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Proem

My father died when he was 45 of his second heart attack. I have multiple sclerosis. These don't seem connected. Heart disease is hereditary, but MS isn't. For me, heart disease and MS still connect. They connect because when I got diagnosed with MS, the neurologist said I'd had had MS for 25 years. I would have repeated episodes of falling, fainting, and being unable to get out of a tub. Because of my family history, I'd get a cardiac workup. The result would always be negative - twice or three times a year for 25 years. Spell, cardiac testing, results negative. I cannot get the incorrect diagnosis code of heart disease out of my many medical records. I really have MS.

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Another story: I have a friend who is 5'3", 5'4", and weighs 137 pounds. Somebody typed in her record that she weighed 317 pounds. The weight was easy to fix the next time she went in she could not get the obesity diagnosis code off her problem list. While mine is annoying, you can imagine hers has severe implications with dosages and everything.

My obsession with documentation errors throughout my career accelerated with the start of electronic health records and supercharged with OpenNotes and increased reading of our own records.

Calculating an error rate is quite tricky. A 2020 study in the Journal of Informatics in Health and Biomedicine compared 105 secretly collected audio recordings of visits with unannounced standardized patients among 36 clinicians. There were 636 documentation errors, including 181 charted findings that did not take place and 455 findings that were not charted. Ninety percent of notes contained at least one error. Yikes.

Introducing Virginia Lorenzi 03:31
My guest is Virginia Lorenzi, the Senior Technical Architect at New York-Presbyterian Hospital and an HL7 Standards Developer. HL7 is a not-for-profit standards development organization that aids in exchanging information across electronic health record platforms (medical records and health apps). These standards for data exchange are required for clinical practice and evaluating the quality of health services. Errors in electronic health information make for faster mistakes. Not good. Virginia also talks about FHIR (Fast Health Interoperability Resources). FHIR part of HL7. Don't worry if they feel Greek to you. Just know they are data standards within a standards organization. Our conversation combines common sense with the technical. I will break in when the gap seems too broad. You might want to skip a section and forgo the details.

HL7's Patient Empowerment Workgroup 04:56
Health Hats: Okay. So why don't you tell me what you're working on with FHIR and errors?

Virginia Lorenzi: So, in Health Level Seven (HL7), the standards organization that develops FHIR, we created a work group in 2019 called the Patient Empowerment Workgroup. The focus of this work group is to amplify the voice of the patient within all HL7's work. I realize that time is a problem, and we're trying to figure out how to include people most helpfully. And when we started this work group and it was founded by Debbie Willis, who's the other person I'm talking about, Dave DeBronkart, ePatient Dave, and myself. The members, many of them, are very much patient advocate voices. So, it's a fairly special group within HL7, in my opinion. You're welcome to join if you'd like. We'd love to have you.

An intelligent customer understands some of the technical 05:45
Virginia Lorenzi: What you brought up before is that sometimes you have to understand the technical to be a smart customer and know an advocate for what you want. And I am a teacher as well, and I teach my students that one of the important goals for my clinicians is to know how to be savvy customers and

ask what they need, not be snowed by the techies. Also, understand why it's hard to do. So that, and then you could be a savvy customer and get what you need.

So, in the workgroup, there are many things that a patient is interested in. And patients are direct customers of FHIR interfaces because data is now being freed from EHR and going through these personal health records. We couldn't do everything. So, we did a kind of prioritization exercise. Several things bubbled to the top: consent and care plans and any kind of patient contributed information: anything that the patient is contributing and corrections, which is one of those contributing data. And corrections were a hot topic, a very big, hot topic of the group. So, we ended up with three projects, and then we watched everything else. Our three projects are patient requests for corrections, the patient contributed data, just trying to understand the whole field and who was helping to run that as Jan. I know you're friends with friends at Jan Oldenburg. A wonderful person is running our advanced directives projects. How do you get your advanced directives where you need them, even if you can't communicate them or someone else can't communicate them electronically?

