Changemakers Podcast episode 7 transcript
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Terry Myerson, CEO, Truveta

Omar Abbosh

Hello, my name is Omar Abbosh, and I am the Corporate Vice President of Industry Solutions at Microsoft.

will.i.am

And I'm will.i.am, entrepreneur, philanthropist, musician and producer, and my mother’s son.

And this is Changemakers.

Omar

There are a lot of people around the world driving change that impacts society. In this series, we share stories of transformation directly from the leaders themselves who made the change. We’ll talk about their obstacles and triumphs, their learnings, and how technology has accelerated their mission.

Two years ago the pandemic shook the world and exposed massive gaps in health care infrastructure all around the world. As COVID-19 overwhelmed hospitals, the lack of real-time data only made it much harder for doctors to diagnose and treat patients. Truveta officially launched in September 2020 at the height of the pandemic with the mission to drive innovation in patient care. By aggregating clinical data like lab results and physician notes from many health care systems, the platform enables researchers...
to analyze data on how drugs are being used and to find cures faster. CEO Terry Myerson joins us today to discuss what they learned from their first full year of business and how technology is empowering health systems to save lives with data. Terry, thanks so much for joining us today.

Terry Myerson

Thanks for having me.

Omar

Terry, you became the CEO of Truveta in I think March 2020, at right as the pandemic began. And I think we all saw scenes of shock from around the world where health systems were genuinely facing this onslaught and not knowing exactly how to handle it. Take us back to that time and how it inspired your mission.

Terry

Sure. I think that Truveta is a new company with a vision of saving lives with data. Our mission is to help scientists find cures faster, help every clinician be an expert wherever they are in the world, and help families make more informed decisions about their care. The word “Truveta” is the union of two things: true for truth and “veta” is “knowledge” in Swedish. And one of the biggest healthcare systems in Seattle is Swedish hospital.

Omar

That’s great.

Terry

We think about, we’re bringing together truth, which is whether all the data that we think of that the data recordings is truth and we’re trying to create knowledge that we all can learn from.

You know, one of the more vivid memories I have from that time, reflecting one of the inspirations for Truveta was, I recall these debates taking place on television where President Trump would be citing these clinical studies saying “we have a cure! we have a cure! hydroxychloroquine works!” And then the leader of the World Health Organization would be going on television and to a press conference saying it doesn’t work. And there was just this confusion in terms of who do you trust, which data is right, how can these clinical studies cited by the President of the United States be incorrect and then what data is the World Health Organization using? Where is the data that made this happen?

And so for me when an old colleague of mine from Microsoft, who had become the Chief Information Officer of Providence Healthcare, offered me the chance to help, it was like an immediate thought. I’m like, ‘I’m at home, my kids are at home, I’m scared
for people I care about, I'm confused. I'd love to get them anything I can do to help. And then when I got inside it just opened my eyes to so many things about healthcare. You know, I was confused as a consumer but there inside the health systems they didn't know either. They didn't know whether this drug works. And it just grew from there.

Omar
You're being very human and describing a reaction that I think many, many people felt, but you actually took steps personally and changed your life around this. What personal experiences did you have that helped drive you here to say ‘I'm gonna do this’?

Terry
There was two real defining moments that led to the creation of Truveta. For me it was, one of the pharmaceutical companies which makes one of the infamous drugs that was being debated, approached the health systems and said “thank you for buying our drugs, but we don't know if it works either.”

Will
Wow.

Terry
We learn from clinical trials, you know, the way we learn about the safety and efficacy of our drug is by running these regulated clinical trials which take multiple years. And this is now a real time situation. That was eye opening to me. And then I guess there was a defining meeting I recall when we were talking about all these public health data feeds that we were making for COVID and it was like, what about every other disease? I mean, my father died of colon cancer, my wife's best friend has breast cancer, I have an old work colleague diagnosed Parkinson's Disease. Where's the data on that? Help us care for all those patients. And you know, Rod Hochman, CEO of Providence, an amazing man, he shared with me, “well, that data set doesn't exist. We don't have data on COVID. We don't have data on anything else.”

Will
Wow!

Terry
The leaders of the American healthcare system have been talking about this for years. We've been talking about the need to build this data set that could inform how we take care of patients.

