

TECHONOMY HEALTH

Finally: Headway with Cancer

Speakers:

Dr. Jill Hagenkord, Chief Medical Officer, Color Genomics

Dr. Andrew Kung, Chair, Department of Pediatrics, Memorial Sloan Kettering Cancer Center

Dr. Eric Schadt, CEO, Sema4

Moderator:

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(Transcription by [RA Fisher Ink](#))

Salisbury: My name is Meredith Salisbury, I write for Techonomy. I also work for a PR firm called Bioscribe. What we wanted to do with this panel is look at the very cool things happening on the tech side, on the science side. The way we chose to look at that was through the lens of cancer. We could sit here for days, and talk about genomics and CRISPR, and all sorts of things. We are going to try and use cancer as a lens through which to view all of this and tease out some of the opportunities and obstacles that we're seeing. With me I have Jill, from Color Genomics, I've got Andrew from Memorial Sloan Kettering, and Eric from Mt. Sinai. I just want to start very briefly with some success stories. I like to do the good news first. I want to look at some of the opportunity we have in cancer, in related fields, through some of the most exciting things we're seeing. Jill, do you want to start?

Hagenkord: Sure. My background, I'm a board-certified pathologist, with sub-specialty boards in molecular genetic pathology. I also did a fellowship in informatics. Essentially, I've been doing precision medicine since before precision medicine had a name.

Salisbury: You see why I'm a fan?

Hagenkord: [LAUGHS] There's been this promise since early in my career, that we were going to get to a point where we could actually start doing real, preventative genetics, and preventative medicine, more genomics-driven preventative medicine. We're at that point in time right now. It's an exciting time in genomics, when we can start to see it reach a price point, where we can get it outside our broken healthcare system, which doesn't pay for preventative health, right? It's not incentivized to do that. Now, it's cheap enough we can get it outside the system and consumers can pay for it themselves or self-insured employers can provide it as a health benefit for their employees. Inherited disease testing I think is one of the lowest-hanging fruits in genomics. Companies like Color, for \$249 you can look at 30 genes associated with hereditary cancer and have all the complimentary genetic counseling that you need. Everything is online, spit-faced, on your mobile phone, connected with your doctor. Your physician is ordering the test. We really removed all of the barriers to getting preventative information about

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yourself, so that you don't have to actually develop the cancer. You can hopefully, if you're at high risk, determine that ahead of time and prevent yourself from getting cancer in the first place.

Salisbury: Jill, just tell people, \$249 sounds great but tell us what that was in comparison to.

Hagenkord: Right. A few years ago, Myriad was kind of the only show in town and they gave me two genes. They gave you BRCA1, BRCA2 and it was about \$4,000. We've really come a long way in just a few years and that's really due to the maturation of next gen sequencing.

Salisbury: Andrew, you've been doing amazing things with actually treating patients who have very advanced stages of cancer with personalized approaches. Tell us about that.

Kung: I think the conversations taking place here today are so timely for cancer medicine. For the first time, in my career at least, I can finally say I'm an oncologist and it's an exciting time to be an oncologist.

[LAUGHTER]

Kung: Why is that? Because we're living through a convergence of new technologies, new therapies, that we're finally starting to see the fruits of 30, 40 years of research actually impacting the patient in the clinic. The personal story I would put to contextualize this, is that when I started as a medical student 30 years ago in 1987, when we went around and did rounds on patients, checked-in on patients, I would carry with me an index card. Each patient had an index card and the information that I needed to know to take care of that one patient was contained on that one index card. Now fast forward 30 years, to where we are now, and in order for me to take care of my patients, I have to now be able to sift through gigabytes of data and find that needle in a haystack. The transformative power of being able to do this is really quite real. I'll give you one example of a patient treated at our center. This is a young seven-year-old girl, who at the age of five had been diagnosed with a very unusual tumor. We look under the microscope, it was very hard to tell what it was, and because of that our therapies are generally guided by what the diagnosis is, this child was treated with a variety of different toxic therapies. She went through some 20 cycles of chemotherapy, endured four or five different surgeries, and then at the end of this course was told, after three years of therapy, there's nothing more we can do. The tumor has grown back, and we have no other options. She was actually transitioned over to palliative care, end of life care. She ended up coming to our center, where we took all the approaches that we could, in terms of characterizing her tumor from a genetic point of view, from looking at her DNA, looking at the RNA in her tumor cells.