Requests for corrections – a sign of engagement 07:12

Virginia Lorenzi: That's another project we have, Debbie Willis and I are the project leads of the patient requests for corrections project. And the idea of this project is patients can get their data more and more now. And there are plenty of studies, even though there are plenty of vignettes and just look at your record and errors. But plenty of studies say that the record is riddled with errors. And that errors lead to bad patient care and other things. A patient looking at their record and talking about their record is engaged. So, they're probably going to have a better outcome. If they're looking at enough, if you want to get someone engaged in some sort of diagram, you're putting an error in it, and they'd be like, oh wait, that's wrong. And then they're paying attention. You're starting to care more about yourself, defending yourself.

Fixing errors - from the fifties 08:01

Virginia Lorenzi: When you see an error in your record HIPAA provides, and this is, we're doing this on an international basis. And there are international rules, and different countries have different rules, but talking about HIPAA, you have a right to get your record fixed. The way to do that it's like from the fifties or something. Usually a paper form. The first thing is no one knows. Like you go to your doctor, they don't necessarily. They can only fix one part. They can't fix it. In other places, they don't do it necessarily. It seems, and then maybe you finally figure out that if you go to medical records, you might get someone who's going to work the problem. But medical records are often hidden in the basement. You don't know where you're going to find them. There's usually a paper form. Maybe you can fax it in if you're lucky. Or you could be a high-tech place with an electronic form. And perhaps the electronic form is one that you don't even have to print out, but you could press a button and send it in, but I'm telling you that's high tech. And so you might have that, but then the request goes in, and HIPAA requires a turnaround time. You have got to get a request return response within 60 days, although the organization has the right to ask for a 30-day extension. So that is, today, where we expect to have a response in nanoseconds, that's a long time to wait, especially if the reason why you want your record corrected is that you can't get disability or you can't get insurance, or you're waiting for the surgery. Do

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you want the doctor to get the correct records? I have a loved one who was in an immunization series, but they were delayed getting their second shot because it wasn't documented. So that's pretty serious.

Patient satisfaction and errors 09:30

Virginia Lorenzi: And as well as that loved one was fed up with the system, like really, and patients, I understand you've got the one thing of dealing with the fact that you're sick. But then you have this whole other thing you must deal with this extra burden of this invisible work of lots of administrative pushing. I know for myself that I judge an organization by its billing practices because that is my last. It doesn't matter how nice they were when I spent time in the hospital. If they're sending me horrible bills for years afterward, and I can't get them resolved until somebody we'll look at me and listen to me, I will drive past them, which has nothing to do with clinical care.

Release more information, find more errors, feel worse 10:07

Virginia Lorenzi: So now we are starting as a country to release more and more information because of the 21st Century Cures Act. It's much more common to have your results and your notes on your portal. And even in these apps, these personal health record applications. And it's going to be more and more of that, which means more and more of the places where errors exist are going to be there. And it's almost overwhelming if you think about it if you. If I kept talking to you and never gave you a chance to say anything, it might make you sick because you see this error and want to do something with it.

Virginia's going to mention the MAR, Medication Administration Record. Providers, electronic health record vendors, and patients probably put most error correction and prevention efforts into medication reconciliation. Medications are recorded in an MAR. Those records are used to keep track of meds given. Yet many people describe instances of medication duplication, medication interactions, and medication not prescribed and given, especially during hospitalization and return home.

Burden on clinicians, burden on patients 11:42

Virginia Lorenzi: With our clinicians, we know that anything outside of the workflow is just downright dangerous. It has to be within the workflow in that workbook. And I think you're a nurse, right? Yep. Yep. So you understand that completely. You can't be doing Medication Administration Record MAR stuff when it's not in the MAR. It has to be right in there. You don't have that kind of time to waste. All of us need to want to do things in our workflow. And the hassle factor, because many people do not report errors in the record, and I'm not surprised because it's so hard. Yeah.

What if you could push a button and start and track the correction process 12:12

Virginia Lorenzi: But if you're on your personal health record, your app, and you look on it, and you say, Hey, that's not right. And you can push a button. And that goes to the mothership to say, hey, this thing on my record is not correct. And then, even though they might have 60 or 90 days, you can track and see a status once they get it. Oh, okay. It looks like it's queued. Oh, it seems like it's being processed. Oh, it's being reviewed. Oh, you know what? It looks accepted but not done yet. Oh, it was processed. It was denied here, but you're giving a reason. You're getting you to get things back electronically within your

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process. At least you could have an idea that you've done something about it by checking a box. And someone's looking at it, got to a queue. And then the other thing is that sometimes there might be some back-and-forth communication. You might be like, hey, I took a picture of it and sent it, or they might say, okay, I hear you say that you don't no longer smoke, but when did you quit smoking? And then the patient could respond. So, we also have kind of a back-and-forth communication mechanism. So, we've created a draft by our specification called the Patient Requests for Corrections FHIR Implementation Guide. We've gone through four Connectathons.

