Wendy Chung, MD: Pandemic challenged genomic data collection

Watch the AMA's daily COVID-19 update, with insights from AMA leaders and experts about the pandemic.

Featured topic and speakers

In the second of a two-part series, AMA Chief Experience Officer Todd Unger discusses genetics at play in COVID-19 with experts Wendy Chung, MD, PhD, Robert Green, MD, MPH, and AMA’s Chief Health and Science Officer Mira Irons, MD.

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Speakers

- Mira Irons, MD, chief health and science officer, AMA
- Wendy Chung, MD, PhD, Kennedy Family professor, Columbia University
- Robert Green, MD, MPH, director, Genomes2People Research Program, Brigham and Women's Hospital

Transcript

Unger: Hello, this is the American Medical Association's COVID-19 update. Today, we continue with part two of a two-part series on genetics and COVID-19. I'm joined today by Dr. Wendy Chung, Kennedy Family Professor of Pediatrics and Medicine and Chief of Clinical Genetics at Columbia University in New York. Dr. Robert Green, Professor of Medicine at Harvard Medical School and a physician scientist who directs the Genomes to People or G2P research program at Brigham and Women's Hospital, and the Broad Institute in Boston. And Dr. Mira Irons, AMA's Chief Health and Science Officer in Chicago. I'm Todd Unger, AMA's Chief Experience Officer in Chicago. Dr. Chung, you mentioned you're on the front lines of a pandemic in New York City, obviously presenting a myriad of challenges, but also in collecting genomic data. Can you talk about what challenges you
faced doing that?

**Dr. Chung:** All right, so we clearly had to shut everything down in terms of keeping everyone safe and at the beginning, conserving personal protective equipment. That was a very high priority for us. And so we had in place—it ended up being just an incredible learning experience for us—we had an expanded newborn screening study that we're doing that had nothing to do with COVID, but because we wanted to continue offering that, we immediately, within seven days, figured out a way to be able to remotely approach and consent all of our postpartum moms for those newborn babies. So while they were in the hospital, we were at home, again, keeping our staff safe, but also being able to contact them and came up with an entire workflow that was like, we'd never done anything like it before, but we had a great team. Like I said, they worked literally during those early days, 16 hours a day, seven days a week, trying to figure out new ways of doing REDCap and texting and using Doximity for our phones and doing all sorts of things so that people would be able to understand that we weren't just random callers.

And I have to say, I think this is one of the things Robert was saying, I've never in my whole life seen patients, researchers, doctors, nurses, everyone pull together. It was just an incredible sense of "what can I do to help? Anything I can do, just let me know." During that time we took what we learned from the newborn screening protocol. We immediately pivoted and we took 20 coordinators who used to do completely different things, but we taught them how to do this remote consenting enrollment. And then we dumpster dived. So what I mean by that is we took all of those discarded patient samples that were used for clinical care. So those complete blood counts. And we said, "You know what? Even though they've been sitting in the fridge for five, six, seven days, we can still extract DNA from that. That'll still be good for research in terms of the genomic DNA we need."

So we pivoted our whole clinical laboratory at the same time. We started recycling, gathering consents at the same time in this remote way. We started doing things like, unfortunately, autopsies because there were specific tissues that were incredibly valuable to be able to look at the brain or the heart or the lungs, and then started a protocol to do a rapid autopsies or warm autopsies to get tissue that would be available for RNA and other studies. So, and I want to be very clear, it wasn't just me on my team. It was really on all hands on deck. We had what we called a crack team. So we had post-docs, graduate students, medical students, nursing students, everyone just mobilized and went from their day job to this new COVID operation. And it was just like I said, like nothing I've ever seen in my career.

**Unger:** Dr. Green, can you talk a little bit about what challenges you faced in collecting this type of data during the pandemic?

**Dr. Green:** Yeah, very similarly. We were a couple of weeks behind New York, but we had a pretty bad time of it here in Boston and the frontline workers. I was never in the hospital, but I was on a list. And if enough of them had gotten sick, I would have been in line to go in and you don't want a
geneticist intubating you, if you can possibly help that. So it was a pretty scary time. But as Wendy said people pull together in amazing ways. So there was the whole clinical responsiveness and then right behind that was everyone trying to make research work, both make their ongoing research work and make any pivot they could to research that would be helpful to COVID. So, as I mentioned before, we pivoted two and a half of our FTEs who could no longer do their clinical research because clinical patients and research participants weren't coming in, we pivoted them immediately to start organizing and helping to implement our participation in this international COVID.

We have some other small projects we're contributing to around home testing kits for antibodies. There's thousands of these studies and thousands of investigators helping in a myriad ways. I will also say that one of the interesting things about this is it's brought front and center the conversation about how scientifically literate the population should be. And this has been large in terms of public health awareness, in terms of simple things like should we be wearing masks? Yes. And also in terms of genomics, I was on a phone call earlier today with an investor who said, "I didn't even know what RNA was. And now I'm hearing about it six times a day."

And I think it's a great opportunity for science, for medical science and for genetic science and genomics within medical science to say to people, "Look, this is important. This is influential. This is going to touch your life in so many ways." And COVID is just one particularly dramatic example of that, but there will be others. The next time you have a baby, the next time you are thinking about what drug you should take and you have the opportunity to do pharmacogenomics, the next time you realize there's a family history of cancer and you face the question of whether someone in your family should have genetic testing to explore that. This is really an example of why everyone should be excited about medical science and particularly about genomics.

Unger: Well, Dr. Irons, we talked about social determinants previously in the conversation and I'd love it if you would talk about why having diverse DNA is so important to addressing the health equity concerns that have been really amplified by this pandemic?

