

### Topic Intro



1. In January 2015, President Obama announced \$215M as part of the Precision Medicine Initiative (PMI)
2. The PMI seeks to accelerate:
  - Deeper understanding of disease
  - Which will lead to better-targeted treatments
  - Models for incorporating precision medicine into clinical practice
3. This panel will discuss:
  - What is precision medicine?
  - How can it be achieved?

#### Topic Intro [00:59]

#### **[Male Speaker]**

"Doctors have always recognized that every patient is unique and doctors have always tried to tailor their treatments as best as they can to individuals. You could match a blood transfusion to a blood type. That was an important discovery. What if matching a cancer cure to our genetic code was just as easy, just as standard? What if figuring out the right dose of medicine was as simple as taking your temperature?"

That was a direct quote from President Obama in January 2015 as he launched the Precision Medicine Initiative. The Initiative seeks to gain a deeper understanding of diseases that can lead to more targeted treatments and then how to integrate those targeted treatments in the clinical practice. The government initiative notwithstanding, precision medicine's been maturing in recent years due to advances in genomics and big data analytics.

In the first part of our session, the panelists will talk a little bit about helping to define precision medicine. What is this initiative all about? In the second part, the panelists will talk about how precision medicine can be implemented.

## Poll Question #1



Based on my current understanding, precision medicine is:

- a) The future of medicine and achievable in the next 10-15 years.
- b) The future of medicine and achievable in the next 15-30 years.
- c) Not a realistic approach to medicine, even in 30 years.
- d) A new buzzword for something that we've been doing for years.
- e) I don't know enough about it to form an opinion.

### Poll Question Number 1 [02:02]

#### **[Male Speaker]**

We're going to start with a quick poll question though. Based on my current understanding, precision medicine is A-the future of medicine and achievable within the next 10 to 15 years, B-the future of medicine and achievable in the next 15 to 30 years, C-not a realistic approach to medicine, even in 30 years, D-a new buzzword for something that we've been doing for years or E-I don't know enough about it to form an opinion.

Great. If everyone could go to session number 34 within their app and give you a few more seconds to respond to poll question number one.

Okay. Let's go ahead and look at the results. Looks like the top answer was A-10 to 15 years had 72% followed by B-15 to 30 years in gaining 22%. Back to you, Eric.

## Session #34: Precision Medicine and Embracing Variability



**David A. Fenstermacher, PhD**  
Chief Research Information Officer,  
Professor of Biomedical Informatics,  
Virginia Commonwealth University



**Samir Courdy, MBA**  
Chief Research Information Officer,  
Director of Research Informatics at  
the Huntsman Cancer Institute,  
University of Utah



**Samuel Volchenbom, MD, PhD**  
Assistant Professor of Pediatrics  
Director, Center for Research Informatics  
Associate Chief Research Information Officer  
University of Chicago Medical Center



**Shawn Murphy, MD, PhD**  
Medical Director of Research Computing  
and Informatics, Partners HealthCare



### Facilitator: **Eric Just**

*Vice President of Technology,  
Health Catalyst*



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Session number 34: Precision Medicine and Embracing Variability3 [03:01]

#### **[Eric Just]**

That's great. Good optimism from the audience. Precision Medicine brings together multiple disciplines -- clinical, medicine, molecular biology, big data, and analytics. As a result, our panel represents multiple disciplines. We have physician researchers. We have chief research information officers and people with molecular biology background.

I won't introduce the speakers. I'll leave that to them. We'll start with Dr. Volchenbom. Sam, can you give us a one-minute introduction to who you are and your role in precision medicine in your organization?

#### **[Samuel Volchenbom]**

I'm Sam Volchenbom. I'm a practicing Pediatric Oncologist at the University of Chicago. I work at Comer Children's Hospital where I take care of patients with cancer and blood disorders. I also have a bioinformatics background and a background in molecular biology.

With my informatics training, I was asked to run our center for research informatics, which provides research support to the whole division. I'm in an interesting position where I get to help enable clinical trials and use of some of these emerging precision medicine tools both from the technology standpoint as well as be a user and champion on the physician side.

