Message to Medical Device Companies: Let Patients Help!

In this interview with e-patients Dave deBronkart, Hugo Campos, and Bennet Dunlap, they tell us why medical device companies should let patients help in an effort to open healthcare information directly to patients on an unprecedented level, thus creating a new dynamic in how information is delivered, accessed, and used by the patient. This will revolutionize the relationship between patients and health care providers, which in turn will impact the entire spectrum of healthcare. Here are a few things that we will learn:

- What exactly is the e-patient movement?
- Why open access to medical device data is so important?
- What will it take for medical device companies to grasp the e-patient movement?
- How can medical device companies benefit from participatory medicine?

Scott Nelson: Hello, everyone. It's Scott Nelson, and welcome to Medsider, home of the free medical device MBA, and on today's program, we're doing something a little bit different, almost a roundtable discussion regarding the topics of participatory medicine and the whole ePatient movement. We're going to try to answer one question or a couple of different questions, but they both centers around the idea of why medical device companies should be giving patients access to their data and why should medical device companies be letting patients help in the innovation and development of medical devices. So, on today's program, we've got Dave deBronkart from epatientdave.com fame. We've got Hugo Campos who leads an ICD user group, and we've also got Bennet Dunlap of the ydmv.net website, which is almost like a group of diabetic ePatients, for lack of a better description, and Bennet can certainly clarify that as needed. So, without further ado, welcome to the call, guys.

ePatients: Thank you. Hi. Thank you, Scott.

Scott Nelson: Alright, so for the audience's sake and for those listening that aren't familiar with the ePatient movement, Dave, I'm going to have you open it up, and I know your schedule's a little bit tight, and you know as the call progresses feel free to jump off, but let's start there with the ePatient movement and participatory medicine. Say that three times, it's kind of hard to say. But let's start there. If you can provide us, kind of set the stage, provide us a little bit of background, and then we'll jump to Hugo and Bennet and have them tell their stories. So, let's start there, Dave.

Dave deBronkart: Sure. Well, my own introduction to caring about healthcare happened four years ago, almost five now, when I found out I was almost dead with kidney cancer, and in the process of getting a miracle cure, I used the Internet in every way I could. My doctor actually encouraged me to join a smart online patient community and I looked up my medical records, my scan results online. I set up a social support site on caringbridge.org and just did everything I could to help myself in a desperate situation. When that ended and I was pretty much pronounced clear, my doctor introduced me to epatient.net, which was a sleepy little blog at the time started by a mentor of his, a doctor named Tom Ferguson, who had died in 2006. Ferguson

was a real thought leader. He was a visionary. He came out of Yale Medical School in the '70s and was very much about recognizing that patients are the ultimate stakeholder. I mean, they are the ones who literally live or die based on how well their case goes, and not just themselves but their kids, too, and their elders.

He saw that when routine healthcare turns to medical care when there's a problem, a major thing that holds people back is access to information. When the Internet came along, particularly the web in 1994, that changed everything about access to information, and he started noticing people including my physician, who wrote the first journal article on how to do doctor-patient email, and he co-created the patient portal on my hospital's website. Spotted people who were doing things because of the Internet that had never been possible before, and he coined the term "ePatients," which at the time connoted using the Internet, but these days it really is more than that because everybody's on the Internet, not everyone is an ePatient.

What he said was ePatients are engaged in their care, they're empowered, they speak up and say what they want. Now, by definition, all of us on this call are in that category. He said they're equipped and enabled. These days people say ePatients are educated about evidence and pick your e, and he started just noticing who was doing what. One of the people he spotted was a guy named [06:39inaudible] Friedman, a Frenchman who started a network of Listservs, just plain old mailing lists, for cancer patients for different cancers, and drgreene.com, which was what the AMA said was the first physician website. He's a pediatrician and so on and so on.

