Perspectives from the Field Interview Series

Interview with Mehret Mandefro, MD, MSPH

Chief Medical Officer for Amida Technology Solutions

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Interviewer: Jane Hyatt Thorpe

Questions:

1) Please tell us about your work and your organization with respect to health information?

2) How is the health care system changing the way health data is accessed and used?

3) What are the most significant barriers to achieving these changes?

4) What strategies would you recommend to encourage greater use and exchange of health information across the health care system by stakeholders?

5) Are there any special concerns about access to data that should be addressed by policymakers?

Transcript:

Question 1

JHT: Welcome to the Health Information and the Law Perspectives from the Field Interview Series. Today we are speaking with Mehret Mandefro, who is the Chief Medical Officer for Amida Technology Solutions. Welcome, Mehret. Thank you so much for joining us. We're very appreciative to have your time today and we have a serious of questions that we would like to review with you and are looking forward to our discussion. So, jumping right in, please tell us about your work and your organization with respect to health information and the exchange of health information.

MM: Sure. Well, first of all, thank you for having me. I'm excited to be a part of this conversation. Amida is an open source data company with a long-standing track record in health. Our CEO, Peter Levin, co-created and led the Blue Button project while he was the Chief Technology Officer at the Department of Veteran Affairs and I was actually his White House Fellow at the time. So, we've been working on health informatics for the past 6 years now, actually. Obviously, a lot has happened in that space. Blue Button has gone on to be the most widely used personal health record and our company has built on its success by building other Blue Button components. Namely, the tool or software we've built is called the Data

Reconciliation Engine, the DRE, and it is an infrastructure component that accepts health data in a variety of formats and consolidates it into an easy to use structure. So the DRE allows enterprises and consumers to reconcile health information from different sources into one single master health record. We believe that access to health information is a vital precondition for enabling a value based care system, enabling patient-centered care, because it allows consumers to actually have the means and the opportunity to make informed choices about their health.

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Question 2

JHT: That's wonderful. So, obviously over the last six years you have seen a lot of changes. What have you noticed that are some of the most prominent ways the health care system itself is changing in terms of the way health data is accessed and used?

MM: So, historically, health data has been trapped in institutions with proprietary systems and customized data format. On top of that there have been poor incentives, misaligned interests, and HIPAA regulations that have all kind of made it difficult to share this information and that climate is what has drastically changed. Now, we have standardized formats, formats like the Blue Button, and incentives between stakeholders. For example, payers and consumers are aligned in a way that they never have been in the past. It is actually in the interest of payers to know everything they can about their patients in order to take care of them better, instead of using health data to select out the sickest ones. I think in addition to that, consumers now have a legal right to access the health information on a medical record in electronic form. Which means institutions actually have to share it by law and, there are obviously also financial incentives for sharing this information that institutions have never had - for example, Meaningful Use. I guess the last aspect of the change that I think is particularly important is the growing consumer demand for this data. Because of things like wearables and fitness tracking devices, consumer attitudes are changing when it come to wanting to access data. Health care systems have to rise up to meet that demand. So, for all of those other reasons, the landscape of health data and how it is accessed is totally changing.

JHT: That's great. Actually, for some of our audience members who may be less familiar, would you mind if we took a step back and you could provide, perhaps, just a brief overview of Blue Button and some of the components that you are building to further enable Blue Button?

MM: Sure. Blue Button started at the VA. The first pilot project was at the VA. It was essentially a way for veterans to get access to their care and it partly leapfrogged the standards discussion. The first version of Blue Button was literally an ASCII file that made it easy for people to get their health information. CMS then joined on and it grew wider. So, there are multiple kinds of formats. But, essentially, it made it easy to extract the data. Then, HHS took over the Blue Button project and it has become kind of a service mark and they started to market it more widely. So, now even private sector companies (lots of payers, insurers, etc.) have pledged to use the Blue Button. I think it's actually over 500 private and public sector organizations. It has become less of a format and more of a way of talking about access to data. So, if you log into patient portals you might see that icon, that Blue Button icon, so that's what I mean when I say it is a service mark. We ingest multiple kind of Blue Button formats now with the DRE and essentially it's more of a back end tool we've built. Most of our customers are actually enterprises. We are in the weeds of the data plumbing and allowing our enterprise customers to ingest various formats into an easy to use structure.

