Adrian Hernandez: 00:04 Hey, this is Adrian Hernandez and welcome to the NIH Collaboratory Grand Rounds podcast. We're here to give you some extra time with our speaker and ask them the tough and interesting questions you want to hear most. If you haven't already, we hope you'll watch the full Grand Rounds webinar recording to learn more. All of our Grand Rounds content can be found at rethinkingclinicaltrials.org. Thanks for joining.

Hi, this is Adrian Hernandez from NIH Collaboratory Grand Rounds. And today we're here with Michael Gibson who will be reflecting on a recent Grand Rounds entitled, The Democratization of Medicine: Open Access, Social Media, AI, Apps, and Empowering the Patient as a Future of Clinical Research.

Michael Gibson: 00:46 Thanks for having me, Adrian.

Adrian Hernandez: 00:48 Well, Mike, you had a really interesting story that actually, it sounds like your passion started really growing up in Oklahoma. Can you share a little bit about your background and how that instilled something for your future?

Michael Gibson: 01:03 Yeah. People don't realize, I'm not at all from the East coast. I'm not quite sure how I ended up here. But I was born in Oklahoma and my mother was a painter, my father was a labor negotiator for Sinclair Oil. We moved a lot back and forth when I was young between Oklahoma and believe it or not, the New York area. But I really spent a lot of the time in Oklahoma and in particular in a small town called Stilwell, Oklahoma, where my grandma and granddad owned an auto repair store. And I spent a lot of time with them.

And it really brought home to me the issue of access. And as I mentioned in the Grand Rounds, my grandma is bored to death in an auto repair store. And she gave me a nickel and told me to go up the street and buy a book at the book fair. And all I could get was the letter C from the encyclopedia, so that was my internet. The letter C from 1927. And today, sadly, still what was in the news, is having the worst mean life expectancy in United States of only 57 years.

And a lot of that comes down to access. Access to healthcare obviously, access to healthcare information. And think we look forward to a world where we can level the playing field and provide much more access to both healthcare and healthcare information throughout the country. I'm really focused, obviously deeply, Adrian, on dissemination at least of

healthcare information and making it free of charge. But healthcare does not mean you have healthcare, and we have a lot of work to do on that side of things.

Adrian Hernandez: 03:06 So one of the things that you commented on is open access, and you shared some great stories about how people felt ownership of even their slide sets, or either the industry did. How did you break the barrier? What was the moment that shifted everything to get to open access of information?

Michael Gibson: 03:34 Well, I spent some time at UCSF, where I think you spent some time, right, Adrian?

Adrian Hernandez: 03:40 Yeah. That's right. [crosstalk 00:03:41].

Michael Gibson: 03:40 So I think all people, Eric Topol, Rob Califf, myself, you, Dean, Kiriakis, a lot of great time was spent at UCSF. I was there during the internet bubble, during the pets.com period. And it's hysterical. I decided I was going to do this internet thing too. And it really started in my daughter's bedroom. I had a desk, it wasn't in a garage, but it was in the corner of my daughter's bedroom. I would watch her and I would set up a website in there called clinicaltrialresults.org. And my idea and goal was to move away from the guy who made up the slides, own the slides, and to move over to sharing that information. And everyone could use your slides.

That may not sound radical these day, but back then, the idea was, "Those are my slides. Only I can share them." And that's how people marketed themselves and how they valued themselves. But it seems silly, really what would work best is if everyone saw your work and everyone promoted your findings. So I set up this website and gosh, it was back during the ASPREE study that Jimmy Chang from Duke led. That was one of the first things I released and I was amazed, 10,000 people in a day had downloaded the slides. And it was clear to me right from the outset, that this was going to be a major seismic change in how we shared information.

So as you know, Adrian, over the years, I've done 2,500 interviews, put up slides free of charge for everyone to share. I really support the site myself and financially support it myself. And I think it's been a great resource for everyone to swap slides and keep up to date, particularly during the time of the meetings, the national, international meetings.

Adrian Hernandez: 05:54 Yeah. So I imagine there are a lot of things that came to you in your days in San Francisco, perhaps even a Mel's Diner, which was one of my favorite places there.