Now, as I say, he died in 2006, but then when my doctor introduced to me to this in 2008, I read the White Paper, a 120-page manifesto, at the top of the e-patients.net blog, and it pretty much blew my mind because I've always been a tech worker working with data and Internet marketing and things like that. I saw all of a sudden a new mental framework to explain what I had been doing when I was sick, using the Internet in every way I could to help my cause while the doctors did their work. Now, I had done things like I would take my tumor sizes from my CAT scans.

I made an Excel spreadsheet so I could grasp their progress because I wanted to know, how's it going. So, then I started talking about it and blogging about it as a hobby, and a number of things happened, and I ended up quite unexpectedly on the front page of The Boston Globe in 2009. That led to my being invited to speak at conferences in Washington policy meetings and so on advocating. I was one of the patient representatives who advocated in 2010 and '11 towards meaningful use rules that say that patients should have access to their medical records.

The other dimension of this, and of course, the data stream coming out of a device is not formally part of a patient's medical record. That's another dimension, but the other thing is that throughout my career working in high tech, I saw innovation happen, and as a result, and I mean rapid innovation happened as a result of open access to data. I know, having worked for manufacturers of equipment, it can feel threatening to have other people have access to the data inside my system. So, the question that we come down to is who's more important? Who's more important? Is the manufacturer more important? And I say that as somebody, I fully understand people's business interests or, is the patient or the family's children, is their well-being more

important? If we're going to have the innovation to improve value in healthcare, is it more important to stay in control of the situation or is it more important to help people get better?

My one closing comment on that is that I have a friend in Israel who is a severe diabetic, and he's far more of a data geek than I've ever been and he's very, very interested in using the statistical tools from other industries, other professions to do early detection on the onset of problems or use perturbations in the data stream to backtrace and troubleshoot what's going on to help get a better understanding of how to stabilize a complex system. Now, he's applied this to cell phone voicemail systems, to high-speed digital full-color printing presses, and so on, and he's produced results in all those fields with making systems more stable and enabling engineering changes that improve stability. Why the heck would we not want to do that, help people's physical systems, the body, become more stable?

Scott Nelson: Right, right. Very good. Well, thanks a ton, Dave, for kind of opening up the call with a good overview of not only your story in participatory medicine and ePatient movement. I would encourage everyone to check out Dave's website, epatientdave.com. In particular, there is a section on there that highlights some of the videos of him speaking at various conferences. I think that one of the first ones listed, the TEDx talk, which is a really, really good one, it's not too long and it's really good to talk. I mean it's a really, really good one, and anyone that's featured on a TED talk, I should say TEDx,

I don't know if it's TEDx or, it was a TED talk period. So, anyone featured on there, that's a really cool thing. I wanted to ask you one follow-up question to your description of the ePatient movement, Dave before you've got to go, and then we'll jump to Hugo and Bennet to get their stories, what's next for the ePatient movement as it pertains to medical devices? I should maybe rephrase that question and say, what's it going to take for medical device companies to jump on the bandwagon? I know you mentioned in our pre-interview talk there that you're starting to see some movement. What's it going to take to cross the threshold?

Dave deBronkart: I'm sorry, which threshold?

Scott Nelson: I'm not sure if the threshold is probably the best way to describe it, but what's it going to take for medical device companies to really fully grasp this ePatient movement and really begin to integrate it into the device development and device innovation?

Dave deBronkart: Well, I can't really answer that authoritatively because I haven't spoken with any of the decision-makers at the companies, and as I say, I have a lot of respect for the business world they live in. What I see throughout healthcare though is, over and over, and maybe true in this industry as well, is that there is a misconception, it's almost a superstition that value in healthcare only arises within the industry and that there's nothing that the consumer/patient could possibly offer that would increase the value proposition. On one level I can refute that by the fact that my patient community had information about the effectiveness of kidney cancer treatments that most physicians don't have, and that's been confirmed for me by my oncologist. I've seen that over and over with other patient communities. I mean, when we formed the society

for participatory in 2009, it was because the ePatient.net gang saw that it was time to get to work. It's no longer just a little hobby and there's something important going on here.