Connectathons – a meeting of the minds in a sandbox 13:17

Connectathons are in-person meetings of multiple stakeholders testing standards and workflows to help ensure that interfaces between IT systems work. Connectathons provide a detailed implementation and testing process to enable the adoption of standards-based interoperability by vendors and users of healthcare information systems. During a Connectathon, systems exchange information with corresponding systems in a structured and supervised peer-to-peer testing environment. Remember, it's tough to correct anything when you don't have standards. Remember Y2K – the millennium turnover? People anticipated errors in dates. They couldn't say I was born in 22. 1922 or 2022? The standard needed to be changed to a four-digit year for mistakes to be fixed, not a two-digit year.

Virginia Lorenzi: So, we've been testing it like real code kicking the tires against it. We do not have any EHR vendors who have written code, but they participate. They pay attention. They listen. They've given us advice. We have some great guy from New Zealand who stood up a server to pretend he was the EHR to respond to correction requests in amusing ways. And then we have a couple of patient apps that are apps that are out there that are trying it out and seeing how they would show it to the patients that use their apps. One allowed an annotation right in the record, and that's how they were able to send it, and people have different ideas on even how the design should be. And that's the whole idea. It still allows innovation to happen, and different people have different ideas. So we've gone through four of those. So connectathons are agile software development and standards development. And now we're going to do an official HL7 ballot. It's our second ballot of the workgroup, but the first ballot up this project is happening in May. So, the ballot is planned where we're going to.

Making decisions about data standards 15:32

Here we discuss how decisions are made about data standards. Remember that birthdates have standards. Is the year 22 or 2022? Gender has standards. Male, female, cisgender, transgender, intersex, and more on the birth certificate. Are decisions made by voting, consensus, who votes? I find this fascinating. If you don't, skip ahead for about 90 seconds.

Health Hats: A ballot means consensus? Meaning that whoever has a vote. Yeah, so that would be the first, so who votes?

Virginia Lorenzi: So, to vote, so to participate in HL seven, like the calls and everything, you don't need to be an HL7 member, and you can even vote on those calls for things or decisions without being a

member. But to attend the HL7 three times a year working group meeting, there's a fee. And typically, there I'm in person, but. Through May of this year, they're still remote. So, it's been cheap because it's remote and the travel cost is too high. But you must be a member of HL seven to the ballot, or you have to pay a fee for the pallets to participate in a particular ballot cycle. And. Members are typically it could be an individual, but a lot of organizations, so hospitals.

Health Hats: So, people who are members pay a fee. Something goes out to them saying thumbs up, thumbs down for standard.

Virginia Lorenzi: And more than that, when you vote, you cannot allow just to say thumbs down. You have to provide what you don't like and exactly how you would correct it. So, if you're, it's like reviewing a document with a vote, so they review it, and you make suggestions on how to correct it with your vote.

Health Hats: Okay. Say that there is no financial burden, and something gets voted up. Okay. So, it's something that is accepted. Does that mean that it's, the process is for one record?

Virginia Lorenzi: What would happen is, let's say, the ballot passed. Now. We would be able to publish standard implementation guidance. We had an international standard HL7 FHIR implementation guide for patient requests for corrections. So that's like the gold standard out there that you would use if you want to implement a patient request for corrections workflow in a standard way. That doesn't say that anyone will be motivated to do it. That's a whole other thing. And that is also why we kind of those things we're looking for from this project. One is we want advice from people who understand the problem. To see are getting it right? And we also want people to help get the word out there and socialize the need for something like this because we wish it adopted. We are the whole reason why we're not doing this for fun. We're doing this because we think this could be meaningful to patients and their caregivers.

Eureka, we have standards. Now, who's going to use them? How easy can we make it? 18:41
I find this very important. Like I've said, data is ink on paper until it's analyzed - what does the data mean? The analysis is a shadow until someone uses it, tries it, adopts the lesson, the learning. Similarly, standards are ink on paper, albeit heavily resourced, time-consuming ink and paper, until it's used, adopted in code, and electronic records and apps.