#### **[Samir Courdy]**

Hi. My name is Samir Courdy. I am the Chief Research Information Officer at the Huntsman Cancer Institute. I want to thank Eric and Health Catalyst for including me in this panel. I head up the Research Informatics Shared Resource at the Cancer Center, which gets computed in the Cancer Center Support Grants by the NCI. We developed a lot of software to support the research mission of the institution that includes population sciences, translational research, and basic science as well as clinical research.

My background is in computer science. I've worked in that area -- developing large-scale enterprise level systems in software that served the needs in health care. I've been at the Cancer Center for 16 years now. A lot of software that we build associates bio-specimen information with genomic information as well as clinical phenotypes for research purposes.

***[Shawn Murphy]***

Hi. I'm Shawn Murphy. I am a neurologist. I'm at Massachusetts General Hospital, Partners Health Care, and Harvard. I head up Research, IS and Computing at Partners Health Care overseeing most of the infrastructure also which extends into an application called Gene Insight which we use to do all of our clinical genomic testing. Over the years, have invented various data warehouses and developed data warehouse called Informatics for Integrating Biology in the Bedside or I2B2.

***[David Fenstermacher]***

Hi. I'm Dave Fenstermacher. I'd also like to thank Health Catalyst for inviting me to participate in this conference. My background is I'm a molecular biologist and geneticist for 14 years. I was a lab jockey then switched to bioinformatics in 1998 as the Human Genome Project was really getting geared up.

My current role is Chief Research Information Officer at Virginia Commonwealth University where I oversee all the enterprise data warehousing that is going on, bringing together the research data, the clinical data. I also oversee all of the big data analytics as it relates to genomics as well as oversee the clinical informatics and precision medicine initiatives that are currently ongoing at VCU.

***[Eric Just]***

Thank you very much. Sam, let's start with you. How do we need to think differently about disease to achieve the vision of precision medicine?

***[Samuel Volchenbom]***

Everybody is starting to see diseases more as perturbations or problems with biological pathways. When you think about it, calling something colon cancer was something we did 25 years ago but now we know so much more about the disease that we can separate it based on what's actually the genomic underpinnings and what's actually causing the disease.

Reclassifying disease in terms of the biologic pathways that are involved I think it's going to be very important. I was trying to think of an example of using this in pediatrics. We have pediatric rhabdomyosarcomas, tumors that children get. The pathology divided it up into two subtypes -- an alveolar subtype and an embryonal subtype.

They look under the microscope and they do some stains. They say, "All right. This subtype is really bad because we know historically that if you have one that looks like this, we're going to give you tons of therapy. We give you less therapy if you have the other kind." That's how they would determine the treatment.

Genomic testing has actually determined that a certain percentage, about 20% of the one cell look really bad and actually act more like one that aren't that bad. Here's the subgroup of kids that could probably get away with a lot less therapy, whereas if you look at traditional, just histology under the microscope, you wouldn't have that appreciation. We're starting to see more and more of these things every day where we can make better decisions based on these very precise ways of measuring disease.

**[Eric Just]**

Samir, over the last 10 to 20 years it seems like bioinformatics has been kind of the area of research and it seems to be moving closer and closer into the clinical realm because of this and the desire to do more precise medicine. Can you just talk really briefly about what is bioinformatics and then a little bit about how bioinformatics will be leveraged in this precision medicine effort?

**[Samir Courdy]**

A lot of times when I'm sitting in meetings, people use informatics and bioinformatics interchangeably but there's a difference between the two. Informatics relies a lot on computer science and mathematics. With bioinformatics, you add those two with biology and having a strong background in biology and being able to analyze sequence information. That's what bioinformatics is basically, doing analysis.

It started out with microarrays initially and then moved on to the next gen sequencing. That's a lot of the research that was going on in biology and in the cancer centers especially was identifying these mutations that are causing cancer and other diseases. Bioinformatics is really essentially deriving information from the sequence theater to identify snips, copy number variance, and the mutations that are causing disease and how it will be used in the next phase of medicine.

One thing I forgot to mention is now we have a clinical genomics precision medicine initiative at the Cancer Center of the Huntsman Cancer Institute and there are vendors in the space that provide data that is related to your patients' mutations, what are actionable mutations that can be treated with targeted therapies and then are mutations that we don't know too much about yet that are classified as variance of unknown significance.