The other thing is that in a situation where access to all the valuable resources is restricted to a limited number of parties and this applies to just about everything medical, then any initiative to create value from those resources requires budgetary justification, and if you unleash the ultimate stakeholder and say, "Hey guys, here. You take this. See if you can do something useful with it," then who knows what can happen. A great example of that is in the area of searching for obscure treatments. The average physician has an enormous number of conditions they have to be responsible for. I mean, who would expect the community doctor or community oncologist to know the latest on kidney cancer treatments when they may see one or two cases a year, and no other cases like mine, right?

But in contrast to that, when you have kidney cancer, there is nothing of more interest to you. So, for instance, I know a woman, a breast cancer patient, who prolonged her life for 18 months, which to her meant another 18 months watching her grandchildren grow up; very happy months. By finding an obscure researcher in some laboratory somewhere who was working on something that would never appear in a peer review journal article, not to mention that there are 6000 journal articles published every day, so who could possibly keep upon them.

Similarly, when desktop publishing killed my first industry, which was typesetting, a key part of the mechanism for it, of course, one essential thing was that it put fonts on everyone's desktop, but another thing was it opened up an ecosystem. Software like Aldus PageMaker and QuarkXPress. QuarkXPress offered an API so that, and this is so essential, other developers could at their own financial risk try things, try to develop a plug-in to enhance the product, and it would be up to them to do the work. They didn't have to. Here's my final question to the device maker. What if there's somebody out there who at their own expense could figure out something with your data stream that could make it six times more valuable to patients or physicians in hospitals, you know?

Scott Nelson: Yup.

Dave deBronkart: And that's this point about there is a myth that the only possible source of value within the industry comes from within the industry itself.

Scott Nelson: Right.

Dave deBronkart: And as long as we stay within the industry, we'll never find out if something more is possible.

Scott Nelson: Yeah, I know. That's a great point. It reminds me of a quote I think I read. I'm not sure if you guys are familiar with Tim Ferriss' "The 4-Hour Workweek", his new book is "The 4-Hour Body," but more particularly, his most recent book, "The 4-Hour Body," there's a quote in there where he says we've got to be willing to go to the fringes in order to uncover some of this more obscure information that you mentioned, Dave. What you're telling me is a lot of times

what's going on, on the fringes is patients are the ones that care the most about their particular disease or condition. They're the ones that are deeply, deeply involved in this fringe-like researcher.

Dave deBronkart: Yeah. Yup.

Scott Nelson: So that's a great point. So thanks a ton, Dave, for coming. I know you have to step out pretty soon, but thanks again for all of the work you're doing in this whole ePatient movement. Your new book is out, "Laugh, Sing and Eat Like a Pig." That's the title, correct?

Dave deBronkart: That's actually a year and a half old but yes.

Scott Nelson: Okay.

Dave deBronkart: That's my cancer journal. I do want to say one thing in parting. I really emphasize my appeal is not just to the establishment, okay? I'm alive because of the establishment. My appeal is that there is another resource available out here, the most underused resources in healthcare, and that's why I say let patients help.

Scott Nelson: Got you. Very good.

Dave deBronkart: Thanks. Thank you. Bye.

Scott Nelson: Very good. Very good. Thanks, Dave. Alright, guys, I'll talk to Hugo, and then to Bennet as well, but I want to open the call up to you guys and have you guys tell your story because it fits perfect into this whole concept of why medical device companies should open up the access to the data that's driven from these devices. So, just real quick. I'm going to forget if I don't mention this, hearing Dave describe this, and you guys might agree with this, there's a new book out called "The Lean Startup." I think the author's, Eric Ries.