What we found was that her tumor contained a breakage between two of the chromosomes and a rejoining of those two chromosomes in a way that had never been described before. It resulted in a protein that no one within the biomedical community had ever seen, but it turns out that one of the partners that the breakage was centered around was a protein called AKT, which we do have drugs for. Now, the traditional way of approaching this patient would've been to say, "That's great. We will go into the lab and study this protein, and maybe ten years from now

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figure out how it works, and whether we can treat this particular tumor using this drug.” But, ten years from now that patient would not be with us.

Instead what we did was, we went to our adult colleagues who actually were testing in a phase I trial, an inhibitor of AKT. We convinced the company to let us try it in this child. This drug had never been in a trial before, but we obtained the drug on a “compassionate use” basis, and gave it to the child. Within 30 days, the tumor had completely disappeared. She had achieved a complete remission. This is a child whose cancer was driven by an alteration no one had ever seen. She was given a drug that no child had ever received. But our ability to match specific deficiencies that result in cancer with potential therapies is really underscored by this example. We have reached a point where we can actually use the kinds of technologies we’re talking about today to impact a patient in the clinic. That’s why I say, “I’m excited to be an oncologist.”

Salisbury: Great.

[APPLAUSE]

Salisbury: Yes, indeed. Eric, How about you? Cancer is just one of the areas that you guys work on at Mt. Sinai. But, this has been so successful there that you’re about to have a major change within Mt. Sinai. Tell us about that, and your success stories.

Schadt: First of all, I’ll say that I’m a mathematician, not an oncologist or a pathologist. I’ve spent the last five years echoing what you just heard, that we’re testing, and that the genome is relevant for everybody today. We now have a throughput of about 100,000 to 150,000 samples a year that we’re testing, that covers largely reproductive health, so carrier screening, noninvasive prenatal testing, newborn screening, heritable cancer screening, and then on into the oncology space, where we’re looking at the somatic genome, both DNA and RNA, very similar to what Andrew has just indicated. The studies we’ve carried out have shown that in the case of cancer patients, what we can uncover by sequencing your tumor—much as was just conveyed on the seven-year-old girl—90% of those cases we can come up with medically actionable guidance to inform the course of care. Us, like Sloan, and many others, are carrying out the larger studies to demonstrate that that actually helps outcomes. There are definitely cases where you can get people into complete remission, but we’re not at that stage for everybody today.

We’re all still learning, what are the right scales of data we need to generate to do that. We’re pretty proud of that fact. We’re one of the largest testing providers in the greater New York City area for informing on genetic conditions. One third of the undiagnosed conditions we have coming through our rare disorder clinic that are unresolved through standard of care pursuits, are resolved through genomic sequencing, where you can give a definitive diagnosis, and in some cases, directly indicate a treatment that the individual can receive.

The thing I’m most excited about is how do we take all of that to the next level and engage broader communities with it? It’s the work we’ve done to engage patients in their health course journey, to aggregate more information around them. What exists on you today in your medical

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record is pretty sparse. The five minutes you might spend with a doctor per year doesn't really give a very accurate view of what's going on inside of you, unless you have something in the tails of the distribution from one of the tests that are administered.

What we had shown with Apple was our ability to basically engage patients electronically. In the case of asthma and COPD, where we had 10,000 people enroll in an IRB approved, first-ever IRB approved research study, where you're electronically consented. We enrolled 10,000 people in a couple of weeks, for the cost of developing that app, about \$100,000. We generated one of the largest asthma cohorts in the country, in a matter of weeks. If you think about what that would've taken through traditional, RO1-driven, National Institutes of Health-funded research, that would've been five-plus years, millions of dollars, multiple investigators, and you still would've been having a very isolated geographic region covered with that cohort. We're super excited about the ability to engage patients more directly, electronically to compliment the information that's being acquired in the medical system, and we believe that as these sensors get better and better and more numerous, that we're going to be able to generate better health profiles on you outside the medical system than inside.