Question 3

JHT: That's great. So, thinking about looking ahead, you talked about how some of the barriers to access and use of health data have been tackled, in terms of proprietary nature, misaligned incentives, obviously you reference the Meaningful Use program and growing consumer demand. What do you think still remains as the most significant barriers to continue to further use and access of health information both on the provider and as well as on the consumer end and others who are in the lifecycle of the health care system?

MM: In my opinion, I think that the most significant barriers continue to be cultural. It's actually not the technology. There's actually great technology that allows you to do this. By cultural, I'm really referring to, essentially the lack of an enabling environment to support the growing demand consumers have for their data and also the lack of an enabling environment to make it easy for providers to share that. I think, framed alternatively, you can talk about these cultural barriers to just supporting patient engagement and encouraging patients to actually own their data. What the Meaningful Use requirements lay out is kind of ahead, unfortunately, of where institutions are still at. Very practical examples are patient portals. Patient portals exist right now but they are kind of anemic, and they are not exactly a top priority for a lot of institutions. Obviously, there are exceptions to this, but I think from what I've seen in the work with Amida, patient portals continue to be an afterthought and if they do exist, there is a very limited utility of data and the scope. So it doesn't engender or encourage certain use from the consumer side and I think part of that cultural problem is reluctance intuitions still have to share this data because there is still a question of ownership. A lot of institutions still believe that patients don't own their data and that's a real problem. You can understand how widespread this problem is if you look into your own health care use and ask the institutions where you receive care, you'd be surprised at what some of the official policies are around who owns this data and that's a problem. Obviously, it creates a tension between the growing consumer demand for health data and the structures that are set up in order to meet that demand, but overall I think we focus too much on the provider side of the equation. I think there's a lot more that needs to be done on the demand side of the equation. Far too many consumers are still not participating in their care in the way they should and still don't know that they have the right to access their care the way that they do. I have two elderly parents who I take care of and I was trying to get my father's health records and it was actually a battle. I couldn't believe how hard it was for me to get it and I'm obviously empowered and educated in the universe of health data. So, I think we have a long way to with changing the culture around it.

JHT: And when you say institutions, reluctance of institutions to share and release information, I just want to clarify my understanding is you are talking about hospitals, physician practices, other healthcare providers in general where people are interacting with the actual health care delivery system.

MM: Right, think largely hospitals. I have less interaction with the smaller provider care networks in my current position; I'm more dealing with large hospitals and enterprises. But, yeah, I would even include some of the payers in this.

JHT: I'm fascinated too by your comments about consumer engagement, I think it's a challenge, and one of the things that struck me was that I was recently at a meeting for the Office of the National Coordinator where there was a group of payers who were presenting on their efforts related to encouraging their provider networks to share and exchange health information at greater rates. What actually struck me, frankly, was the focus on their providers and their provider networks and the fact that they hadn't really jumped the hurdle to thinking about patients. I'm very intrigued by your comments about encouraging, pushing consumer demand because I think that's the other side of the coin that has received less attention and as you noted, has been one of the barriers. As you mentioned with your elderly parents, uncertainty about what they can or cannot access, hesitation on the institutional perspective on what they can or can't share, or the payer perspective. What have you found, working with hospitals and the larger enterprises in terms of ways to break down those cultural barriers, ways to better enable and empower patients to become more engaged in their healthcare?

MM: Yeah, you know I think technology has a real role here which is why I'm so excited about what Amida is doing about putting technology into the hands of users that could start to build this culture around patient-centered care. I mean, the idea of patient-centered care has been out for quite a while – it's not a new idea. It's just that, we haven't been practicing in a system; i.e. we were in a volume based system where listening to patient voice and empowering patients wasn't incentivized on any side of that equation, right? So, I think that part of what technology can do is help put people truly at the center of their health information flow. So, for example, when that happens, issues or barriers in the past like HIPAA kind of go away because it is the patient who owns the data. People always forget that HIPAA came at a time when third parties were exchanging all of this information on behalf of patients. It's a whole different conversation when you're actually saying that the patient is in control. I think part of how you build demand and part of how you change culture is empowering patients with tools like technology and making it easier for them to do that. I think the other piece of it is that there needs to be a lot more done around patient education efforts when it comes to demanding these rights. I think a lot of people don't realize that they have this right to access their health information. When I told my father, he had no clue that the doctor was supposed to provide this information and actually that there is even a time requirement around how long you should wait, and guess what- if you don't get it, you can actually complain. The idea for patients and, obviously I have taken care of patients as well, that they can kind of talk back to their doctors is kind of foreign. Some of this is having a broader conversation around health literacy, actually, and even changing the dynamics of how people think about participating in that care. At Amida, we very much believe that access to actual health information, *your* health information, is the first step in redesigning the flow and engendering a new culture around how you access data.