But he mentions a lot of times the concept of a lean startup is the idea of creating a minimal viable product, and the whole notion of this idea is to get something out there so people can use it, people can experience it as quickly as possible you can make a decision on, do I move forward with this or do I drop it or what iterations need to happen? The whole idea is we need to get it into the hands of the consumer to let them use it, and it's somewhat similar to this topic right now. I think medical device companies would be better off getting that sort of input from the patients themselves, which I think personally could lead to further innovation for the development. I'm sure you guys would agree with that. But let's go to Hugo. Why don't you kind of describe yourself and tell us a little bit about your story? Then we'll jump to Bennet as well.

Hugo Campos: Right. Thanks, Scott. So, I'm a patient with an implantable cardiac defibrillator. So, I'm at risk of sudden cardiac arrest because of hypertrophic cardiomyopathy, and I have the device for primary prevention of sudden cardiac arrest. So, the way I sort of got into this ePatient movement is much the same way as Dave. It's sort of a natural way into this. I wasn't getting information from my doctor. I passed out at a train station and had no symptoms up to that point except for some mild palpitations on occasion. For a number of years, I kept getting misdiagnosed

with vasovagal syncope, mitral valve prolapse, benign murmur, and a number of other things that potentially would not put me at risk of sudden cardiac arrest. I was unaware of that.

Eventually, when I was properly diagnosed with HCM, that is when I realized that I was at risk and I had been all those years, and so I decided to take matters on my own hands and really look for a provider that I thought would be the best for me, and that's what I did. So, I went to look for, and this sort of came about online. By finding other patients online who told me where to go. Go to this center, they specialize in HCM or go to that place. That doctor is the best doctor for this specific situation. This is sort of what's happening. Patients are getting information that is accurate from other patients, and a lot of times the inaccurate information from doctors.

In my particular case what happened when I realized that an ICD would probably be in my future, is that I asked the doctor that we'd seen at that time, a cardiologist, not an electrophysiologist, but a cardiologist, and he said to me, "Oh, you know, I don't think you want one of those things," referring to the ICDs, because they go off for no reason. A third of the time, he said to me. So, this is obviously inaccurate information that I got from a cardiologist. That's the chief of cardiology in the hospital where I was being seen. So, this is to illustrate the need for patients to engage, particularly patients with chronic... I mean, for me, this is a chronic illness, right? So, I need to manage this for the rest of my life, and that's where data access comes in.

Scott Nelson: Right.

Hugo Campos: So, I have paroxysmal atrial fibrillation. It's very important for me to know when I'm in atrial fibrillation. The device knows when I'm in A-fib, but I will only know when I'm in A-fib six months later when I go see my cardiologist. Then he says, "Oh, you know, there has been mode switching on your device and this happened a number of times in the past six months." This is useless information for me six months after the fact.

Scott Nelson: Right.

Hugo Campos: It is only valid for me when it's happening. I would like to get a text message from the device or from the remote monitoring network that is used to monitor my ICD to say, "You've been in atrial fibrillation for 12 hours. Do something about it. Take an extra aspirin. Call your clinic," or stuff like that, but it's really important. Although data access, when you start talking about data, it's incredibly valuable to patients it can be very, very threatening for industry, and very threatening for doctors, right? I mean, for me it's about access, it's about openness, and it's about transparency. I mean, we're looking at not just having access to the data that is collected about my heart and about my body by my device, which can be incredibly insightful for me as I live my life, but also I'm talking about the moment I open this. So, the moment I get this data, I would like to share it with other patients that have devices like mine.

Scott Nelson: Right.

Hugo Campos: So, I want to be able to see if my device is performing as well as is expected, and how does it compare to other people who have the same device? Is its longevity going as well as

expected or is it depleting its battery too soon? Is my device any good for detecting, I don't know, ventricular tachycardia, or is it missing some episodes or am I getting shocked inappropriately for atrial fibrillation? So, all of this data can be very, very useful when patients start sharing that information.

Scott Nelson: Right. Right.