And so really it was starting in that March April 2020, but really through the spring/summer last year, was daily calls, multiple calls with lawyers, and CIOs of health systems around the United States, and saying can we put together a consortium.
Because you don't want data from one locale or one health system, we wanted data representative of the United States.

In September, four health systems—four large national health systems—those CEOs said 'we have the moral imperative now to do this,' and they stepped up and provided the first financing. It was, I was, a little nervous 'cause you're starting a new company and we had the support of four health systems which was frankly not enough to achieve the mission or the vision. But since then 16 other health systems have joined Truveta and these are the providers of care that provide over 16% of every clinical encounter in the United States every day are now providing their care to Truveta. And so we announced data on a daily basis that's represented at the full diversity of the country: geographically, race, ethnicity, gender, age. And it's exciting. It's exciting the impact we think we're gonna have.

**Will**

How did you get them to cooperate? How did you get these 16 health systems to come together and join a new company? And how did you work around one of the healthcare systems wanted to do it and corral the rest of the systems themselves?

**Terry**

Well, this was their idea. I mean, this is something they have been talking about. The name Truvada was actually a project that had been talked about within these health systems since 2018, before the pandemic. They knew this was a good idea, they knew they needed data like this to inform how to take care of patients. The pandemic created the moral imperative to get it over the finish line and they brought me as a potential leader and somebody that really also wanted to make it happen and really wanted to achieve this mission.

And very core to Truveta was this idea it wasn’t about one healthcare system it was about a consortium of health care systems. And this wasn’t, ‘hey let’s go raise venture capital and you guys partner with us’ this was ‘let’s bring together the health care systems of the country, that they can own and govern this new company.’ I think that was key.

**Omar**

It sounds like there were a whole lot of obstacles you had to figure out to get to that position, Terry, where the providers were like actually, we're really going to do this. You mentioned lawyers in the calls that you were dealing with beforehand—help us understand that, because obviously personal patient data is about as critical and private as one can get to. How do you think about that?

**Terry**

I think about four really big problems, we got a lot of work ahead of us. The first one you mentioned is privacy. When you talk to your doctor and these things you share
with your doctor, it’s a very personal moment. Nobody cares about that more than these health systems. I mean, these are the doctors and nurses that you trust with that information. And our board of directors are those health systems, they are those doctors.

So that deidentification such that we can bring together data on our population so that we can learn about what’s going on and learn about people like you such that we can take better care of you, that deidentification or privacy really is probably the most critical and problem number one for Truveta.

The second thing is fragmentation. The data really is everywhere. You visit multiple health care systems and your doctors record information about you within their own systems and we need to bring together that longitudinal view of you as a patient by defragmenting the data, bringing together data about you from your provider, from your insurance company, there’s actually socioeconomic data which is very relevant to your care. And, you know, only 1/3 of people die inside the health system so you need to bring in mortality data. And so, linking all this data together, that fragmentation, was a big challenge and we’re pretty excited about a partnership with LexisNexis which is bringing together a lot of, you know, they’re leaders in the financial sector but they provide all this data. You bring it in now to the healthcare domain.

Will Is that the reason why, like, if a person goes to their ENT doctor (the ears nose and throat doctor) and then something happens a couple of months later, they go to their general doctor, the general doctor doesn’t know the information that the ENT has? It's all over the place.

Terry In the United States, each of your providers keep track of your medical history with that provider. Your insurance company sees you across all providers. So we gotta solve this fragmentation problem such that we can really study. You know, because what's going on in the past, you know, could lead to how effective a treatment or safe a treatment is for you right now.

The third problem we have is the data’s unstructured. I mean, this is not a relational database this is doctors notes, this is images. We need to use the leading edge machine learning and artificial intelligence to extract out of these notes concepts.

And I think the final thing I think a lot about his trust. When President Trump was off debating with the leaders of the World Health Organization about medical truth and neither one of them was sharing the data they were basing that decision upon, I think I see that now with the CDC, I see that in the US where CDC’s citing studies, we have no idea what data they’re using. And, you know, you see the societal outcomes of not trusting the data, or not even seeing the data.
Omar: You’re still early in the journey resembling this giant massively complex unstructured data set and trying to make sense of it. So how are you bringing the providers along with you have you shown them any wins or have you found any insights from the data sets you’ve played so far or even have you had any wins in being able to put the data together in a useful way? Would just be great to hear your perspective on that.

