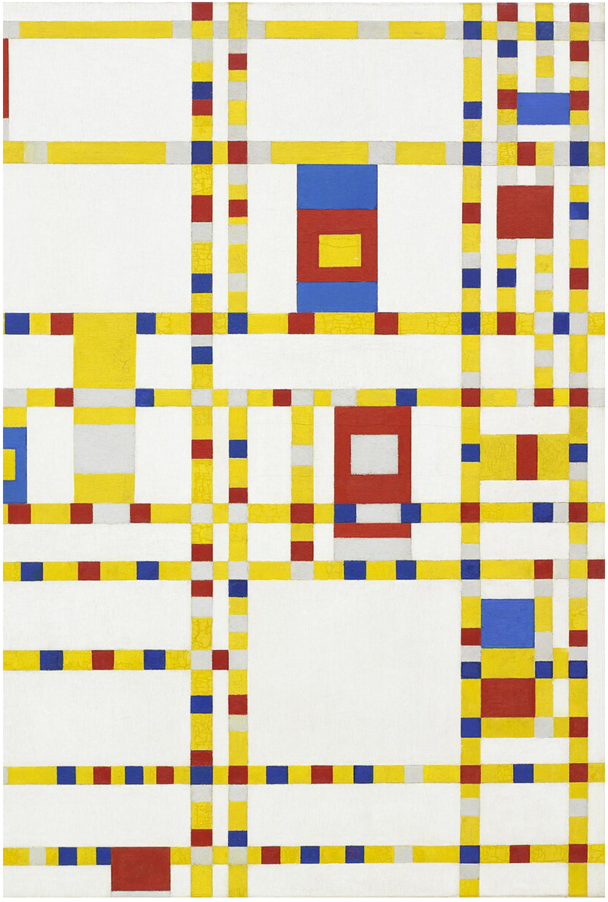
I started my rotations at Brigham and Women's Hospital, where we use Epic, a common EMR system. My next rotation was at Boston Children's Hospital, which at the time used Powerchart. I had just gotten familiar with drafting notes in Epic, and everything changed the next week. Two weeks into my time at Boston Children's, they transitioned from Powerchart to Epic. As a medical student, it's not surprising I was struggling with these changes. What was surprising, however, was that everyone around me was too.



Charting is a major responsibility of the modern physician. When patients are unable to tell their own stories, the clinician must rely entirely on the medical record to learn the information necessary to provide safe and effective care. However, despite the importance of the EMR, it is not standardized (1). Hospitals across the country use different systems, and even those that use the same system may not have seamless data sharing (1).

This is a problem for three reasons. First, without a universal data system, it is impossible to elegantly coordinate care. Physicians have no choice but to reorder tests or retry treatments unnecessarily when information is not transmitted effectively, contributing to waste in the healthcare system. Second, this can pose real risks to patient safety.

For example, a patient may have an allergy to an antibiotic. It is unconscionable to imagine that this allergy may be documented by previous healthcare providers in just a city over, but that this patient may nonetheless suffer a life-threatening reaction because that information wasn't available. Finally, the lack of a universal data system is a hindrance to health equity. Unfortunately, many patients have not had access to resources to achieve strong levels of health literacy. It is inevitable that these patients are the same ones who may not be able to recount their history to a physician and thereby may receive lesser quality care. **A universal data system levels the playing field, giving all providers all the information they need to take care of patients, regardless of where they show up for care.**



As the capabilities of artificial intelligence grow, now is the ideal time to work towards a universal data system. In a universal data system, secure, real-time learning could occur on patient data to inform continuous care improvement (2-3). If implemented, the possibilities are limitless. AI, with the help of real humans assessing its results, could tell us which hospitals may need certain resources, what types of biases may be impacting care, and which patients may have diagnoses that haven't yet been considered.

I imagine there are many reasons that a universal data system doesn't yet exist. One of those reasons might be that current vendors profit from their proprietary systems and are thus disincentivized from allowing interoperability. Surmounting this would likely require federal mandates and regulatory oversight. I also empathize with concerns some may have over data privacy. Questions surrounding who has access to the data and how it may be used are important to consider. I think there would have to be strict limits of the commercial use of this data as well as the ability for patients to see exactly how their data is being used. On the provider side, there may be resistance to the AI aspect I proposed specifically. I think some of my colleagues would worry about the real-time continuous care improvement increasing workload or threatening their independence by making rigid suggestions. As with all uses of AI, it is critically important to co-design tools with the critical stakeholders and frame the data as a way to reduce harm as well as workload, and importantly not as a means to police decision making.

In the status quo, patients are receiving worse quality care and healthcare costs are rising, in part because of the lack of unity across health data systems. We are also missing out on opportunities to improve care by failing to leverage new tools to analyze the vast amount of data that healthcare professionals spend much of their time creating.

Our generation must build the health system we wish we had because our patients cannot wait another decade.

If we dare to build a universal healthcare data system, we choose a future where every patient encounter becomes a step toward safer, smarter, more equitable care.

References

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