Salisbury: All right. One of the things I want to get to, Andrew I think you kind of led us to this point. This was an amazing story you shared. But, the other side of it, the one we're not talking about, is that it's not really scalable, right? Having to go personally to a drug company, and convince them, and get the compassionate use from FDA, we can't do that for every single patient. Someone at an amazing place like Sloan has a much better chance of that than someone in rural Ohio. How do we take advantage of this and really scale it up? Is that possible?

Kung: I think that there are aspects of the genomic analysis that I do think is scalable. At Memorial Sloan Kettering, for example, we have now done genomic characterization, if you will, of 17,000 patients. In that particular case, we're focusing on the approximately 500 genes that are associated with cancer. That now is an approved test that has a turnaround time that is clinically tractable. The idea of using maybe not whole genome characterization, but broader gene characterization to actually guide patients to the right treatments, I think is a reality now. The ability to bring those costs down, the value proposition in making sure that we get the data out, in terms of how these types of technology impact outcome so that ultimately they are reimbursed not only by commercial insurers but also by government plans, I think those are the ways that we propagate the type of technologies that exist right now, maybe more so in the ivory tower than in rural areas. That's how we get it to be more democratic and widely dispersed.

Hagenkord: Yes, I think it's a matter of accessibility. Now that the price has come down and that's not as much of a barrier as it used to be, now it's just a matter of making it more accessible to more people, at the time that they need it. This conference is great, right? It's this combination where we're talking about healthcare, and tech, and Silicon Valley. A doctor like myself, after spending decades training and working in the incumbent health system, move out to Silicon Valley and partner up with some senior executives from Google and Twitter and start

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to take a problem and break it down. Use design theory to make healthcare easier and more streamlined and remove the barriers. I think we really are at a point where there's companies like Color, that everything's accessible from your mobile phone. If you're in rural Ohio, as long as you have a mobile phone, you can start to access information about yourself. Getting your tumor in a spit kit in the mail is a little harder, but we've got to start where we can start.

Salisbury: Right. Accessibility and consumer empowerment have been themes so far, but we have this rising tension where we're giving consumers more and more hope, that they can afford the tests, and that they can get access to things. But, we still have this medical system that says, "The consumer has to be kept at a remove," right? There's got to be a physician gatekeeper in there. They're very uncomfortable with the consumers having direct access to anything. Do we just deal with that as it is? Do we get past it somehow? Eric, do you want to—

Schadt: Yes, I think it's a good question. What we can't do is throw all caution to the wind and directly engage consumers around this kind of information that can have very significant consequences on their health. Something even as simple as drug safety PGX. A big push-back from the FDA on just going direct to consumer with that information. Why? Because a consumer may stop taking a medication based on that information, without the proper consultation, and that could ultimately affect their outcomes. I think it is about how to engage technology in a way that facilitates more seamless connection to physician counseling, genetic counseling, and so on.

One of the products we've built is an electronic genetic counseling platform. Why do we do that? Well, it's to modernize the IT side of the genetic counseling. As the tests grow, sequencing on a super Moore's Law curve. There's not been a technology in human kind where that's been true before. The complexity of the tests is growing exponentially. The demand for counseling, and our carrier screening—70% of the women tested, test positive for something. That demands some kind of counseling. As the tests grow exponentially, the genetic counselors are growing sub-linearly. It's not a scalable solution, it's not sustainable. The only way you're going to solve that problem is through software. By leveraging software to help facilitate more seamless engagement of patient with the medical information, I think it is going to be one of the ways that it gets solved, the telemedicine approach you're seeing in wide use today.

Salisbury: Jill, what about you? For Color, there is this difficulty where if I wanted to—and this is not hypothetical, I have done this—I wanted to get myself a breast cancer risk test, and I wasn't entirely sure the insurance company would pay for it, because there wasn't a clear sign that it was relevant. I actually called some companies, and they said, "No, even if you're willing to fork over the money yourself, you can't have this test without a physician signing off on it." How do you deal with that?