Terry: It’s pretty exciting for us. We built an internal research team.

Will: How big is that team?

Terry: Three people. (laughs) So, I wanna put this in context. You know I think we are now four people. But at the time, last fall, we decided to take a look at COVID first as the first place we dig in just ’cause. And you know, after about three weeks of work that team published a study that showed how comorbidities impacted breakthrough infections. And we were very excited about the work, it was the first time putting the platform through its paces. And what’s exciting but very interesting (I’m actually not sure what adjective to use) I think it was in January—so we’re talking three months later—the CDC publishes a study that had the almost identical results.

Now months later (I assume more than three people worked on it) but I think what’s exciting to me is that with the Truveta study it’s completely transparent and reproducible so anyone in that Truveta community can rerun that study. They can build on it, they can take it apart. And so that excites me because trust, you mentioned trust is new currency, Will, but it’s gotta get built over time. And I just think transparency and reproducibility of these studies and the ability to poke and prod and change the study a little bit – that’s how I think we can really build trust and accelerate knowledge.

So that was our first and there’ll be more. We’re going to try and get things out on a regular basis and we’re growing the team. But really our goal is to be a platform that empowers others to do this research, so we will always have a small team at Truveta. But our goal is to partner with researchers around the world to ask and answer their own questions.

Will: How big is Truveta now?
Terry: About 150 people.

Will: So that’s a huge difference from when you were over at Windows, how big was your team there?

Terry: (laughing) You know, I don’t actually remember. I remember one point it was 12,000 people but I think it actually got a little bit larger than that towards the end. I don’t remember. It was a big team.

Will: That’s awesome. But working with a small team allows you to move a lot faster. Do enjoy smaller teams or bigger teams solving problems like this?

Terry: You know, the way I think about it is, there’s that expression “if you wanna go fast go alone if you want to go far go together.” I think about the whole extended team working on Truveta. So yeah, we’ve got 150 people and we’re hiring and will be growing, but really there’s twenty health systems that are working with us, LexisNexis is working with us, Microsoft is working with us. So I’m always thinking about the whole extended team of people that are engaged trying to pursue this vision of saving lives with data, and it’s much bigger than 150 people. And you know, I don’t know how many people at all of these health systems are really contributing to the success of Truveta or the momentum of Truveta, but it’s not a small number.

Omar: Terry and his friends are building a giant data set and they’ve got brilliant people then using AI to build algorithms to understand ‘what is the date set telling us?’ And if I understand it correctly, Terry, you want to provide that data set and the tools, the algorithms, so that folks like the CDC and the government that you’re talking about, Will, could use those tools to do their own research.

Terry: It’s not open source data sets. So, you know, I think there will be knowledge which we do contribute openly and there will be data we contribute openly. But right now Truveta is a community of people that have committed to protect the patient privacy, that committed very much to the ethics of Truveta. So, for example, the usage of data is all about patient care, it’s not about sales and marketing. We don’t want, and our providers don’t want, this data to be used such that, you know, when you come out of a knee surgery there’s three people waiting at home for you with knee braces to sell to you. This is about improving the patient care. There’s these certain commitments that we expect we require of anyone getting access with regard to alignment with the
mission and really commitments not to use the brilliance today of AI to re-identify the patients because protecting that identity is so critical.

And so it's a community which we welcome researchers to be part of, but the privacy and the ethics requirements do cause us to have a gate there.

Omar Yeah let's talk about the data and who wants to get their hands on it 'cause the information as you hinted with the knee brace example, Terry, is like super valuable. So actually you talked about the gating and not everyone can come and play with the data. So actually how do you really get into that and how do you genuinely protect patient identity?

Terry That is a rich, statistical, very intense process that we have third parties auditing us regularly on. But you know, the first thing it involves is stripping out all your strict identifiers so everything related to your name—your Social Security number, birth date, your address, your phone number—all that's dropped just completely dropped from the record.