There are companies in the space that provide reports that indicate how you should treat people with these specific mutations. I think that's where it's going. I think there still needs to be more work in those areas because sometimes we take a guess about the instigator mutation versus those mutations within the tumor that are just there along for the ride, so to speak.

**[Eric Just]**

Thank you. David, genomics is so often mentioned with respect to precision medicine and we've also heard the term genomic medicine. Is precision medicine just a re-branding of genomic medicine?

***[David Fenstermacher]***

That's a great question. No, it's not. Precision medicine, also many times called personalized medicine is really not just about genomics. We have to think about how we can use our data whether it come from our various systems such as our radiology systems, such as our PACs, the images that we take about our patients.

Not just the information that we're collecting within a clinical setting; it's also the information about our patients' socioeconomic status. What can we learn from their community, where they live and how can we then apply that to the patients themselves? When we start thinking about the treatments, we have to think about how it relates to the patients.

If we even look at value-base care and we look at how the reimbursement model is going to change, precision medicine is going to be a huge part of what we are doing. We're going to be trying to stratify patients into particular groups knowing who will respond to which treatments and who will not.

When we're looking at certain drugs especially in oncology where it's easy to get \$100,000 a year for a particular treatment, the insurance companies are not going to reimburse unless you have some evidence that that particular patient is actually going to respond to that therapy. This is just the reality of where we are going in medicine.

When we think about precision medicine, we have to think about the ecosystem of data that is available to us to do analytics on. Genomics is a part of it but is also the rest of the health care data, the socioeconomic data, and hopefully in the not too distant future, the mobile information that we're going to be able to get from things like Fitbits in our mobile phones so that we can be monitoring patients on a more real time basis. This is what precision medicine truly is about.

***[Eric Just]***

Shawn, we spend a lot of time at Health Catalyst reducing variability in health care. Precision medicine really seems to embrace variability. Are these two concepts at odds?

***[Shawn Murphy]***

There's different kinds of variability. There's a variability, which is kind of a random variability. For the statistician it's kind of that epsilon. That's certainly what we're trying to reduce in medicine because we found that many of the choices that doctors make are somewhat random choices with the built-in error, which is associated with that randomness. That variability I think is in all of our best interest to reduce.

On the other hand, there's a different use of the word "variability" which is that it varies but by a certain algorithm or logic which is very important to the patient and their specific situation, both their environmental situation and their genomic situation. In that context,

the word “variability” takes on a meaning of precision and treating something in a precise manner and that is to the patient’s advantage.

**[Eric Just]**

Thank you. Shawn, we’re going to ask the next question to you as well. How do we need to change the way that analytics is performed to achieve the vision of precision medicine?

**[Shawn Murphy]**

It’s interesting. In most of our logic that we use in medicine, it’s kind of a rule-based if x then y then z. In our new precision medicine especially when it comes to genomics, we have to look at several other things.

Number one is how does the population fit together around that patient? For example, if your one race and age, you really have to go and think of that patient in that metric not against just a general metric. That’s one. You have to always be aware of how things relate to population. You have to do population analytics on top of what you’re doing and think always in terms of population analytics, which many of our EMRs don’t support.

The second is, we have to be very precise about the phenotype. Currently, we have kind of a real lazy attitude towards the phenotype of the patient because we kind of treat them the same. If they have asthma, they have asthma. If they have depression, they have depression. On the other hand, depression is probably four or five different things and they respond to different kinds of medications.

Defining the precise phenotype is very important. You can actually do this algorithmically. You take different kinds of variables from the medical record in kind of statistical average, which can actually lead you to grouping depression into various subtypes. Some will really respond to SSRIs like Prozac and so forth. Others will respond to tricyclics or different kinds of model inhibitors.

There’s different types of phenotypes which we have to be very precise about. I think those are the different things that we’re going to have to think about with precision medicine.

**[Eric Just]**

Thanks. Same question, Samir, how will we need to change the way that analytics performed to achieve this vision?