Hugo Campos: In terms of transparency, it's about post-market surveillance of medical devices from my point of view. I want to put that data out there because you know well that the mod database is like a year behind. There's basically hardly any data out there for patients in terms of post-market surveillance of these devices. How are these devices performing? This is very important stuff. So, in my point of view, it's sometimes difficult to make medical device companies get on my side because it can be very threatening to have this level of openness. But I don't think there's any way to avoid this. This is the way that the industry's going. This is the way culture is going. This is the way we're going. So, it's just a matter of figuring out how we can work together and at least solve some of these challenges.

Scott Nelson: Right. That's a fantastic actually endpoint that you just made. That's the way our culture, that's the way the online communities go, not just the online community, but that's where our whole culture is going, to come up with what you said, is transparency, openness, etc. Now, that's great stuff. I want to circle back around. What I thought is we'll pass the baton to Bennet. Bennet, I'd like you to kind of explain your story, give us a little background information, and then we'll kind of close up with just having a little bit of a roundtable discussion to answer some of these questions as it pertains to access to data, letting patients help pertaining to the medical device manufacture. So, I'm going to pass the baton to you, Bennet, and shoot.

Bennet Dunlap: Thank you. Thank you, Hugo, and I'm a parent with two patients. I have two kids that have Type 1 diabetes. That's the type of diabetes where the pancreas stops making insulin, and to stay alive, to get energy into their cells they have to inject insulin multiple times a day, either with a syringe or from an insulin pump. Unlike Hugo who says that he doesn't get information from his devices ever or every six months when he sees the doctor, and he can't make lifestyle changes based on that information. If he knew that something that he did cause a problem, he could stop doing it or modify it.

Diabetes is a lot different in that we just get a ton of data, but the data doesn't really play nice in the sandbox. So, in our lives, the kids do three things to manage their blood sugar. They eat food, carbohydrates- a source of energy or sugar; they're active and they exercise, and that new sugar makes them more efficient in using sugar and it lowers their blood sugar a little; and they take insulin to get the sugar into the cells of the body. So, it's sort of a balancing act, you know. There's a fulcrum or maybe the hinge of the seesaw is driven by the data. So, they stick a little piece of the needle into their fingers and get a drop of blood that's going to go in the machine, and it tells them a number, and they do that many times a day. Four sticks, four or five sticks depending on their activity level and their blood sugars and a lot of things. So, they get data from that and they react to it.

They also wear insulin pumps, and they take the information that they get out of the blood sugar machine, they enter it, and the insulin pump will do a little bit of calculation based on their personal ratio of insulin to blood sugar. They take a little bit of insulin, very specific ratios [29:22 inaudible], and all that fun stuff. Sometimes they'll wear a machine that continually monitors their blood sugar [29:31 inaudible] machine, a continuous sensor that's getting data every three minutes, finger sticks getting data four to eight times a day, an insulin pump for pumping insulin [29:44 inaudible] all creates data that we can see it on screen and put it into three separate computer programs. Each one of them shows that part of their life with diabetes. One shows your continuous glucose feed, here's your finger stick feed, here's the insulin you pumped in. Those machines don't talk to each other. They speak different languages, the Tower of Babel.

The process of managing life with the data is similar to Hugo in that none of those systems allow you to go in there and really coherently log your activity in a way that relates data. So, you know, here we're swimming in a sea of data that if we enter it into a spreadsheet manually, that's acceptable by the current rules, but if that data is electronically transferred, then the FDA has to get involved. They want that regulated data and transferring electronically is going to have smaller scores of input error, but that's sort of forbidden. So, Dave was talking about value arising only in the industry, and in our lives, that kind of extends down into the proprietary firms that are helping you to take the blood drips in the glucose meter and sees value only in their product. Their product, their strip, and their proprietary data system. But what happens is when you change insurance companies, we just went through this week where the formulary brand of the strip was changed while our history of data doesn't [31:36 inaudible] with the new history of data, so even if I was completely up to speed with the stick and all these things, the data stream's been blocked.