Michael Gibson: 06:05 Oh, well, Mel's. We used to go to Mel's all the time, and me and the boys would call it Melsitus. We'd come home and we would fall asleep and take a two hour nap after a big meal at Mel's with some shakes and some carb loading. So I'd loved Mel's.

Adrian Hernandez: 06:22 Yeah. So I'm sure there are a lot of ideas all of us had from there. And I guess, we never really think about this fundamental right to freedom of information, and what you've driven through this and just getting access here. Now you've really been a huge promulgator of this through social media, talking about something born out of Silicon Valley that's had a big impact, Twitter. So how did that start in terms of you joining Twitter and then quickly getting to hundreds of thousands following you?

Michael Gibson: 07:01 Well, what's interesting is the guy in charge, or the woman in charge, is the person with the microphone. That was always the expression, but now everybody has a microphone. And I do think social media has played a major role in leveling the playing field. I was a little skeptical. I was in that one-way communication of information from a website mode. But my son, particularly my son, Will, who's a physician, this was on me all the time. "Dad, dad. You got to get on Twitter. You got to get on Twitter." And I thought, "What it is this Twitter thing? It sounds like the Kardashians family or something."

And so I got on and my first follower, or my one and only follower for a while, was Deepak, but I didn't have anything to really say. But I started to dip my toe in. And then things really changed when the Boston Marathon took place, where the bombing happened. And my son, believe it or not, played semi-pro football while in medical school and also ran the marathon while in medical school. And he would get done with the marathon and go back to class and he texted me, quote, "I'm okay." And I wrote back, I said, "Well, you must be tired." And he said, "No, dad. A bomb just went off at the finish line of the Boston Marathon. I crossed the finish line about 10 minutes ago."

And we have a place downtown where he lives, and my son Mikey lived, right literally around the corner from where the bombing occurred and it really shook the house. So I thought, "Wow." I started looking on Twitter what was going on, and

really all the information that I was getting about the bombing was coming from Twitter. And I was unfortunately on call that day and went down to the ER to help with vascular issues, shock and everything else. I got to say it was unlike any scene I'd ever seen. I mean, I had been an ER physician back in the days when you could be an ER physician with an internal medicine license at the Brigham, that's where I would moonlight. And this was not like that, this was a scene out of a war movie, people with missing arms and limbs.

And I began to tweet about it, obviously without pictures, without names, but just begin to describe the waves of patients coming and what I was seeing. And suddenly my following just exploded, using hashtag Bostonstrong. Next thing you knew I was getting calls from news agencies all over the world asking to interview me to describe the scene. And that was the first bump in my following. And it became very clear to me, wow, this is a very, very powerful tool. And I also said, "If you have a loved one and you want to know if they're here in our emergency room, call one of these two numbers." And I worked with the administrators to set up hotlines so people could call in and see if their family member was there. And then I said, "Also use the hashtag, I'mokay. And that's became popular too on Twitter.

So that was the first moment. The second moment was during the Ebola crisis. And as you know, Adrian, I run an open source, open access textbook called WikiDoc. We begin to put up enormous amounts of content day by day based upon what was going on with the Ebola crisis. And I would tweet out several times a day what was happening. And that was the second huge bump in following. But the most amazing thing was I got asked to come to a UN meeting on communicating about Ebola and Ebola awareness. So again, it was another lesson for me that this is going to be a very, very powerful tool in immediately getting information out about what is going on in healthcare and healthcare crisis in particular.

I also do a lot related to art and people like that a lot. And I think that's important. I think people always say, "Oh, you need to have your site be professional." Well, I'm a professional artist, so why can't I do both? So I think people want to see physicians as human, and we shouldn't avoid being human. I just stay away from politics and religion and things like that. I never say anything about politics or try to avoid it, if at all possible. I think there's been excessive politization of everything that's going on right now in the healthcare crisis. So I try to

avoid that and try and get people to be more unified and seek consensus.

But it's clear it's going to be here to stay people, aren't going to give their microphones back. And this has really revolutionized things.

Adrian Hernandez: 12:18 Yeah, that's terrific. It's a good reminder that we actually need to consider the field of human medicine and making sure the humanistic parts of this are seen, such as art and culture here.