**[Samir Courdy]**

Well, I haven’t a background in all of this data deluge. I would think we need to start figuring out better ways of refining our search mechanisms in analytics to drive down to the level of detail that we are interested in when it comes to serving a specific population with a specific disease or a specific mutation.

Where I see a weakness right now and what I haven’t seen, so to speak is good tools that allow you to do searches on the genomic level besides having the genome browsers and doing comparative analysis using genome browsers on experiments that have been conducted prior to that on different organisms.

It would be nice to have these types of tools that can mine data and identify mutations with patients with specific genotypes and phenotypes and then segregate them into pools for different clinical trials. I feel like that would be a strength of any analytic tool and I don't know if there are many in this space or any in this space. I certainly haven't seen any. I don't know. Maybe others have. That would be really helpful for our benefit as research informaticists and bioinformaticists and clinicians.

**[Eric Just]**

Thank you. Sam, how are researchers going to have to change the way that they interact with clinicians and vice-versa in this new paradigm?

**[Samuel Volchenboun]**

These lines are getting very blurred. A lot of our clinicians are researchers and when we see patients in the clinic, we're seeing them as their clinical physician, but at the same time, you may be running a trial. You may be collecting some of their blood to do DNA testing on. Separating out whether you're a clinician or a researcher at any particular moment is very hard to do.

Rather than ignore that or try to solve it, I think we have to embrace that and we have to think of ways that we can better enable both the clinical and research side. I think right now we don't do a very good job in supporting clinician researchers as they collect data. You think about how we do this now is we have very separate portals of entry for different kinds of data.

I do all my clinical work in Epic. If I want to enroll a patient on trial, I turn and I answer the same information in another form right here. Even my clinical research assistants when they do reporting forms, they actually open up an Epic window and they key in the lab results into a reporting form. We're not doing a very good job supporting this line that's between clinical work and the research work.

If we can bridge that, think of all the amazing things we can do when it comes to genotype phenotype correlations and we can start to actually mine the data in a really meaningful way if you have the research and clinical side working together. There are groups that are trying to do that, but it's been very difficult especially as we're locked in to these different clinical systems it's been very difficult to grow in that way.

**[Eric Just]**

Thank you. David, how will technologists play a role in this?

**[David Fenstermacher]**

Technologists are going to play a huge role in understanding what data is needed, how to organize it in such a way that it can be analyzed and then making it available to the communities that are actually doing the analysis. The most important thing about this though is to make sure that your technologists are not sitting out in a separate building somewhere outside of the group that when they're asked to do something they actually have no idea what the question is.



You have to embed your technologist with your analyst with your clinical teams so that you can start to answer these questions effectively. It's very difficult if you basically say, "Build a data warehouse," and you don't know why you're building a data warehouse.

You need to have use cases. You need to understand how you're going to use the system, how you're going to actually do the analytics, and what questions are you actually trying to ask whether it be from an operational point of view, an administrative point of view, a clinical point of view or a research point of view. These are all extremely important and you have to take that into consideration.

Technologists can certainly help get you to the point where you now have the systems where you can start hitting them. You can start querying them. You can start finding trends in the data that are important, start making hypotheses. Unless they're a part of the team from the very beginning, it's going to be very hard for the technologist to truly understand what they need to do to make these systems better and more usable by the entire community.

***[Eric Just]***

Thanks. We'll start the next question with you, David as well. There seems to be so many moving parts in this initiative. Moving research in the clinical practice has been a long-time challenge. We seem to be getting better at it but still seems like there's a long way to go before we can really achieve that. What do you see as the biggest challenges to getting all of this to happen? We'll go right down the line. We'll start with you...

***[David Fenstermacher]***

Again, that's a very good question. There's a lot of challenges but there's also been a lot of successes. I think people overlook that. One of the things that was already mentioned was the fact that we do not actually characterize phenotype in a systematic way across our entire health care system. It's almost comparing apples and oranges. That's extremely important to do.

When we look at some projects that are going on that are trying to do that, the TCGA, The Cancer Genome Atlas. Yes, it is genomic data but they do have a database that's basically a standardized common data element database of the pathological data and some of the clinical data that come from centers all across the country. You are also seeing other types of programs and projects that are going on all over the country to make this happen. I was thinking about this while I was listening to some of the speakers this week.