So, their view on their value is, well, this proprietary thing is to keep you loyal to our brand of strip or device. I think that there is a much larger value in standardization, and if you look to other industries, that's true. The VCs took when there were standardized operating systems, and standards have been the engine of explosive growth in a number of fields, and even if it didn't generate growth, if there was a standardized data format, each of these firms is maintaining their own proprietary data form, and database is based on that. So, if they just established the standard, everybody wouldn't be reinventing the wheel for every device. It's just economically inefficient.

So, I would love to see the industry turn it around and say, you know what, there is value in standard from an economic standpoint, even if it's [32:45 inaudible] to us. They're going to weigh that against proprietary advantage if you can be locked into their device. But, you know what, if patients saw an ability to connect data from multiple devices and manage their lifestyles and take the actions to improve their health, they'd go and facilitate that integrative approach to not just data but lifestyle information as well.

So, I've been writing about this on and off since, I don't know, since 2007 or so, and it was all stemmed by being in a seminar where somebody was talking about a whiz-bang piece of proprietary technology that would text message a parent, or not a parent but the doctor, which

gives blood sugar every time they tested it. That's a [33:38inaudible] doctor [33:39 inaudible] all this time, and the guy next to me says, "Well, you know what? What really matters is the doctor. What matters is my wife and I because we're our daughter's primary caregivers, and I think getting data to the primary caregivers is important. I think it's not just true in diabetes." He just very clearly made his case for his condition and I think for a lot of conditions, probably all of them. So, I'm very much an advocate for let's set data standards. I also agree with Dave that I don't want to [34:15 inaudible] the industry. The industry's what's keeping my kids alive. They're the people that are making the machines that make pursuing your dreams possible instead of dealing with their diabetes because that's really what it's about.

Scott Nelson: Right.

Bennet Dunlap: You know what? Let's nudge the industry a little bit to open up and open up the standards bodies to understand what patients really want. At a conference Dave and I were at, there was a woman with rheumatoid arthritis that [34:44 inaudible] led me to bring an observation that nobody asked me what I wanted from a device, and maybe that's a really good question to start.

Scott Nelson: Yes. It's such a simple question, but definitely, it causes you to take a step back and actually think about that, which really comes back to... I'm not sure if Dave mentioned that, and you actually just kind of referenced this earlier, that industry is only really looking to industry for new ideas and innovations and iterations on certain devices when in reality, it would maybe do industry well to look to the patient, the patient that's receiving therapy from various devices. So, thanks Bennet for telling your story and giving us a good idea of your take on the whole ePatient movement especially as it pertains to the diabetes space or arena.

So, let's go back to this because I know we've got to somewhat kind of reach towards a conclusion here and you both could probably answer this or speak to this a little bit differently, because Hugo, in your case, I'm kind of summarizing here, but it's really access to data is a huge issue. I know that that data's there because I used to play in the CRDM space, but that data's there because Medtronic actually just announced an iPhone app for their CareLink systems. So, the data's there, it's just giving patient access to it, where on to your point, Bennet, the data's there, it's just it's a mess, almost because nothing's standardized and there's no really standardized data format from the manufacturer, etc.

So, you both could probably answer this a little bit differently, but say I'm a CEO of a medical device manufacturer. I understand the importance of data, why patients would want access to their data. That makes sense to me, and there's enough movement in the ePatient world, there's enough interest in there, there are enough patients that really, really want this. This is like a really, really growing movement here. So, the idea that patients don't want access to the data, I don't really buy into that. So, where does this not fit in with the device business model, do you think? What's kind of the underlying reason here? I'll have you guys answer that question individually.

Hugo Campos: Well, if I may go first. For me, the way I see this is basically there's no business model there. I mean, there's, oh, what's the billing code for it? I mean, if I'm a medical device manufacturer, why would I bother to commit some dollars toward creating an infrastructure to provide this level of access to patients if there isn't really a clear way to get a return on this investment? So, it's a very tricky proposition, although every time I talk to somebody like this, I feel like it's a weird place to be as a patient because I feel like I'm always trying to defend. I'm always on the defensive, in terms of saying, why do I need this data? Well, first of all, I feel like this is my data. I mean, the device is paid for and it's been in my body, it collects data about my body, and in fact, I've taken a stance to not adopt remote monitoring because of exactly this very reason. If I don't have access to this data, no one will, and so I've not adopted remote monitoring.