Hagenkord: The founders of Color all were touched by cancer in their background. One of our founders is a BRCA2 carrier. His mother is a BRCA2 carrier, she's had cancer twice. His grandmother died of cancer. Even this affluent family had trouble getting themselves tested and their at-risk family members tested. That was really the story of what started Color and why our

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flagship product is around hereditary cancer. There's just so many ridiculous barriers in our incumbent healthcare system. As a matter of deconstructing it and watching the workflows and whenever we can, engineering each part of that workflow where you're keeping the responsibility, right? You don't want to give people this important health information and not give them the proper support to understand it. The scaling of genetic counseling is part of what we did. The engineers just sat and watched the genetic counselors go through their day, everything that they had to do, and then went back to the whiteboard and said, "Where can we cut the fat out of this?" The accessibility is a really important part of the philosophy at Color. The regulatory aspects around, "Where is that line between direct to consumer?" We don't actually have a definition of it. You're never really quite sure, but we've tried to work with regulatory bodies to make sure we're CLIA-compliant, CAP-compliant, CE-marked. We're a physician-ordered test, it's always ordered by a physician.

If you've got your physician, great. Your physician can order it. If not, we work with multiple external physicians, third party network of physicians. If you're curious and you want to know if you've got a risk for hereditary cancer syndrome, you can just go to the website and sign up. If you don't have a physician, we'll connect you with one. That third-party physician reviews your health intake survey and determines whether or not this is the right test for you. Then, they'll order it, and everything else comes online at an eighth-grade level. I think our incumbent healthcare system is so frustrating, and inefficient, and dissatisfying to everybody, both the doctors and the patients, and everybody involved in it. Why can a shoe-shopper go to Zappos and have such a lovely experience shopping for shoes? Why can't our healthcare be more like Zappos?

Salisbury: Andrew, sticking with this regulatory tension concept, you and I had talked earlier about this idea that you're doing this amazing personalized work, but then you've got two troubles. You've got the FDA still requiring randomized clinical trials, which really does not work at all with this personalized concept. And you've got the potential to find drugs that would be effective that have nothing to do with the actual thing you're looking at. Maybe a diabetes drug is magically going to cure this tumor, but it's very hard to get the off-label prescription approval for that. How do you deal with this?

Kung: I think part of the problem as a pediatric oncologist is that there are very few drugs that actually have a pediatric indication. Even if we find a mutation that is well-validated in an adult disease, we can't just prescribe that drug, because most of the time the payers, insurance companies, will say, "Well, there's not an approved indication." That's why I think, as we've talked about, I can analyze the entire genome of a patient's cancer in two to three weeks, but it often takes me six to eight weeks to get approval to give a drug that's associated with a change that I see.

I think that's something that we and many others in the community are working on in terms of, "How do we deal with some of those regulatory burdens?" The question of, "How do we ever, going forward, prove that a drug works or doesn't work?" This is fundamentally what randomized trials were used to answer in the past. I think that's also changing, because if

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through the genomic characterization and the precepts of precision medicine, if we can actually identify a highly enriched responder population, there are already examples of drugs that are moving towards approval on the basis of trials that involve 20, 30, 40 patients. I think that part of what we need to try to do with this precision medicine paradigm is also change the regulatory approaches in terms of proving and disproving whether those drugs work or not, and we have to move away from this concept that everything has to be proven through a placebo, double-blind, randomized, phase III trial. There needs to be innovations in clinical trials that is matched to the innovations in diagnostics and therapies that we're bringing forward.

Salisbury: Great. Eric, your team has done a lot of work with personalized cancer therapy. Are we finally at the point where we can say, "The concept that lung cancer is lung cancer is lung cancer," is that just dead now? Is everyone's cancer completely individual and personalized?

Schadt: In terms of care, or in terms of...?

Salisbury: If we could just blow up the system and start over.