About ten years ago, Francis Collins who is the Director of the NIH basically said, "Precision medicine is going to happen in this country by 2020." Back in 2005, I thought that was a ridiculous statement because there was no way we're going to get there in 15 years. But we have seen advances to molecularly characterize patients, which was a huge hurdle to overcome. The fact that we can do that now for less than \$1,000 and it takes less than a couple of days and we can basically have a whole person's genome. The cost keeps coming down and the technologies continue to improve.

If we get better about how we collect data, we find new ways to, instead of filling out forms over and over again, we populate forms with data that already exist, we are going to get there. That vision of there being precision medicine is going to happen in 2020. It's already happening today especially in oncology, but we're going to make those advancements in other parts.

It's basically taking what we have learned today in the little limited precision medicine that's going on and then extrapolate that in to the much larger health care paradigm. It's transforming the ability to fight disease to better do prevention. We're now actually making healthier people rather than just continually fighting the disease over and over again.

***[Eric Just]***

Same question.

***[Shawn Murphy]***

We talked about what our EMRs don't do right now, which we need in this new paradigm. They don't do population analytics. They don't resolve phenotypes in a way that we need it to be able to help us or assist us to do. They don't integrate our data very well. Epic I think has 10,000 tables and 100,000 columns. That's not really data integration.

If you go and tried it now, pool other data into there, genomic data, which we're not even touching right now, as well as all this health data that we're feeding and that we want analyzed essentially on our cells, then we're going to need a much better integration engine than we have in EMRs today, something that truly knows how to take and put these concepts together into something and then confine the associations between them, can look at things, visualize them together so that they kind of get integrated in a way that our clinicians can appreciate and our patients can appreciate as well.

***[Samir Courdy]***

I think, and this is my opinion, that research and clinical care are converging together especially in the genomics area. A lot of the genomic work that's going on in the clinical setting now evolved from the research setting. In return now we have to be able to see these patients and treat them based on their molecular subtypes and genome and that data can feed back into the research labs to do more research and recruit more patients for different research projects.

I also agree with my colleagues here that data integration is essential. I don't think Epic does a good job at that, but they also are adding new tools that include patient-reported outcomes where you start managing your populations based on how their outcomes are and you get to learn more about how they're responding to the disease, to the treatment and what side effects they have based on these outcomes, that they are self-reported. There's been studies that show that self-reported outcomes are the best type of research when it has to do with research outcomes.

The other thing about integrating the data, I feel like the data warehouse is a point of integration. The electronic data warehouse is a good point of integration if institutions have to think more electronically and less paper-driven and less Excel sheet-driven that they have

to create this robust, expandable, and extensible research data warehouse that includes all the types of data information that comes from the labs.

And try to make—this is for our friends from the labs that do the reference lab work—that they need to start reporting the clinical, surgical pathology, physicians' reports into discrete data elements that we can as researchers get to much faster. I know I love to do NLP and text mining and all of that, but it would be a lot easier if they reported that data in a more discrete fashion. I feel like these are areas that we need to look into to grow with the Precision Medicine Initiatives and facilitate research and improve outcomes.

**[Eric Just]**

Sam.

**[Samuel Volchenbourn]**

I obviously agree with everything that's been said. I'm thinking about the barriers to making this a reality. One thing that I've noticed is that a pretty significant barrier has to do with the top-down view of what the top executives in the organization think about integrating research with clinical care. If there's no commitment from the President or CEO on down to do this, it's not going to happen because the clinical mission is going to win every time.

Somebody comes along with a new bio banking protocol. If they want to integrate it into Epic it's just going to lose if it's not prioritized in some way. A lot of the time I spend is actually in courting the institutional leadership, meeting with the CIO, getting in front of the people that make the decisions, going to the CFO and telling him why we really have to do this because then that trickles down. Then all of a sudden you have the head of the Epic team saying, "Oh, we're going to put your project in place. We're going to start working on it." I think that's really important.

I also think you need a grassroots effort as well. I think about when our molecular pathology group started a couple of years ago I went to their first meeting. I said, "How are you guys going to report out your results?" They said, "We'll do it as we always do it. We'll print a sheet and then we'll fax it over to the lab. They'll scan it in. That will be how we report our results." I was like, "No, we're not." To the group I was talking to, that was business as usual and they thought why not do that.