Dr. Irons: Absolutely. Todd, I think it's important to talk about diversity and having diverse databases, but also the importance of data to follow up on what Robert was just talking about. So sadly, the original databases that were available were really based on European populations, because those were the individuals that were consented for the research studies and that's what the databases were built on. And that was helpful if we wanted to provide some guidance to people of European ancestry, but totally not helpful to people from other backgrounds. So there is a better understanding now that the reference databases need to reflect the population of the of the world.

There are many international efforts going on within the genetics and the genomics community now to ensure that we have broad representation of all populations, all races and ethnicities in those reference databases. The NIH All of Us study has said that the million people that they are going to involve in the studies will reflect the population of the United States. And so I think there are efforts in
that direction and it's at least come up to the front. But data is also important. And the AMA very early in the pandemic began to call for the collection of racial and ethnicity data in the patients that were diagnosed with COVID and that were dying of COVID. And once that data was collected, we began to see the absolutely disproportionate impact on minority and marginalized populations.

And if that data was never collected, we would have never known that. And so the next step then is to ask ourselves, "Well, why are they disproportionately impacted?" And an easy answer could be, "Well, there are more comorbidities in minority populations," but it may not be the full answer. The social determinants of health come into this because many people in minority populations actually are in jobs that predispose them to getting infected in the first place. So the collection of data is really important to help inform us.

**Unger:** Well, last topic, looking ahead, obviously, very accelerated work going on right now, but when do you think we'll likely know more? And once we do, how do we use this research to help inform future diseases? Dr. Chung, why don't you start?

**Dr. Chung:** So I think we're going to be learning for a while. And unfortunately, I don't think we're out of the woods yet. And I personally am very concerned about what happens this fall and winter as we come back indoors. And as we also have other viruses that are floating around. And I don't think we'll have a vaccine, unfortunately by then. There are, emerging, some other medications that might be helpful, but certainly none of these is going to completely wipe this out. And so I still think we're all concerned about overwhelming medical centers. I think there's a lot that I can say—specifically in New York—that I think we had worse outcomes when we got overwhelmed. It just stands to reason in terms of when we had scarce resources, scarce people, overworked people. And I think that's one of the things that we're hoping to avoid in the future; that alone, improve outcomes.

I do think long term, I'm waiting to see a fuller picture and I mean that in a couple ways. So number one is I think we know about people who were sick enough to come into hospitals. There were a lot of people who were infected, who didn't come into hospitals. And I think to really understand from an epidemiological point of view, and to have real good data behind it, we're going to have to backfill who was sick in part by looking at antibodies or serologies and understanding who either was protected in some way more resilient, if you will, from many of the adverse outcomes we saw.

And as we've all had a chance to breathe now, also thinking about how to do better prospective data that will allow us at the point of entry in the health care system, can we triage who's going to do better or worse based on some of the data we've collected so far, but also collecting real-time data that might be of the omics sort that Robert was talking about in terms of, for instance, RNA sequencing, if you do a nasal pharyngeal swab and you know what the epithelial transcriptomics look like, what does that do? Or if you're looking at some of the markers that we know, IL-6 or D-dimers or other things at the point of entry, again at the emergency room, in a doctor's office. Can that prognosticate with us, in addition to some of your other risk factors, what your clinical course will be, and can we
triage better in terms of how to take care of folks?

So I think those are some of the ways that we're going to fill in the gaps, but I think there's still a bit to do. And I'm still not sure that people who were sick before are out of the woods. Thankfully I think they're out of the hospital, but I do think there's going to be a new sort of post-COVID chronic illnesses that we're going to see. And I'm worried about that. And I think we're going to have to follow those folks to see everything from lung disease, to renal disease, to heart disease, to mental health. I actually worry in terms of what it's going to do to many people having been through this really traumatic time. So there's still work to be done. I don't think we're finished yet.

**Unger: Dr. Green?**

**Dr. Green:** Yeah. I really think Wendy covered the medical front very well. I guess on the sort of social front, I hope that the awareness and evaluation of medical science continues. I think in much of the population, this has reminded people why it's important to know what an epidemiologist does, why it's important to know what a pulmonologist does and maybe even genomics. I think that it's exciting that all of these investigators are sharing and I hope that continues. I think it's forced us to confront some new, interesting edge cases, like we all were voting for pre-print servers and putting things up on pre-print servers before COVID and it was a big push to say, "Yes, that's good." Now we've had to confront whether it's always good. If something goes up on a pre-print server that influences treatment before it's had a chance to be vetted by peer review is that a good thing? Is that a bad thing? Do we just really need to train people to understand what that means better?

So there are fascinating questions. And one of the most interesting, I think, in terms of taking care of patients is telemedicine. We've all switched to telemedicine for at least part of our practices. And there are obviously places where it's less advantageous when you need to examine a patient, but it's remarkable how much medicine can be practiced by telemedicine. And this could really help genomics. Where there's overly concentrated experts in various academic centers and urban centers to really distribute knowledge throughout the world. So I just hope that the good lessons of this emergency, the transformational opportunities for medicine in this emergency really stick and help propel us forward at a pace faster than we were going forward before.

**Unger:** Well, thank you very much, Dr. Chung, Dr. Green, Dr. Irons for being with us here today and sharing your perspectives. That completes our two-part series on genetics and COVID-19. If you missed part one, you'll find it on AMA's YouTube channel. Have a safe and healthy 4th of July holiday. We're off tomorrow, but we'll return on Monday with another COVID-19 update. For updated resources on COVID-19, go to AMA-assn.org/covid-19. Thanks for joining us and take care.

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