Schadt: I think we all agree that the molecular characterization of the tumors gets to a far deeper level of what's going on and could guide treatment. The bottom line is we haven't run the big studies that show, without a doubt, that the outcomes of those individuals who are so informed are dramatically improved to the point where you want to shift that to standard of care. I think that evidence still has to be built, and I think it gets to one of the important points we haven't really touched on here. How to access to the data, how do we free the data? What I've learned, not being a cancer guy, but now interacting with lots of cancer guys, is that it's an intensely competitive arena, especially in New York City. There's not huge collaborative want amongst the institutions to share the data, to open that data, to empower patients to take their own data and share it with whomever they want. The fact of the matter is, to get to the level of evidence, we need to make this super routine. It's not going to be 5,000 or 10,000, this is going to be a million. The numbers have to be really big.

If you look at all the different subtypes of cancer that exist, and the molecular features that can inform. Think of what we need for deep learning. What have the other big information companies shown us to appropriately pull out the features that are most predictive, out of hundreds of thousands of features, to predict something accurately within any given subtype. You need 10 to 20,000 at least, to start having those deep-learning procedures take hold, and deliver value. To subsample 10 to 20,000 of a given type, you need millions of people to sample from to get enough numbers in that given type, for that to take hold. Obviously, no single institution is going to have those numbers. The only way you're going to win this game is by opening that data, being able to aggregate it across all institutions, putting the patient first in that journey, so that they can benefit the most from that data. I think the openness, the sharing of that data, how privacy is protected when you're doing that, what role the patient should have in the data that's generated on them.

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My position is that the patient owns that data, right? It's not the medical system that owns that data. That patient should be empowered to take their own data and share it with whomever they want during the course of their care. In oncology, they're fighting for their lives, and who are you, who is the medical system, to stand in your way, to port that data to somebody else who may be able to advance your care. I think, Andrew, the case of the seven-year-old is a good example of one who can benefit by going to different groups to try to resolve their disease.

Salisbury: It seems like such a common-sense approach, but unfortunately it flies in the face of what we actually deal with in medicine. Eric, you've been a proponent of data sharing for a long time. Is it possible though, given that it is seen as a competitive advantage, whether it's a company, whether it's a hospital, there are reasons that this data is "siloes," and we don't like it. Is it possible for a company or a hospital to share data and still succeed?

Schadt: I think it has to be. This company I'm transitioning out of [from] Mt. Sinai, Sema4, has as one of its main charters to engaging patients along their health journey and putting the data in the hands of the patient. Again, if we can empower patients to—Obviously, the gigabytes of data Andrew says he has to deal with, you're not going to want a lay person who's having that information. They can't directly manage that information. But if we can host that information for them in the cloud, and allow them through apps to decide who they want to share that information with, where they want it to go, what research studies they want it to participate in. If we can do that on a global enough scale, then yes I believe we can free that data.

The idea would be, once you have big enough numbers, so say our testing volume, 150,000 patients a year today, we're expanding nationally, we hope to have that to half a million to a million in the next year or two. If we're engaging all of those individuals electronically so they're consenting for us to aggregate their information, to put that data in their hands. Then, they can decide what to do with it. If we get to a million, where we have high-dimensional data built up around people and it's open and accessible. In order for you to benefit from that, you're going to have to contribute your data. If you want to reflect your data off that system to get a better clinical interpretation, then your data becomes part of that system. If we can get to that first-mover advantage, where you get this network effect, where the outcomes you are able to produce based on the more informed look, then I think we have a shot at everybody now having an incentive to see the data aggregated in a big, open space.

Kung: Can I comment on that? I don't think that the existing barriers to sharing are actually simply because of competition. I think with the genomic data, there's already large movements afoot in terms of how to aggregate that data. It's really the electronic medical record, the hospital record that is a problem. That's where, on an institutional level, there are real concerns about privacy that we have to come to grips with. As a hospital, as a medical organization, we are subject to a fine of up to one million dollars per patient record that we disclose inappropriately. We have to make sure that that data can be aggregated in a way that all the privacy concerns are ameliorated. The other thing that is the major barrier is it would be great if all that data were in some sort of structured and standardized format. But to hand a patient, let's say, a EMR that's a big PDF document, I don't know how useful that is in terms of the patient

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then taking that to aggregate with other data, that might come in different formats. How to pull together the electronic medical records in a way that is respectful of the privacy concerns but also in a standardized format or a format that is useful, is something that we as a community have to surmount.