Virginia Lorenzi: And I think there's another benefit that puts things on a work queue for a provider, that then they can have a queue. It's a way to communicate with them versus them answering the phone. I think it also has a benefit as on the other side of it. It helps streamline things.

Health Hats: Yeah. I guess what I'm asking is that this is wonderful because I see an error here, and then I could push a button and start a process. That is a combination of an electronic and personal process to correct an error. I'm a person that has. I see six different specialists, and they're on different systems.

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And some errors are unique to a record, and some are universal, meaning that errors got populated in many places. And I know the difference between a process with a clinician that writes their note collaboratively with me versus those clinicians that don't. And so, with the clinicians that have real-time writing notes with me. First, they're about me instead of about them. And then the negotiation about what's accurate happens in real-time. And there are way fewer errors.

An error is not an error, is not an error 21:11

Health Hats and an error is not an error is not an error. There are errors where it's the wrong med, or there are errors where. My weight is a hundred pounds off, or there's an error that we didn't agree to that. Do you know what I mean? Like in terms of planning. So, there are different kinds of errors.

Virginia Lorenzi: And that's different from two other things, but there's. People can still ask them. I'm 10 pounds lighter now. That's an update... I no longer smoke, that's an update, but the fact that you've recorded that I smoked last year when I quit ten years ago, that's the error. Another one is I'm not obese, right? Maybe that is the clinician's terminology was appropriate for the chart. But still, having a patient's voice on that would help activate the patient. There's still a benefit in that conversation because the patient does feel concerned that they were there and want to be heard. So that's still our interactions. Demographics are different too.

Health Hats: I led a couple of EHR implementations in my day. And one of the things that I insisted on, which was not popular, but I insisted on, is that the core data sets needed to be cleaned up before any implementation or transition. That we weren't going to. And the errors were very basic, duplicate patients, duplicate clinicians, wrong information that were in like basic files, and so whether that's identity files or demographic files and that was months and months of work.

Virginia Lorenzi: And, you might say, you might look at your chart, and you might say, I don't have this. I don't have HIV. And then when the medical records people look at it, they might say, yes, That's someone else's result. Oops, let's move it. Like it could be old charts, some very serious intertwined charts happen, maybe rare cases, they need to be worked.

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Ink on paper 24:07

Health Hats: Okay. It sounds like what you're working on is necessary but not sufficient. And that's what you're talking about in terms of socialization. In my last episode with Bryn Rhodes and Laura Marcial, I

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had a rant through it: data is ink on paper or bytes on a drive, and it is meaningless unless it's interpreted, used, or acted on. Data by itself is not information or action, so I appreciate that there are many pieces to this. You were the one that initiated this conversation. What can I do for you?

Virginia Lorenzi: I want to bring up one more thing, though. You're saying you've got these errors, and some of them are with one provider, and some are proliferating. Welcome to the world of interoperability. If you had one of these personal health records, they could allow you to get your data from many different organizations and bring it together. It's still not how we'd like it to be, but you usually can look at a directory. You don't even have to have the data in your system say it's wrong. You can just say, I know I have data wrong in a system. You could get a directory of systems and say, 'okay, that system, I want to correct there. This other system I want to correct there. And then, you could have a list of requested corrections from five different systems. That is, in theory, possible. And that's just some more examples.

Here Virginia is talking about directories. Directories are listings. Here is a listing of medical records systems. As I've said before, I see seven specialists who use three different electronic record systems. There would be a directory containing those three systems. Knowing about directories is all part of understanding a bit of the technology behind the problem of fixing errors. The more understanding we have of the technology, the more we can hold our own in conversations about fixing whatever we're trying to fix. Remember, it's the technology experts' job to explain it to you so you can understand. As Virginia has said, take a stab at it. If you're wrong, they'll jump on that and want to correct your misunderstanding. Be like a mule. Hang in there.