But then the harder challenge is one of other attributes which might identify you. If you have a rare disease and there may only be one of you in a zip code. So we need to take that into account. We're looking at signals, any statistical signal, that could cause you to be re identified and we will potentially remove your whole record, we potentially will just redact those signals, I mean we literally go through each and every data point to remove the uniqueness of you such that you can't be re identified. And then we have third parties come in and audit that process and say we can't re-identify anybody in this data set.

So that's a very intense process that we're going to keep working on. And then, you know, of course we contractually say to anyone who's accessing this data you're not gonna try to re identify this data. I think that's critical too because everyone using this data contractually is saying 'I'm using this to save lives with data, I'm using this to improve patient care, and we want the data to stay deidentified.'

Will I have one question that's kind of a touchy one for myself and my family because we see that some illnesses are impacting communities of color. How does Truveta’s data address health equity?

Terry I think what it's gonna do is bring transparency to health inequities. I'm pretty excited about this. With the data that came from LexisNexis into Truveta, we had race previously but now we get all these other socioeconomics factors: access to
transportation, household income, veterans status, so many other attributes about society and the people that are getting care. And we're gonna bring transparency to that and we're gonna let care be benchmarked across systems across geography.

Omar
That makes tons of sense. You talked about the unstructured data and I was thinking 'Ok, I'm super impressed by what I've seen from Nuance Technology's ability to use AI to understand physician conversations with patients. But you also talked about physicians handwritten notes and if I remember correctly doctors—my dad's a doctor was practicing surgeon—their writing is horrible (laughs). So can you talk to us about the AI—

Will
Yeah how does the machine vision be able to detect sloppy handwriting?

Terry
We are not doing anything with handwritten notes but we are dealing with typed notes so that the transcription from handwriting to the typing we let someone else do. But the natural language processing is a challenge, it's very it's very interesting because when you visit your doctor you don't talk about things in the present, you talk about things in the past, you talk about things in your family, you talk about body parts, you talk about levels of intensity, you're talking the positive and the negative meaning like, 'I have pain, I no longer have pain, I'm taking this medication, I'm not taking this medication.'

Will
And using similes and metaphors, kind of like, “I feel like pins and needles” or you're using examples.

Terry
Yeah so it's a very interesting natural language processing challenge. You know, we're very fortunate that natural language processing has as a core language, AI has advanced quite a bit, we're actually really lucky that the medical research community has been working for years to create ontologies to represent things like the body and symptoms and diseases. The fact that there is a ontology for all human diseases that's been built up over decades and what we need to do is then take the natural language processing and correlate 'oh they're talking about this disease.'

Will
Can I ask a question as far as the your NLP if a patient says “this is killing me” how does your NLP extract “this is killing me” and relate it to level of pain versus “I'm gonna die from this” because when you say things it's different than the actual “I'm being killed.”
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<th>Terry</th>
<th>You are absolutely right, Will. This is our challenge, this is our challenge and our opportunity to be able to make this information analyzable. Today when you go to the doctor they literally read these notes; they scroll through your record and a human reads what a human typed. But our challenge is to aggregate that data, identify it, structure it, and make it easy to analyze. And we're early in our journey. This is gonna take years to really get right and it's really gonna stretch the frontiers of natural language processing for sure.</th>
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<td>Omar</td>
<td>Part of what I understood, Terry, you and Truveta are doing to help get us from illness to wellness is about the use of real time data. So is that right, like one of the powers of Truveta is that the data is updated in near real time?</td>
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<td>Terry</td>
<td>It's updated at least daily. Ok, I don't wanna, you know, like I said we're early in our journey and you know we're focused on daily. I think right now just being pragmatic and transparent some of this is living through a pandemic. I think if we weren't living through a pandemic then we might have said, we might have asked us and our health system partners might have reasoned, “gosh how often do we need to refresh multiple sclerosis data? How often do we need to refresh Parkinson's Disease data?” We might have said monthly we might have even said annually. But because of the pandemic, it really opened our eyes. The world changes daily and interactions with new drugs change daily, society is changing daily. If you're going to track the safety and efficacy of value of any drug or device, you really want to understand how it's changing on a daily basis. And if you're looking for clinical trial patients where somebody has a very unique situation you wanna know if that patient is available, has shown up on the radar anywhere in the US, and give them the opportunity to participate in a clinical trial. So seeing the data on a daily basis has really opened our eyes to opportunities to have an impact. I think real time will be critical when we want to impact patient care. Right now the data is being used to study populations of patients as being able to understand what's going on amongst all of us.</td>
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<td>Will</td>
<td>Yeah. That’s powerful.</td>
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<td>Terry</td>
<td>If we ever wanna impact how you are treated then we're gonna have to be right there with them in the treatment room, and Truveta’s not there today.</td>
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<td>Omar</td>
<td>When you think about the next 10-20 years, how’s Truveta gonna help with new things like preventive medicine, personalized care pathways. Like in your most aspirational case, what do you think we can achieve?</td>
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“Saving lives with data” is a vision statement that’s been very impactful. Lisa Gurry and Jay Nanduri, two of my colleagues, came up with that, and it's resonated strongly since then. But below that we talk about, you know, our mission is to help scientists find cures faster, make every clinician an expert wherever they are in the world. You don't have to travel to an elite institution, any doctor anywhere in the world should have the best knowledge, take care of any patient, and we want to help families make more informed decisions about their care—again, anywhere in the world.