Schadt: I will say two things. First of all, if the data is so publically accessible, I would love to get the 17,000 Fast-Q files you have from the impact panel today. Can I get that? Are you going to send it to me so I can do better research and help the patients at Mount Sinai? I know you don't, because I've tried to get the data, and I can't.

I think there are barriers to sharing the data. What I would say on electronic micro-record information, privacy is a big deal, but there are meaningful-use laws in effect today, that give you the right to your medical information. You can go into your electronic medical record and pull that information down today. I think that is being addressed. I think it's all about, if you want to protect privacy, it's about appropriate informing. Inform the individual of what the risks are, what the benefits are, and let them make the decision. Don't stand in the way, and pretend that there's some issue that the individual can't figure for themselves. How many people here today use Gmail? You digital click through consenting on Gmail, that gives Google ownership of all of your content. They can read your emails, they can use that for whatever reason they want, and yet you gladly consented. I don't care if you have Yahoo or Hotmail, it's all the same. You don't own the content of your emails, it's owned by the company that's hosting that. Yet, you agreed to that because you get a benefit back.

With Gmail, I use Gmail even though I know I have more personal stuff in my email, I can guarantee you, than I have in my medical record. I would far rather people access my medical record information than my Gmail, yet I agreed to that. Why? Because I get free emails, I can send large attachments, it's super reliable, I can archive stuff forever. It's a benefit. I think it's all about helping to educate patients on what's the right level of benefit that you get from doing this. We don't want the digital click-through consenting of Gmail, where you don't really understand what you're consenting to. I think in the medical space we can give a more informed consent, just appropriately educate individuals and empower them to leverage the meaningful use laws to take control of their information. I agree, you don't want it in a PDF. I 100% agree that that's not useful, but if you can digitize that information and store it for them, and then let developers, app developers, or other physician groups figure out ways to access that information and provide meaningful content back to the individual. The individual doesn't have to be sifting through it themselves, you can help them manage it in the iCloud. You can then provide apps that engage that information in ways that benefit the consumer. I think that's the revolution that needs to take hold.

Salisbury: All right. I'd like to go through some comments, because we have some. Do we have microphones? Please introduce yourself.

Moore: Hi, Jim Moore. I'm interested in this competitive advantage question and I was interested in the pushing back and forth there and that interaction. I really would like to know,

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what was going on there? What's the issue here? What's the 17,000 or whatever data sets that you've got? What is your notion of competitive advantage that that gives you? Are there alternative ways to think about that where you would make that more publically available in a wider pool and still be advantaged as an institution? I'd love to go at that.

Kung: We've gone through a period of time where the early adopters and the pioneers, in terms of this characterization, were doing so on the basis of the institution to actually bear the cost of doing the analysis, because payers still don't pay for these things. The initial acquisition of those data was very much funded by the institutions for the patients that they were treating. That said, the analysis and the product that resulted from that analysis is being made publically available. The data is posted on a publicly-facing portal, the cBio portal that many institutions are now adopting as a common portal. There's a project being spearheaded by the American Association of Cancer Research to aggregate data even more. What's being posted is the result of the analysis. What Eric is speaking to is the raw data from which that was derived. I think that we have not, as a field, come to terms with whether that data is the data that should be/can be shared.

Moore: Why not?

Kung: Well, in some cases it's just the size of—When we're talking about, for example, whole genome data, how to transfer that. I think there's a movement, and people are trying to move towards ultimately being able to aggregate all that. I think we're just not there yet. The desire in science, and in research—This is the movement to move towards posting raw data.

Salisbury: I know we've got other comments. Right behind you, yes.

Audience 1: Thank you. I just have a question. I agree that there are barriers right now to getting all the data consolidated, so that physicians can use it to make more smart diagnosis. What can we do proactively to make this move faster? Is it going through regulation? I know you say that we're not there yet, but what can we do to accelerate that?