By working with the molecular pathology group and becoming part of their group and standing with them in the last three years while they built their practice, I think we've had a big effect. I think now when they report results it's going to be done in a granular and discrete way that can actually be used for meaningful research. I think top-down bottom-up you have to get in there and advocate for this integration.

**[Samir Courdy]**

Can you integrate a bio-specimen protocol into Epic? I wasn't aware you could.

**[Samuel Volchenbourn]**

For us, what we did is we got a mandate that every patient that comes in has blood collected and their DNA gets sent to the tissue core for banking. All we wanted was a box in

Epic that could be checked that says the patient's consented or not for the protocol. Simple, right? Simple from a coding point of view maybe, maybe not. From an institutional point of view, it was a big deal. It took months and months of red tape and wrangling just to get that as a prioritized project. That's where I think we have a long way to go.

**[Eric Just]**

Fantastic. This ends the questions that I have to ask. We have a great response from the audience. There's lots of questions that we will get to. First, I'd like to go to our analyst, Chris. Do you have insights into the presentation so far?



# Analytic Insights

# Questions & Answers



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**Analytic Insights/Questions and Answers [30:31]**

**[Chris]**

Thanks, Eric. First, it was interesting to note that based on the audience applause results, one thing that resonated strongly was the concept of embedding the technician within the clinical team.

Also, looking at the screen, we saw that those who think precision medicine is a buzzword tend to report more success in their population health and shared accountability initiative to date. That same group of those who think precision medicine is a buzzword, you can see now they also tend to have less tenure in health care. I will note though that the sample size of that is fairly low so we'll need to do some further study.

***[Eric Just]***

Very interesting. Thanks, Chris. The first question, by far the most popular question, we'll start with David on this one. Maybe David and Shawn can take this one. In terms of cost effectiveness, can precision medicine co-exist with the aim of reducing costs across the health care spectrum?

***[David Fenstermacher]***

Absolutely. I think this is one of the main tenets of precision medicine. The fact that now we know what treatments, what therapies to provide to our patients, what treatments and therapies they will not have severe adverse events to, those that will be effective right from the get go rather than having to go through, and I'm talking cancer now, regimen after regimen after regimen of treatments that are ineffective, create really horrible adverse events in many case.

Now we increase the cost of our treatment just because we don't know if it's going to work or not. We don't know how the patient is going to react. This changes that paradigm. A lot of people are worried about the fact that all of this molecular technology is going to cost a lot. If we talk about precision medicine as a whole, integrating all of this data, making it useful is going to also cost a lot.

If you add of all of that up, are we really saving money? In the long run, absolutely. I don't see how we can't. The more we become data-centric organizations, the more we become evidence-based, when we understand our populations of patients then we will be able to do the right thing at the right time for those patients. Therefore, reducing costs and overall increasing the quality of life and the quality of care.

***[Shawn Murphy]***

Fundamentally, I agree with David. It seems almost absurd that the way I treat migraine is that I just start you on something and then I say, "Oh, after three months well, that didn't work." Then I try the next thing and then same thing. There must be some determinate that could tell me if I should be starting topamax or propranolol or nortriptyline.

The other edge of the sword is that these tests especially the genomic test, they're very expensive and they can be misused. They can be misused in the following way: if you have a very low probability that someone has a genetic disorder to begin with, the chance that the test is going to show a false positive and lead you astray is extremely high, probably higher than it's going to give you some information that's going to be useful.

Determining the prior probability of the test being positive is actually very important. If you're below a certain threshold, you don't want to order the test because it's not going to give you useful results. Having that built in to our decision support mechanisms so we don't just focus on interpreting the test, but we focus on should the patient be getting the test at all. It's going to be important and that will help us cut cost as well.

**[Eric Just]**

Thanks. The next question I will direct to Samir and Sam. How can precision medicine be accounted for when doing variation analysis?

Josh, do you want to clarify the question? Otherwise, we can just move to another question. Okay. What are the most effective methods for engaging patients and their families around precision medicine practices? Maybe we'd go with Sam and Shawn, the two physicians in the group.