Question 4

JHT: That's great and that makes a lot of sense. You mentioned earlier that patient portals exist but they are somewhat anemic, they haven't been widely adopted on the patient end. In your reference to technology and putting technology in the hands of the users, have you found that there are better types of technology, or forms of technology, that are better suited for consumers or that have given a better chance of breaking down these barriers to patient access?

MM: I don't know about types but with technology I think about functionality. Very critical capabilities for all portals to have are view, download, and transmit capabilities. There are still tons of portals that are just views, you just kind of look at it but you can't actually interact with your data. In order to empower patients to actually have a voice in their care process, to own health, the holy grail of patient-centered care is shared decision making and shared power. People not only have to have the access to view it, but they need to download it, they need to talk with their caregivers, talk to people about it, they need to actually interact with it to use it in some kind of way and then they need to be able to share. All three of those functionalities are incredibly important, I think. As well as the other functionality is this idea that hopefully the access to health information is starting to be bidirectional so it's not just about receiving the information from the medical record or from your laboratory or from your pharmacy, but it's also patients having the ability within these portals to actually upload their own notes and thoughts about care so that communication is something that can truly be shared. Because the minute you enable something like that through technology, the entire flow of that clinic visit will change. You can imagine a situation where your primary care provider will have seen what the patient concerns are so that when that patient walks in you don't have to wait for them to share that information, you can just say, "Oh I see that these are some concerns. Let me address that." I think those are the kinds of proactive steps the providers have to take in order to level the playing field to every clinical encounter.

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Question 5

JHT: So in thinking about greater access to and use of to information by the patient population in particular, have you seen or experienced issues in terms of data integrity or data security that are involved with some of these forms of technology and different types of functionality where you may have providers and patients supplying information to the platform for the data?

MM: Yeah, you know, I think, obviously, data integrity, security – Amida actually has a cyber-security background as well – I think they're very important, but I think we have put too much time focusing on data collection overall. I think the data is definitely out there and we have ways of making sure that we can access it but, I think, in my opinion, where we should be placing the focus, especially from a policy perspective, is on the actual *use* of the data. So the security question should be: who is using my data and for what purpose? So said differently, the question is more: is someone doing something nefarious or unauthorized with my data? I don't think we're having that conversation in Health IT. There's good news here, because there's actually technology that allows us to track the use of data. We need to start thinking very broadly about block chain technology and the use of health data, which actually allows you to track flow of data. Block chain technology is widely applied in economic applications, like Bitcoin technology uses it, but it has yet to be applied widely in health and health data and I think it represents the next frontier of policy concerns regarding access and security.

JHT: So, in thinking about that, and in thinking about the role of policy makers in particular, what would be your advice or guidance for policy makers in general to be thinking about what would help further, as you're saying, greater focus on the use of data, and then also thinking about who's tracking and using the data for particular purposes as well?

MM: I think we need to look outside of health to see how others are dealing with this. One thing that is very clear to me is that although 95% of Amida's work has been in health care, issues with data interoperability and security and integrity are obviously not unique to health. Data accumulates in isolated silos in many sectors and individuals want on-demand access to their data in all of these sectors. There are ways that other sectors have solved some of those problems that I think could benefit the health sphere. So, I think the application of block chain technology in the economic field and understanding that better from a health policy perspective could be huge.

JHT: Mehret, thank you again for joining us today. This has been a wonderful conversation about patient use and access to information and the tools that Amida is building. We greatly appreciate your time and expertise and look forward to more conversations with you in the future. Thank you.

Further Resources:

- Learn about Amida Technology Solutions on their website
  - http://www.amida-tech.com/
- Health IT describes the Blue Button initiative
  - http://www.healthit.gov/patients-families/blue-button/about-blue-button
- Video explaining Amida's DRE (Data Reconciliation Engine)
  - https://www.youtube.com/watch?v=GUAbxBqzTYw
- Health Information & the Law Comparative Map on the Right to Access Medical Records
  - http://www.healthinfolaw.org/comparative-analysis/individual-access-medical-records-50-state-comparison