Hagenkord: In some ways, we are there yet. I did a tour of duty at 23andMe, and I think they're a pretty good example on how you just get completely outside the system and you can get past a lot of these barriers. I don't know what their latest numbers are, probably pushing 2 million people who have just voluntarily chosen to spit and they do a genotyping array on you, and they [LAUGHS]—Esther is on the board of 23andMe—and then they ask you questions, right? You're on your mobile app, you're waiting in line at the grocery store, and you answer some quick questions about yourself on, I don't know, 500 different phenotypic data points. The participants in this experiment are really happy to share their data. Are they worried about privacy? Somewhat, but not to the point where they're not willing to share their information. They do all their online banking. If they're going to trust online banking, they're happy to trust a reliable, independent entity with their personal health information. You can actually do participatory research, and actually get information back in real-time about yourself, and as new publications come out. It's a completely new research paradigm and I applaud 23andMe for

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being one of the first people to get completely outside the system, so that you can start to do this a different way.

Schadt: I would say that, having collaborated with 23andMe, that their data is not really that accessible. In the early days they did allow you, you could, if you knew what you were doing, try to pull in all that genotypic information. They now make that incredibly difficult, and when we collaborated with them on the resilience project, which we published recently in “Nature Biotech,” the idea was one of can we identify people who are harboring very deleterious mutations that should’ve caused early childhood death but these individuals are in their 40s and 50s, harbor this mutation of never manifesting that disease. Those are pretty amazing individuals that have some way of buffering disease, that are in some way of benefit to humankind. Our ability to go into that information and aggregate it more completely, to do better at identifying those individuals was not so easy to do. The access wasn’t there. I think, again what it comes down to, to the question is enabling individuals to take control, facilitating ways that they can pull that information down, and facilitating ways to make that portable, so they can share it with whomever they want, and drive that revolution. You put the power in the hands of the consumer, where they demand that to be happening, and I think that’s what’s going to ignite a way more open framework than existed.

Salisbury: We’re almost out of time. Esther, final comment.

Dyson: Esther Dyson and I’ll be really brief. On 23andMe very simply, you can download your entire genome and do whatever you like with it. If you don’t know what you’re doing, like my older sister, it’s tough. Our contract with the customers is that we need to maintain their privacy, it’s their option to do it. What I was really going to about is the personal genome project, where you can go online and find my personal, entire, sequenced genome, and that of a lot of other people. You can join the Open Humans Foundation. If you want to do something to make this happen, do it yourself, and talk about it, and say that, “No one took my genome, and stuck pins into it, and harmed me in any way.”

Dyson: As Eric said, my email is a lot more personal, my behavior, than what I was born with.

Salisbury: Great. David, did you want to add?

Kirkpatrick: I was just going to say, we can take one more question.

Herman: Herman. It sounds to me like it’s a question of decentralization. I think that’s what I’m hearing from a technology perspective. I’m curious if you have any thoughts, Eric, about what you can do if—It sounds like you’re trying to buy or somehow get access to stock data. That’s obviously what this is on a political level. But, if you could access individual data, can you do anything with it on a smaller level?

Schadt: Smaller level being—?

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Herman: You know, if you get n number of patients giving you their genome, and not a million, or two million individuals. Technically, is that something you're working on?

Schadt: I think Andrew, Jill, myself—I think we all have—I have 400 papers. In those 400 papers are what genomic loci is associated with this disease? Or what network of things are associated with this disease? Those happen in n s of a hundred to thousands. We all publish lots of papers on there. Do you know what's my frustration with that? We still don't have any model that really informs whether it's cancer or diabetes. What's really going on in this individual? What's the trajectory they're on and how do we bounce them off that onto a well-trajectory? We just don't have models that are sophisticated enough to do that. Why don't we have them? The algorithms are there but it's the data we need to fit those models, we just don't have the scale. I think we have to move beyond what we can do with the local numbers and have to start thinking about population scale information to really affect a precision medicine, personalized medicine revolution. It has to be in the millions. That's the whole reason I'm moving out of a pretty comfortable position at Mt. Sinai, as chair of a department, making good money. Taking this high risk of going to a company, is to take a shot to getting to those big numbers. That's the only way we're going to get to the accurate models to affect standard of care in an information-driven way, in my opinion.

Salisbury: Great. Well, thank you everyone. Thanks for taking the time.