**[Samuel Volchenbourn]**

As you know, the patients are becoming more informed all the time. They get more and more information there. The kids that I take care of, their parents are in Facebook groups and they go to all sorts of different forums to get information about the disease. They're often coming to me with ideas and with therapies some of which are not standard and some of which are more standard.

The contract I always I have with them is, "You bring it to me and we'll have a rational discussion about it." More and more now they're coming with a genetic test and with wanting to know if they should...their friend with the same tumor in Michigan had it sent to a place to have their genomics done. Should we do it for this person?

You have to be really careful with this because as we just said, you have to really know what you're going to do with the results. In kids, that's especially important because you may find out you could do a genetic test on a child and find out something else about the child that maybe they didn't want to know.

You have to really counsel the families as to what you're testing for and why you're testing for it. I find families to be very engaging in wanting to explore the options as long as you're totally transparent with why you're doing the test and what it might mean and what the drawbacks would be. I just think you just have to be very open with it.

**[Shawn Murphy]**

We're computer people. To start with, how do we approach this today? We don't really approach it in genomic medicine. I'll get to how we could do it, but in radiology we do it. A patient will often come with a CD about the MRI of their brain and they'll have looked at it and then you'll look at it and then you'll get the radiologist involved in looking at it as well like uploading it and sending and so forth. You review with the patient. The screen's right there and I'm going on, pointing to things.

For us computer geeks, wouldn't it be great to have an app that can be used to get into the medical record data, but be used by the patient to help them see things about whether this test is actually meaningful or not and whether they should believe it and show it against other tests which are similarly maybe unbelievable to the doctor who can now look at it and try to make some sense out of it, too, with the patient and for herself or himself and the lab people. This is really important I think.

The people in the lab are critical in being able to help interpret somebody's test. I'm not talking about technicians. I'm talking about the big data technicians that we're talking about, the bio-informaticians who can actually help us through it as doctors because it's very complicated to understand somebody's test results. Acting as a threesome to try to understand some of this data I think is really important going forward.

**[Eric Just]**

Excellent. Samir and David, where do wearable devices fit into precision medicine?

**[Samir Courdy]**

I think in terms of trying to engage your population of patients in population outreach, if you're measuring their activity on a regular basis, you know how physically active these individuals are, what their sleep patterns might be. I also feel like outreach and education are big important factors in improved outcomes down the road if any of these individuals are diagnosed with bad disease like cancer.

I feel also that prevention starts at the home and reaching out to the population of individuals. We can derive information from these wearable devices now that can tell us what's working, what's not working, how we can engage individuals in a real time fashion to instigate exercise and physical activities and diet and more healthy habits because diet is a crucial part of the equation, too. A high-fat diet and sedentary lifestyles always can lead to cancer.

These things can engage the patients at the molecular level, the individual level and make them more active and involved in their lifestyle and in their care down the road because of some of these wearable devices. And you have apps where the physician or the genetic counselor can be directly engaged with the individuals, sending them information that's relevant to their disease.

You can have apps and tools that can mine information kind of like what Google does for your Facebook by driving ads to your page based on your last search or whatever else you just bought. Similar types of engagement will happen in this space to drive individual good lifestyle habits.

**[David Fenstermacher]**

I agree with everything Samir just said but I think there's another issue that we have to really think about here. It's how we're going to pick out the data that is actually relevant. There is so much data that is available whether it be for Twitter, whether it be for Facebook, whether it be for your wearable devices, your watch, your phone. There are so many data

sources today that it's basically going to be data overload for the physician and the clinicians and the nurses and everyone working for that patient.

If we basically just send them this whole bolus of data and say, "Well, here. You figure it out and see if the patient is actually doing well." That's not going to serve anybody. What we have to do as informaticists, we have to be able to understand what is the issue.

I talked to a physician who is a cardiologist. He wants to do remote monitoring of patients at home. Just basically, how much are they walking everyday? If they basically see patients that they start out walking half a mile and then they go to a mile and then they go to two miles. They might even cancel their appointment because they feel, you know what, they're on the trajectory of doing very well.