I realize that there is some risk that I'm taking with it of a lead fracture that is not detected in time or any other issues, but it's a risk that I'm willing to take to make a point. So, this is how important it is to me, and it's either I'm included in this data loop and I'm considered just as an important stakeholder as my doctor and as the medical device companies, and I'm included in this or I will not adopt it, and no one will have this data. So, this is how I take this.

Scott Nelson: Okay.

Bennet Dunlap: So, I guess that your question is, what do I tell the executive from pharma or device manufacturer as to why they should be getting in this space? Well, I think the first thing is, you know what, there's an opportunity here for you significantly reduce your cost if you're creating your own proprietary database. [39:34 Making the database is a process the FDA for approval. Wouldn't it be a lot cheaper if everybody built a part of the wheel than everybody reinvents the wheel? An industry does have sort of a conglomerate to do that.

I don't know if you guys have heard about the Continuum Health Alliance, a group of big industry players that are trying to create standards, and I was talking to them and I said, "Well, how do patients fit in?" The guy was just friendly as could be but was sort of dumbfounded by the question, sort of like, "Well, what do you mean, the patient?" These are all huge companies. They've got a lot of employees. They're taking care of their employees and that's how the patient gets involved, and I was like, "Thanks, but no thanks. We would actually like to be involved." Coming at it from another perspective, there are four points involved with medical ethics, and the first, and some articles will state the first among equals, is autonomy, and that is that the patient needs to be able to knowledgeably consent to treatment.

I think knowledge is significant in that. I don't want to beat up Hugo here, but if they say, "Hey, we're going to put this device in your chest and it's going to take care of your heart. Don't worry about it, Hugo. It's fine. We know what we're doing," well Hugo has a right to know what that device is doing. He has an autonomous right, this ethical principle of medicine that patient should autonomously consent to treatment, and how can he consent to what's going on if he doesn't know what it's doing? So, I just think from an ethical standpoint, it's just flat wrong that there isn't a way of providing access, because every patient [41:20 inaudible] data stream, they can't make sense out of it. So, I think there's a responsibility to provide that information in a way that

is useful, but I think it's an ethical responsibility and bottom line notwithstanding, they have an ethical responsibility to do it.

Scott Nelson: Very good. That's a very valid point. I would almost conclude, and I mentioned this earlier, not only that it's the right thing to do, and in fact, as you mentioned earlier, Hugo, it's the patient's data. It's your data. It's your device. You paid for it. It's yours. You, without a doubt, have the right to access that data. I know the business, you mentioned, Hugo, that the business model may be doesn't necessarily make sense, but also, as companies began to be challenged with developing truly disruptive technology, I have to think that there's room, there's this whole world of patients talking about their devices and etc., etc.

I have to think that if you go to the fringes and look at some of this, who's to say that that next disruptive technology isn't down there? So, I think there has to be value in that, in hearing from the patient, hearing how they're using devices and seeing where that device can be either iterated upon or where there's maybe a new disruptive technology that can be developed. So, cool, guys. I know we're going to kind of conclude this call, but any last closing remarks that you guys want to make? I mean, I really appreciate you coming on, and after your closing remarks, I'm going to inform the audience of where they can go to learn more about your blogs and your websites. But any closing remarks that you want to add?

