

The Person at the Center By Anil Sethi
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Start of Transcript

I have been doing for a little while and by this I mean working in the tech sector and I know right now the tech sector is taking on the chin a little bit with our addiction to mobile technologies or technologies in general where there's that sort of technical compass going. I think in healthcare tech has yet to arrive in personal health tech I think the palliative component to follow the footsteps of — you know we've got jobs and security but with health and security, I think we have health data and security that's about to come, and I really do think that tech can play a part in it.

And *Glimpse* — you don't need all the gory details on a medical record. You just need a glimpse into your health [00:01:00]. Apple acquired the company in early 2016 and I spent some time there with amazing people and colleagues and then went through a caregiving journey myself. And I wanna give you a glimpse of the *Glimpse*. There's a little two-minute video I'd like run and if you can queue that up, it'll show a real user using the technology that I'm gonna pick up after that.

[Video Presentation Playing 00:01:29 to 00:03:09]

When Apple brought us in — and they talk to a lot of small companies — typically companies will pull up their slide back, we never did. We just went straight into showing a live *Glimpse*. That's a live *Glimpse* and the voiceover is my little sister, Tania. Stage 4 diagnosis in the Spring of 2015 and she recently passed so it's... pretty fresh and I have realised that my professional life and my personal life have found an intersection. When a company like Apple acquires you, it's a red-letter day and I thought [00:04:00] “Ohh hoo! I got to go to the beach and have a little drink with a little umbrella in it.”

Through the time that my other sister who's in the audience here and my wife, we took care of Tania, we were her caregivers. I was actually building a new product in my head... for palliative care because when Tania had her *Glimpse* in her hand, whether it was in her mobile device or up in the Cloud, that's just technology. We can ignore that. She was able to literally — you saw in about two minutes. We sort of compressed that but it was about 15 minutes — to collect about 8 years of information, CVS, Walgreens quest, and we're gonna talk just in a minute about how there's a regulatory framework that allows for that so I'm gonna talk a little bit about the past, a little bit about the present and maybe [00:05:00] starting my next venture, the art of the possible, how we can help patients collect and do certain things with them that sort of brings them that security that — what was that drug? What was that pill? What was my lab result? I don't know. And there's a level of angst that comes not only for the patient but for the caregiving sort of team around them. In Tania's case, luckily for her, it was her family.

But I'm ahead of myself. Let me talk about the regulatory framework that has allowed something pretty special to start resonating these days. And it goes back to the meltdown of — financial meltdown of 2008 and right after that Congress enacted what you and I know is the American Recovery Act, the ARA which paved way to another sort of mandate called *Hitech*. And *Hitech* provided for hospitals to start digitising them [00:06:00] -selves with medical information.

So you and I, the taxpayers, we spent about 40 billion dollars digitising the records technology and about the 5500 hospitals that are in the US are major hospitals. The problem is this. Those systems are essentially building systems. They're about charge, capture and about order entry

because that's how the system gets paid and I'm not digging them but that's not healthcare, that's not what we in this room aspire to.

So fast forward to the slide deck, there were some requirements that are called "Meaningful Use" Hey we're gonna give you this money, taxpayer money, you better show us that you're spending it on electronic health record systems or what's called EA charts and you're using them in a meaningful way; so "Meaningful Use."

It came in three buckets [00:07:00]. The first bucket is you gotta start digitizing. Okay check! The second one is you got to start sharing. Hmm... not so much. And the third one is you gotta start outcomes analysis. You gotta start looking at how the outcomes are either improving or not and swing that back so you can start to figure out, close the loop, to figure out what's working, what's not. One of the things that came out of that story is that healthcare technology is following banking technology because in the old days, you and I had to go to a brick and mortar place and was only available for a few hours. Then we had an ATM, that was available to us for the 23 hours that the bank was close and then we had web. So we could do some web banking and now we had mobile, we can pick a photo and sort of it gets put into my account. I think that banking is about [00:08:00] a decade ahead of where healthcare is going.

But I'm excited because one of the things that came out of the "Meaningful Use", "The Hitech Act" and the 40 billion dollars was that what you saw in the video for. Tania was able to log in and create an account, much like you have maybe an email account here and here and here but you have a reader that pulls all that information down into one place so you can make sense of it.

A part of the Hitech act said there will be patient portals in front of Stanford, in UCSF, at Sutter, in CPMC, will have a patient portal where you can create an account and certain kinds of information are pushed at the back of that portal and then Tania can download it. We saw was Tania was releasing her information. This is all live. This worked. This isn't not a demo. This isn't a [00:09:00] proof of concept. She actually used this and I'm gonna describe that in a second. And she was able to get those core screen documents and pushed them up into the Cloud, whether it's on a device like your mobile phone or a Cloud where some of our software, we call it the Chipper Shredder and it took those core screen documents and just blew them apart and said, "Well, haemoglobin is the same as HTB over there or hemob over there so we're gonna pluff them over time."