Michael Gibson: 12:35 I think also, Adrian, people want more than information. They want to know the context of that information. They want to know what you think and what I think about the information. They're looking for their healthcare providers to tell them what the truth is. And we need the truth now more than ever, and we're really there to be truth-tellers and to hold other people in check.

Adrian Hernandez: 13:00 So let's talk a little bit about that. So I think you've noted that while social media gives everyone a mic, there can also be ... And the benefits for that has been the rapid dissemination of information, but then there are also some risk, which is misinformation or disinformation. What's a role of clinicians in this new world to help patients or people with that?

Michael Gibson: 13:29 Well, we didn't sign up for it, but I think our job is to be the antiviral agent of combating disinformation or misinformation. Yes, we are healthcare professionals, but it extends beyond just providing care. I think we have an expanded role now in being healthcare educators. And it's a big responsibility. We can't just say, "Well, it's not my job." It's horrible that there's this disinformation, but it's important that all of us speak up and correct that disinformation and that misinformation. I know I do. I know you do, Adrian. And I think it's really now one of our expanded roles as healthcare professionals.

Adrian Hernandez: 14:18 It certainly seems like this needs to be incorporated into the curriculum for medical school and other healthcare schools. Some people actually take advantage of this new way of getting information or education to patients and other clinicians.

Michael Gibson: 14:42 Well, I think if medical schools, hospitals, and other educational entities, if they ignore it, they ignore it at their own peril. I think, people really should get credit for the impact that they're making. Not quite sure how you quantitate that yet, but they do. They should. They really should. I think it's a new metric that

needs to be integrated into the promotion process. And it's up to institutions to figure that out. I hope they do soon.

Adrian Hernandez: 15:07 Now let's talk about the Giga Trial. So you see that as now being enabled through lots of different features. What's that like?

Michael Gibson: 15:20 Well, we had great visions of doing a trial of 180,000 patients and a randomized trial, but then the pandemic hit and it's really taken a whack out of enrollment. But I think what we're learning is that you can do a virtual trial. You can cut out a lot of the bricks and mortar and do these kinds of trials for 1% of the usual cost. 40% of the cost of these trials is, you know all too well, Adrian, is the cost of human beings, monitors going out and checking every single thing that it matches what's in the electronic health records, something they call monitoring.

We've gotten rid of that. We're using insurance claims data to see if someone had an adverse event. We're saving money by randomizing people over an app using a central IRB process. We're using a lot of media to advertise the trial. Of course, doctors and nurses can refer a patient into the study, but they don't have to do the work of consenting them. They can also follow them. But as I said before, we're cutting way down on the costs by managing so much of the trial virtually and electronically. And while we may come up short of our enrollment, what we're not coming up short on is learning how to get the job done and do it all virtually.

I think one of the things we've learned, which we're actually quite surprised by, is how sticky this is. We thought, "Oh my gosh, people are going to stop participating virtually in putting information into the app after six months." But we're seeing people continue to stay very engaged throughout the process. They're not dropping off as we would have thought. So again, I think the importance of this is not the question or the answer. The importance of this is the new way we're going to make our way forward, which is through electronic apps and virtual trials, rather than bricks and mortar. We just can't afford to spend a billion dollars every time we want to ask a question.

Adrian Hernandez: 17:38 That's terrific. Well, Mike, it really's been a fascinating discussion here on our podcasts and talking about lots of different things. Ultimately trying to get better information more widely to everyone and having everyone participate in that, including the large clinical trials. So Mike, thanks for spending time with us on this podcast.

Michael Gibson:	18:02	Adrian, thanks for having me on. It's been great collaborating with you over several decades. You're doing great stuff. And I look forward to our continued and expanded and strengthened partnership.
Adrian Hernandez:	18:14	Absolutely. And everyone, thanks for joining this podcast. Please join us for our next podcast where we continue to highlight fascinating and informative changes in the research world. Thanks for joining today's NIH Collaboratory Grand Rounds podcast. Let us know what you think by rating this interview on our website. And we hope to see you again on our next Grand Rounds Fridays at 1:00 PM, Eastern time.