Adrian H.: [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.

Adrian H.: [00:28] Welcome everyone to today's podcast. This is Adrian Hernandez. I just recently moderated a great Collaboratory Grand Rounds with Rob Califf who is vice chancellor for health data science at Duke University, and also an advisor for Verily. He just gave a great talk on data science and essentially the era of data everywhere. I want to welcome Rob to our podcast. Rob, you started off with that data is being curated everywhere and that's not going to be the big problem. Do you see difficult issues with the curation of data, or the so called data janitorship?

Rob Califf: [01:10] Adrian, what I'd say is data are everywhere, I would say curated data actually not everywhere yet. In fact, one of the biggest issues we need to deal with is organizing, correcting, collating data and making it presentable in a way that all these fancy analyses can be done. The opportunity is fantastic right now, but one of the main things we all need to focus on is how to take the data we have, which is everywhere, and make it as good as it can be.

Adrian H.: [01:47] Right. Then when you think about users of data, often we seem to miss important users, clinicians and people. How do you see that working out in terms of users of curated data and what's needed there?

Rob Califf: [02:03] That's a big topic and I'd say right now almost everyone is overwhelmed with data and there are multiple dimensions of this. What they're lacking is data that can be digested, that's useful for making good decisions. It's almost like we have too many choices, and there are too many opportunities to be misled by information. One aspect that I don't think we talk about enough is that it's not just the amount of data, it's the fact that it's a two-way street. The communication is occurring constantly. That's not a surprise to anyone because we're all on our iPhones or other android phones or whatever we're using constantly.

Rob Califf: [02:52] We're overwhelmed with information and I think there's a lot of substance to the old axiom about we have data, information, knowledge, and wisdom, those are our continuum. I would say it's a big pyramid with an enormous and growing base of information of data, not so much information, even less knowledge and very little wisdom at this point. One way to think about it is that I don't think the issue is any longer technological. The issue is really cultural and social.

Adrian H.: [03:31] You gave an example of people actually using search to find out about their health. I imagine it may be actually quicker and easier to just get online and do a search about a set of symptoms like chest pain rather than trying to set up an appointment, park in a garage, find your way to a clinic. Do you see that having good things or bad things? How is that going to be handled in the future?

Rob Califf: [04:01] Well, I have great confidence in the long run it's going to be good. Who could be in favor of staying on hold on the telephone, eventually getting an appointment that's at the convenience of the doctor and not the patient, and then going and waiting in a waiting room with people sneezing on you and sitting there while the doctor's busy, for things that could be taken care of with a text message.

Rob Califf: [04:30] A number of niche providers are already doing this for people who can pay for it, and I think a lot of the work now is automating things so this can happen in everyday practice. Again, what we have to do is to figure out how to actually make that work and then employ the clinicians in a way that takes advantage of that automation, so they spend their time doing useful things instead of feverishly trying to type notes into Epic.

Adrian H.: [05:03] I like that. What's going to be that evidence base or how to create such a platform to note that that actually works and it doesn't have any unintended consequences? Is there going to be an easy way to prove it can work or actually show where it has limits? How do you see that evolving?

Rob Califf: [05:24] Potentially, the beauty of everything about medicine, based on what we've learned through the history of trying new things, is that the proof is in the pudding. You need an objective evaluation, preferably with randomizations. This is where entities like PCRF, or the NIH Collaboratory, I think, are leading the way because ideally you can use approaches like cluster randomization to measure what works.

Rob Califf: [05:56] Now, Adrian, you said without any collateral damage and I would argue there will always be unanticipated consequences. It's more a matter of anticipating them, measuring them, and then putting systems in place that take care of them. But I would also just point out, it seems highly unlikely that if you had a simple question, an email exchange would be worse than waiting for an appointment and going into a crowded waiting room and sitting around for a long time. That just doesn't, you don't need to be a genius to figure that out. The question is how do we set up a system that makes that both practical but also interesting and fun for those that are doing it.

Adrian H.: [06:48] Now, one area that you emphasize is that there are going to be some cultural changes needed. Some of the examples you highlighted such as how people investigate their symptoms of depression. That could be online and that could actually trigger, potentially, responses to those people in a different way than what we do clinically currently. Or other ways in terms of how to actually be okay taking care of patients who are recommending health decisions virtually. For that kind of cultural change, what's going to be needed? Is it going to be new training of clinicians? Sharing different models? What's going to drive the cultural change?