HIPAA-federal rules about requirements to correct errors 26:38

The other thing is that the HIPAA rule says that if a record is amended or if a record amendment is denied. Especially if the patient disagrees, that disagreement or the amendment is supposed to be sent to other places where you've sent the data. And that was written in the paper world. And I don't necessarily think that necessarily happens now. Especially the disagreement. I doubt that gets sent on a care transition. And it might matter where you say you don't smoke; they say you smoke. And you disagree, and you explain why you disagree. You might want that disagreement going along, or you have the amendment that says you don't smoke. But so, even though it's fixed, they may have already sent the data. It's a problem. Another thing that we're looking at, as a phase two, is to start looking at those kinds of data types and also potentially proposing them as USCDI fields. USCDI is the United States Core Data Set for Interoperability.

An interoperable Core Data Set means that a set of data components are standardized and agreed upon and used across healthcare to transfer data across those applications. A simple example would be that the core data set only allow last names to be one word, not two or more as some appear on birth certificates, or that we record temperatures in the US in Fahrenheit, not Celsius.

Virginia Lorenzi: Grace Cordovana is a big advocate for this project.

Health Hats: I love Grace.

Virginia Lorenzi: You'll notice that she'll tweet about this. I'd love you to retweet it.

Health Hats: Oh yeah. I do.

Virginia Lorenzi: We would love your help in socializing this, helping us with vignettes, and helping us just understand how we can do this to make sure we get this right. So, what are we missing? Yeah. I think this is important. And if you try to correct your records, I'm very interested. If you try to walk the process and get your records corrected, let me know it goes.

Misdiagnosis – Out damn spot! 28:54

Health Hats Corrected, meaning through this process or corrected, any which way possible? I can tell you. I have multiple sclerosis. I'm almost 70 and was diagnosed in my fifties. The neurologist said I'd had it for 25 years when I got diagnosed. He could see that in my brain scan. My wife and I could piece together the episodes and what happened is since my father died at 45 of a second heart attack, I always got a cardiac workup. That was always negative. I'd say one to four times a year over this whole span. And I would get a workup that would always be negative. Then finally, I had a PCP who dogged it till I got a diagnosis. She was convinced this was not cardiac and dogged it until I got a diagnosis. But I still have cardiac diagnoses in my record because I've been worked up tens of times for cardiac, and it's always been negative.

I just can't get that off my record, it's, and it's not worth it, but I have to say to everybody, whenever I have a new physician, this was MS. But that was like a manual process of speaking to the doctor, whoever was new, and they were like, oh, it's just too much work to get it to change. I know. Thank you for telling me. I'll keep that in mind. Do you know what I mean? And even being a nurse and being in the C-suite of healthcare, I couldn't. It just was so burdensome

Virginia Lorenzi: Talking to some medical records people, I've heard that we've had to change things in 10 places in the record, and then we must go and figure out who can make the change because that doctor's not with us.

Health Hats: And I moved quite a bit, over my life, from Detroit to upstate New York, I mean to Western, Massachusetts, to West Virginia, to upstate New York to Boston. This has followed me. Again, until my PCP and here in Boston, I just kept saying to her, something's wrong. I don't feel right. Anymore, it's I don't care. It's okay. So, I understand I gave up. But and so that's, and that's not even that I don't find that my story that's serious compared to Jan, I love the story of Jan, she's a small person. Maybe she weighs 135 pounds, and her record ended up saying that she weighed 315. And she'll talk about what she tried to do to get that changed because it affected her, the dosage of her meds that she was

considered obese. Do you know what I mean? And it was just like, they transposed some digit one time, and then it's this crazy. And not to me, that's dangerous.

Virginia Lorenzi: Yours is dangerous, too.

Impact of errors 32:07

Health Hats: Let me just talk to you about time, so you have a sense of what I'll juggle in thinking about this. I believe error correction is an important issue, and I've been on this issue for the last 25 years of my career. It had come up repeatedly in different roles, especially when I led some EHR implementations. I was telling you that brought it to a head for me. It was just common sense to me to clean up data sets. And when I saw how difficult it was, it heightened my awareness of the problem.

My obsession with the proliferation of errors in health care data (claims and clinical) extends into research through my clients, PCORI, and PCORnet. Research depends on data filled with errors. When I ask about cleansing data, Researchers tell me they have ways of cleaning that data. But they don't take the corrected data and then amend people's records so they're accurate. I realize that's impractical with our current systems. Yet we live with it.