The nice thing is that Tania could use that information to share with her caregiving team and two really pristine uses. One is much like some of us in the room have a work profile on LinkedIn. It's a LinkedIn profile it's got a little link or URL across the top and you can send that by email to whoever needs to see your profile. Tania had a LinkedIn or a little link of her *Glimpse* and she was able to share [00:10:00] that across state line for a second opinion. A whole hour was spent revealing this information. Another time she was at UCSF where she was getting treated and the entire medical record system went down — crashed hard for 36 hours. But because we had shifted the definition of sharing information to portability, Tania, wherever she went, she had her health information. So she was able to spend 45 minutes with her on college's Hope Rugo. Even though the system was down. They went through her iPad and they looked at all her information. I didn't know that was up but I'm gonna let you read that for a moment.

{{On-Video Script}}

Unless Tania surprises all of us. We are end-of-life. The intubation and blood drainage tubes have been removed. The ventilator is off. The vitals monitors have been

unplugged. And the room is quiet. Sedation is keeping her comfortable. She's on her own globe path now without any engines, so let's see where Tania decides to land.

When Tania **[00:11:00]** was — we're gonna keep that on the screen and there's probably one more and I'll just ask you hold it for a moment — This is four days before Tania passed. It was Thursday and intubation, tubes were out. And we wanted to honour her, have her pass without any pain. So that was at Johns Hopkins', we all grew up in the Maryland. They titrated her meds according to her wishes and sort of knew we were around but she had lost her voice. She didn't have enough energy to push the air out to create sound. So when she did, it was more like cooing; a little bird. That is my sister. She was more soul than body. She was always connected to how can I take care of you, so as the nurses would come in, "How are you feeling?" — How are you feeling? And she put her... **[00:12:00]** and they creeped me out, man!

[Crowd Chuckles]

I remember the first time she had met Hope Rugo in colleges and Hope said, "How are you doing?" Tania goes, "You know, some of these days were the best days of my life!" Hope was so taken aback, she's pushed us all, out the family, closed the door and 1 hour and 45 minutes later, there were still doing this. So I think that we are at the cusp of the regulatory reigns, encouraging and allowing the patient to be at the centre of not only accessing but controlling their health information, they get to decide for — with whom to share it with. And much like the panel said before about organ donation, when Tania was diagnosed, people came out of the woodwork and said, "What can we do to help?" And there's not a lot that people can do. But here's one thing they can **[00:13:00]** do. Instead of doing the, let's say a Cancer Walk and donating money to the NCI, which has plenty of money, how about collecting your health information and donating that. I think if we do that, we can accelerate and time-compress solutions to things like cancer. And I'll say this, I think cancer's a data problem. I think computers and the tech industries is really good at this. I'm not saying it because I'm in the industry, I truly believe it.

One of the recognitions is that you do some research in three years out, the publication comes out. Well that's not much use to people who were three years ago diagnosed. Cancer sort of mutates every three months or 100 days. Three years out is just too long. So we can have people help collect, organise and share their information, pull it in to that 100 days, we can go after cancer. We can actually get it before it **[00:14:00]** starts to change and I think that those are the kinds of examples where a tech, can both be palliative, I can feel better that I can answer the questions with my caregiving team, and also I can pay it forward, for researchers.

I'll finish with one more slide if you wouldn't mind putting it up.

{{On-Video Script}}

Unless I am not thinking clearly, but usually I try my best, Tania's life being cut short represents the tipping point in the death of cancer. IMHO I now "know how" to kill cancer, and I'm dedicating my life to this cowards' painful death. Pulling it apart, limb by limb, cell by cell, gene by gene — record by record. It turns out that like all cowards, cancer survives only in the shadows. So we're going to bring the heat and light to its murky world. Millions of people strong, global citizens all, sharing everything possibly knowable about cancer. Continuously. Only together will all of us kill cancer, dead. My next venture is gearing up with incredibly skilled and driven colleagues. Hey you fuck, start looking over your shoulder. You picked on the wrong "kid sister"

I apologise for the profanity but this is how I felt and this was the day after she passed. I realised at that time I wasn't gonna have my little drinks there with the little umbrella. I had to do something more. Citizen was more about two hours after she passed **[00:15:00]** and we're just getting started. We're actually in CBC doing something today and we're sort of announcing that. I promise I'm gonna my very best to kill cancer in my lifetime.

[Crowd Applauding]

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