Rob Califf: [07:43] Well, I think, ultimately, people who have to be patients will be the biggest drivers, because the current system is not serving them particularly well. I'd say particularly in the United States, we have costs that are off the chart and an increasing divergence of our outcomes compared to other economically advantaged countries. This is quite a stark thing that's happened over the last relatively short period of time with an increased mortality rate in the U.S. now for three years in a row, and a lot of

dissatisfaction with outcomes in a setting where the costs are not really coming under adequate control.

Rob Califf: [08:34] I think there'll be a lot of pressure from many sides to change what we do. Ten years ago, people would've thought it was insane that you would get in your car and talk to your car about where you want to go, and your car would talk back to you and change what it says, based on simultaneous integration of information across the whole U.S. If you're going to take a trip across several states, everything happening between you and your destination is taken into account. There's just no reason why we can't do that for human health at this point. It's just going to be an interesting journey.

Adrian H.: [09:11] One thing tied to that journey is the ethical considerations. All the attention towards the data that's being compiled at say, Facebook or other systems, what do you see the issues there in terms of how that will evolve, in terms of privacy and confidentiality? Then, also, actually making sure that people have results that influence the right health decisions?

Rob Califf: [09:44] We all need to work together on the answers. I believe that veracity on the internet is the problem of our time, and that universities in particular, because universities are a safe, not for profit harbor for multiple sectors; law, business, religion, policy, medicine, to commune together to try to solve problems. I think this is the biggest problem. For every question someone has about his or her health, there is an answer on the internet.

Rob Califf: [10:20] We now know from empirical work that untruthful answers get to more people faster and last longer than truthful answers. Very good empirical work on this now that's been done. We have to develop an approach to identifying and putting forward reliable answers that are based on actual knowledge as opposed to just opinion, when the most satisfying answer is going to be one that is totally made up because it can be said with great authority and certainty.

Rob Califf: [10:57] Whereas a responsible person giving a scientifically correct answer should point out the uncertainties, the caveats, the remaining work to be done and always the possibility that new discoveries will change the answer. So this is a huge issue because the internet is ubiquitous and the digital divide is pretty much gone in terms of access. Because whether you're talking about the poorest counties in the U.S., or the poorest countries in the world, cell phones are everywhere and in many circumstances, there are more cell phones in underserved areas than wealthy areas because people are very dependent on those communications.

Rob Califf: [11:46] Then I think this issue of how to give information to people is just daunting, but a great area for people to focus on. I learned a lot about it at the FDA. Something like writing a food label that 320 million people need to interpret, and you've got very limited space, it's daunting. There's a great article that just came out yesterday, and I've forgotten the source. It was more of a popular magazine about the issues with returning results in Iceland, and the article really focused on the psychological trauma of people getting results they didn't necessarily want to see.

Rob Califf: [12:29] I think many of us are committed to returning results to people, but we need to think of it as return of results to people in the right way, taking into account their preferences and issues like their psychological state and their personal preferences. There is a huge body of work. It's like we're on a frontier now. We have this amazing tool called the ubiquity of information, but we're just getting started on how to curate, organize it, present it, and use it in a way which accrues to human health.

Rob Califf: [13:11] Then, finally, on this topic of ethics, obviously, this approach is being used for marketing and political persuasion on a large scale already. I think this is a case where medicine needs to learn from the marketers but for a different purpose. To improve health as opposed to separate people from their wallets or persuade them to vote a particular way.

Adrian H.: [13:34] Last thing is when is this all going to happen, the digital transformation? I noted your slides and discussion was that it sounded like it was going to be immediate, 2020 is what you had described. Is it that quick?

Rob Califf: [13:50] Well, it's already started and, as you know, Adrian, if you are paying for concierge medicine today in the United States, and you've got a problem in the middle of the night, a child with a fever, you just send a text message to your clinician and they'll answer right away. It's part of the package. So I would say it's already started. As I've mentioned many times, in my life at Verily I've seen the evidence that many patients, the minute they get home from the doctor are surfing the web trying to figure out what the heck the doctor was trying to say.

Rob Califf: [14:32] It's here but it's going to evolve. I think it's up to us as a community, as a multifactorial community, to guide this in the right direction. One way of saying it, just like I think ethics is too important to leave to ethicists, I think the digital era of medicine is too important to leave to tech companies. We need to all be thinking about it and working on it.

Adrian H.: [15:01] Well, that's great to end this podcast on and so I want to thank you for your time here and thank everyone for listening to the Collaboratory podcast. Our next podcast will be with Doctor George Hripcsak, and he will be talking about "Odyssey: Drawing Reproducible Conclusions from Observational Clinical Data."

Adrian H.: [15:24] 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 p.m. Eastern time.