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Sharing EHR Data Is Essential for Precision Medicine

If every dental clinic and medical-care facility fully shared their data, then, as a totality, these data would be profoundly more valuable and useful than they are in isolation. Collectively, these data could do extremely useful things: reveal the comparative effectiveness of treatments, identify links between oral and general health, and identify regional trends in disease, to name just a few. These are all components of the learning health system highlighted by Dr. Walji. The learning health system has a distinct and important population-level perspective. Precision medicine, on the other hand, emphasizes the individual patient. As President Obama said when he announced the Precision Medicine Initiative in January 2015, “That’s the promise of precision medicine—delivering the right treatments, at the right time, every time to the right person.”⁽¹⁾ As dentists, the era of precision medicine will allow us to ask and answer questions like, “How can all the information we have amassed benefit Mrs. Patel, who is sitting in my chair right now?”

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(EHRs) all around the country and the world. Alas, with the exception of research efforts like the BigMouth Dental Data Repository, which was highlighted by Dr. Walji, clinical data exchange across institutional boundaries in dentistry is often limited to demographics like name and address, rather than substantive clinical information. Needless to say, demographics alone cannot drive robust learning or precision medicine. So what's stopping us from reaping the rewards of all the countless hours of data entry into our EHRs?

There exist three major barriers to the broad-based data sharing that is required to drive the learning health system and precision medicine: 1.) data standards, 2.) privacy concerns, and 3.) institutional factors.

As Dr. Walji noted, we need to ensure that our systems can communicate. Think about it like people having a conversation: meaningful communication relies upon a shared vocabulary. If one person speaks Urdu and the other speaks Mandarin, little communication is going to occur. The same holds true for our EHRs. Having been isolated for so long, the terminologies underpinning our systems have become idiosyncratic, much like dialects within a country. This is a serious impediment to communication between two systems, let alone

among the thousands of systems in use across the United States.

Because procedure codes (Code on Dental Procedures and Nomenclature, CDT) underpin billing, these have long been standardized across dental practices, so communication across systems about procedures should be relatively straightforward from a terminology point of view.

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A promising recent development is the emergence of standardized diagnostic terminologies, such as the Dental Diagnostic System (DDS) (2) and the Systematized Nomenclature of Dentistry (SNODENT).(3) Of course, it would be ideal if there were a single diagnostic terminology used by all dental clinics, but mapping (“translating”) meanings across the different terminologies is at least a tractable

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problem. The larger challenge to the use of standardized dental diagnostic terminologies is both technical and social: These terms must be available in the EHR, and dental team members must be motivated to enter them.

The second impediment to broad-based data sharing is a concern for the privacy of our patients. In the clinical setting, the Health Insurance Portability and Accountability Act (HIPAA) serves to protect the privacy of individually identifiable health information. A first step, then, is to share data that has been de-

identified, such as is being done in the Big-Mouth Dental Data Repository. The so-called safe harbor method to de-identify data is to remove a range of identifiers, including names, all elements of dates that are directly related to an individual except year, full-face photographs, etc. One can make substantial progress with de-identified data sharing, particularly in the context of learning health system population-level considerations. With that said, in the precision medicine setting, such as in the case of rare conditions, the act of de-identification makes the data substantially less useful. Broad sharing of identifiable data across institutions



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as part of clinical care will require fundamental shifts in HIPAA. Thus, this type of data sharing currently occurs primarily in the research setting, in which participants give informed consent to share their identifiable data.

Finally, institutional factors can present barriers to the kind of data sharing that will fuel both a learning health system and precision medicine. Data are viewed as both a commodity and a risk to healthcare institutions.

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They are a risk because release of the data could reveal information about the institution, such as success and failure rates, e.g., proportion of dental implants placed that fail. Data are a commodity because they represent a perceived competitive advantage in terms of learning and improvement. In an ecosystem

without data sharing, practices with large datasets enjoy an advantage over smaller practices with yet smaller datasets.

All these points about data sharing may seem extremely theoretical. In fact, I have seen that data sharing has tangible implications for our patients. In addition to being a dentist, I am part of the National Institutes of Health-funded Undiagnosed Diseases Network.⁽⁴⁾ The network is comprised of 13 Institutes working together to help patients with mysterious medical conditions find a diagnosis.

Ultimately, these people most often are diagnosed as having extremely rare diseases. The patient and family adviser to our project is Matt Might. His son, Bertrand, was born with a mysterious disease. The family was able to obtain a diagnosis thanks to genetic sequencing, yet struggled to locate others with a similar condition. It wasn't until Matt blogged about it that he was able to locate other children with the same condition as Bertrand's. Today, as a group, they are able to understand the condition better and to advocate for research that may improve their children's lives: They would not be able to do this as individual patients. I am personally inspired by the ingenuity and tenacity of people like the Might family; at the same time, I am inspired to

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wonder why we have not been able to create a culture and practice of clinical data sharing that would do some of the legwork for them.

I am not the only one asking these questions, and the Precision Medicine Initiative has the potential to catalyze the incorporation of data sharing into clinical practice. As individual practitioners, as a profession, and as institutions, we will have a choice to make: to embrace the promise and change of precision medicine or to continue to keep our knowledge and data siloed.

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