Virginia Lorenzi: I'm also interested in research, and I'm not a researcher, but I'm on the faculty at Columbia University. I don't know how that happened, but it happened. So, I'm thinking about this a bit. Wouldn't it be nice to have people research how much work goes into getting your record corrected, like measuring that invisible work? Some of that has already been done, and how many errors are there? What do these errors mean to be able to do research for quality of care?

Motivation to fix errors 33:50

Health Hats: The people that are key to that, as far as I'm concerned, are Joint Commission and NCQA because if Joint Commission and NCQA say that this is something, we're going to evaluate your process for correcting errors. There will be a lot of attention paid to it.

Virginia Lorenzi: But before anything's end up in their court. Yeah. Like I think, and even if it doesn't end up in their court, I believe having science helps to have some science around it. So having science that shows that there is a problem with getting records corrected might be a helpful thing, in my opinion.

Health Hats: Here's what I would be willing to do. I will consider doing at least an episode about it, if not a couple, because I think this is important. You've motivated me to delve into it more since I got your email. And I would be willing to, and since I love Grace, she and I have worked on several projects together, and she's a dream to work with. Just so much fun and so bright. I can think of a couple of other people I don't know if [Kistein Monkhouse](). She's a vlogger. She's a smart communicator. She has grown with the use of her communication tools. I would be interested in knowing more about this stuff. I would commit a couple of hours a month to finding and, like when would Grace puts out something and

I see. I retweet it or whatever. Whether it's on LinkedIn or Twitter, those are things. I feel like it's the least I can do. And so that whole idea about how you communicate this stuff I'm interested in. How do you tell the story about this stuff?

Virginia Lorenzi: There was an article written in JAMA recently, and then, graced tweeted that out. But if, not Jan, but grace, but if Grace writes something or if you do a podcast or if Kistein does something, then it's just this, all these different media sources that are all saying something about it. Then all of us retweet it, then that also, I just think, will lead to the

Health Hats: Do you know Peter Elias? He, Grace, and I did a project together with the Society of Participatory Medicine. I'm maybe at the end of next week. I'm going to interview him because he's a guy who changed his clinical practice to deal with the problem of errors and really what he did from a participatory medicine point of view. I think he's a guy whose voice I want to include because he's taken the bull by the horns and changed how he did practice.

Virginia Lorenzi: That prespective is significant for this project. Just a problem.

Health Hats: It's so big. It's so big. And to think that we research crap data. Oh, we believe that medical records are good data. It's like, how could we believe that.

Virginia Lorenzi: We have sophisticated methods to clean data. Yeah, we do.

Health Hats But do we use them?

Virginia Lorenzi: We will. And I'm going to introduce you to Debbie.

Health Hats: I met her in the blue button plus initiative. Is that possible? That was I my first foray 20 years ago into national informatics. And I was ineffective. I did accomplish one thing. I got them to increase the definition of the care team to include the caregivers.

Virginia Lorenzi: That's big. You should give yourself some credit for that because the caregivers get left out no matter what we do. Make this like extra credit. I don't need to do the extra credit. No, yes, you do. The caregivers are critical.

Health Hats: That was the one thing I accomplished weekly for 18 months. That one thing.

Virginia Lorenzi: So, we'll join very technical HL7 calls, and we'll be like, wait a minute, but did you think of the caregiver? Oh yeah, we left that out. Okay. We'll put it in. That'll be a big accomplishment, but I think it's a big accomplishment.

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Health Hats: Yeah. All right. It's lovely to see you and talk to you. And I w this I'll put you in my loop about this, and you do the same alright. Take care of yourself.

Virginia Lorenzi: Thank you, Danny. Bye.

Reflection 38:44

A wide-ranging conversation, indeed. I want us to appreciate that electronic health systems are full of errors. Those errors have an impact on lives and research. We could correct those errors, but we need an infrastructure beyond going down to the basement and asking clerks to accomplish the impossible. Too technical? Virginia's HL7 Patient Engagement team tries to work the technical end – the standards for processing errors. However, as with almost everything in health care, you can't separate the technical and the human. Error gum up workflow and lives. Correction won't happen unless fixing becomes routine—one step at a time. I have a recorded chat with Peter Elias in the queue. He's a primary care doc who shares his approach to patient engagement, Open Notes, and correct documentation. Keep the faith. Keep up your good work. We appreciate all you do.

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