Whereas another patient who basically is doing hardly any exercising for the last month has done nothing, that's the kind of information they can look at and make decisions about how they need to treat that patient. They may have to make a phone call. They may have to get them in for a new visit more quickly. That same cardiologist may not give a hoot about other data that basically is generated.

We have to look and say, "What data is needed? What data is relevant to the patient and the condition that they're being treated for by the clinical care team?" We have to get them that data at the right time so that they can make true clinical decisions for the patients both on an individual level and at a population level because I really think home health is a future of reducing cost with health care.

Home health comes with a lot of burden on analytics and how we use analytics to get to the point where we truly understand what's happening with the patient at anytime that we're looking up.

**[Eric Just]**

Thanks so much. This will be the last question and we'll direct this to Shawn and Sam. How does precision medicine fit into the larger population health model? I'll add my own follow-up, for making investments in population health right now, how will we be able to leverage that in the next 10 to 15 years, as precision medicine gets more prevalent?

**[Shawn Murphy]**

I think everybody in this room can see that promise of being able to do a much better job taking care of our patients but I would heed to David's warning and Samir's warning. We need to be very careful about how we act on some of this data, which is relatively new and unknown in terms of how we should use it to help our population management.

For example, a lot of times patients will come to me. They'll have their genome done. They'll point out that they have either the cholesterol gene or the Alzheimer's gene or something of that nature. We have to really sit down and talk about this. If I had data in front of me which I don't I would feel so much better because I could say, "Look, in your demographic this gene has no penetrance. It's not that easy to just say because you have this gene you have this."



Epigenetics is putting a whole new layer on top of this so it's very difficult to interpret this data that we're getting. I think that we have to be cautious about how we figure it in to population health and accept our limitations and work with what we can.

***[Samuel Volchenbom]***

I think at the same time we have, everybody agrees, this remarkable opportunity right now to look at whole populations and to look at whole groups and to try to understand how they respond to certain treatments or how they develop certain diseases. I think it's a remarkable opportunity that's singular right now. We just have never seen anything like this, the ability to collect data from all these different sources and try to bring it together. It remains to be seen how we're going to do the analysis. One of my mentors, actually Zach said, "The Human Genome Project is going to bring ten years of frustration and bad news," or something like that. He was saying something again, "We have all this data. It's a torrent of data right now. We just don't know how to analyze it and what it means." We have to get in there and we have to try to do something. We have to get use cases and we have to start educating people and getting everybody invested in this process because the opportunity is just incredible.



# Thank You



Thank you [44:55]

***[Eric Just]***

Thank you so much, panelists. Really enjoyed working with you and I think your answers today and your responses and your insights have just been very helpful. Samir, you can get the last word.

**[Samir Courdy]**

I just want to do a shameless plug for a meeting that David and I are co-chairing in La Jolla, California in October. Health Catalyst is one of the sponsors at the meeting. David and I are co-chairing a Cancer Informatics for cancer centers and it's all centered on precision medicine. If you guys want to learn more about it, it's [ci4cc.org](http://ci4cc.org). Go up there and sign up. We'd love to see you guys there. We can engage you more about precision medicine. Thanks a lot.

**[Eric Just]**

Thank you so much.

## Lessons Learned



1. Precision medicine is about more rapidly determining the molecular cause for disease that will allow a finer-grained classification of diseases and alternate treatment paths for these new disease sub-types.
2. Over the last 20 years, bioinformatics has been creating tools and frameworks to understand molecular underpinnings of disease. This data will be leveraged in clinical decision making.
3. Precision medicine is more than just "genomic medicine." Genetics will play a big role, but many new types of inputs will be involved including more imaging, device data, and proteomics.
4. Precision medicine will require new ways for researchers to partner with care delivery professionals to speed the time of discovery to implementation as clinical practice.
5. The road to precision medicine is fraught with challenges, including regulatory, organizational, and funding, but we should be encouraged by early examples of success.



# Choose one thing...



Write down one thing will you do differently  
after hearing this presentation

 #HASummit15



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## Lessons Learned/Choose One Thing [45:52]

### *[Eric Just]*

Everyone make sure to fill out the thing you would do differently at the bottom of "Lessons Learned" page. Thank you very much.