Hugo Campos: Well, you know, I would like to say that I think we need to be a little more open-minded as far as the [43:29 inaudible] medical device industry. Things are changing, right? So, the world, maybe they need to revisit their business model, and maybe there are great opportunities ahead that they have not seen because they are so tied up in the old way of doing things. There is incredible value in data, maybe even to the point in which, as we talked about, particularly in the cardiac rhythm space, as we look at injectable pacemakers and loop recorders and devices like that. There might be even the possibility for people to have elective devices placed under the skin just for the data that it collects. There's an incredible amount of value there. So, I just sort of would like to leave the medical device industry folks with the thought that maybe you should sort of like open up your mind a little more and try to see what we need to be in five or 10 years from now.

Scott Nelson: Yup. Cool. And how about you, Bennet? Any last words you'd want to add in there?

Bennet Dunlap: Yeah, you know, I think that this is a new conversation. I think that patients being interested in their data really is an outgrowth of, first we were [44:48 inaudible] whiz-bang technology that helped us a lot and few people knew to ask, what was it doing? I think that moving forward that giving people the information that they can use, that the devices we create that can help them manage their health is really important. I think that we don't in general take actions that are proactive [45:16 inaudible] for help, and a lot of us don't know how to do that. But if we had data streams that afford doing that, you know, we certainly should be using them. I think that it can create healthier outcomes, and this is what Dave talked about early on, was, "Well, how can in the real world we get to the healthy outcomes?" You know, a lot of times we can [45:36 inaudible] controlled study. Well, let's get it out in the real world for people who are

living real lives, pursuing real dreams. How can we facilitate health as secondary to pursuing those dreams?

You know, so my kid's trying to be an actor or whatever it is, and he realized he's bringing his healthcare along, kicking his dream [45:59 inaudible] he can. but he thinks that that sort of is a new, adventurous world and it's his paradigm shift. Maybe device manufacturers have always thought about, "Well, you know, we sell it to the doctor and the doctor treats the patient. It's very paternalistic." You know, "Here, patient, take this. It's good for you." "What is it?" "It's a blue pill. Don't worry about it."

Scott Nelson: Right.

Bennet Dunlap: I think that we need to have a three-way dialogue, and I think the device manufacturers are staffed by wonderful caring people. They care about our conditions. They are there more often than not because they love it. That's great. I think that the same is true of the medical profession, that they need to just open that up and say, "You know what? We want to be embraced by both [46:45 inaudible] sitting at the table."

Scott Nelson: Right.

Bennet Dunlap: "Data is how we're going to do that and get it done."

Scott Nelson: Good. That's good stuff. I really mean that. That's great stuff. So, we'll wrap it up there guys. I want to direct the audience if they want to learn more about kind of what you guys are doing online. Where would you direct them? I'll start with you, Hugo.

Hugo Campos: icdusergroup.org or follow me on Twitter, Hugooc, H-U-G-O-O-C.

Scott Nelson: Okay, and that's icdusergroup.org?

Hugo Campos: Right.

Scott Nelson: Got it. Okay. And then, Bennet?

Bennet Dunlap: I write the blog "Your Diabetes May Vary," ydmv.net. I'm on Twitter, and my Twitter handle is BadShoe like you're walking through Disney World and you see somebody wearing stilettos hobbling out and you go, "Man, that's a bad shoe for this location." That's actually my Twitter handle and that is exactly how the handle came to be a long, long time ago.

Scott Nelson: That's funny.

Bennet Dunlap: And I try to write from very much a folksy, down-to-earth point of view, and my selling is absolutely atrocious, so keep that under advisement, and I don't mind folks going in and going, "Hey, you doofus, you spelled this word wrong," That's fine. I'll go correct it.

Scott Nelson: Right. Right. No, that's good. So, for now, I would highly encourage everyone to jump on both Hugo's website as well as Bennet's website. There's some great information, and especially if you're highly in tune with either the CRDM arena or the diabetes space, jump onto this good stuff. I'll speak for Dave here; if you want to learn more about Dave's story, go to epatientdave.com and there's lots of good information, I guess, for lack of a better description of Dave's website as well. So, again, thanks guys for joining me in this call. I'm going to ask you to hold on the line here after I end this, but thanks again for coming on, really appreciate it, and thanks everyone for listening.