And we’re just scratching the surface, Omar, we’re just getting started helping our health systems understand what's going on in the populations of their patients, helping some life science firms understand the safety and efficacy of their drugs within the US population. And if we go out several years, that full vision of finding cures faster, making every clinician an expert, and helping families make more informed decisions about their care, I mean, that's what we're working towards.

Omar
Thank you so much, Terry. It's been really awesome to hear about your and Truveta’s journey.

Terry
I’m honored, thanks so much for having me.

Will
Thank you, Terry. Thank you for your leadership and it's an honor to meet you, like, truly honored to talk to you and ping pong on your new venture and it's been great.

Omar
So, Will, what do you think of Truveta’s mission?

Will
Truveta’s mission is, if they could pull it off, there is a big vision. And what they've already accomplished is pretty big, but if you think of how isolated everyone's medical information—it’s too isolated and scattered all over the place for the benefit of people—it's constructed this way so that people are safe. That's not the reason why it's all over the place; it's all over the place just because it hasn't really been brought up to speed to how technological, how advanced machine learning machine vision, artificial intelligence, natural language processing, natural language understanding, is it's kind of old school in a way.

Omar
Yeah, a lot of paper.
Will
Lot of paper, a lot of different agendas as far as insurance, pharmaceutical. It's really all over the place. So to make sense of it for this era, for the new age that we are in now, it's a pretty big task. And so if they could pull it off, we as a society benefit from that. We going from, you know, the individual isolation illness to wellness—Malcolm X, thank you for that one.

But, yeah, it’s a powerful one. That's why I started asking questions like, what about daily data daily? Activity data? And what about data as far as like, you know, the environment you live in? Because people could be sick just because of the lead in the grass, the asbestos in the building, and if you don't have that data—and how are they gonna aggregate that data? Can they use Esri GIS data and plug it into what they're doing so they don't have to go out and build that themselves, you know?

Omar
I'm guessing that as the data set comes together and the insights come out, it's gonna show the inequalities that you already know about—like, very stark. They're gonna show up very clearly. I mean, if you’d asked me two years ago, like, what's the obstacle for something like this? I’d be like, “hospitals don't share data.” That was like the thing. So, actually, I'm amazed that they've pulled this off with all these provider networks coming together themselves to create this capability in Truveta, and being the owners of it.

So, do you like the way they've handled the ethics around the data here, or any questions in your mind buzzing around that?

Will
I don't know the answer to that one, the question you asked. Because as optimistic as I want to be, I’m still skeptical to be honest.

Omar
Yeah, no I mean, it's an area fraught with difficulties and challenges. But I think that the strong focus on privacy and deidentifying the patient data is definitely critical.

Will
Yeah, that’s awesome.

Omar
And I mean, you know, we're doing Changemakers to find people who are using tech and using modern innovation to improve the world. This is a good one, hey?

Will
This is powerful to see the folks that are out there putting a face to the change as they're making it. And they're showing you what it is they want to do as a
Changemaker. You know, you're seeing the change happen—it's not *changed* maker, no ‘D’ on it because the change hasn't happened yet.

**Omar**

Let's leave it there. It's great to chat again, Will, I'll see you next time.

**Will**

Yeah yeah!

[MUSIC]