Open, accessible data is key to involving patients in their own health

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Featured topic and speakers

In this episode of Making the Rounds, Shuhan He, MD, emergency medicine physician and instructor at the lab of computer science at Mass General, talks about his research and focus on the use of data to help patients take interest in their own health. This episode is part of the Health IT series by the MSS Committee on Health Information Technology, hosted by Shivani Bhatnagar, a medical student at the Texas College of Osteopathic Medicine.

Speakers

Shuhan He, MD, emergency medicine physician and instructor, Mass General

Host

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Transcript

Bhatnagar: Hello and welcome to Making the Rounds, a podcast by the American Medical Association. Today's episode is part of our health IT series from the AMA MSS Committee on Health Information Technology. My name is Shivani Bhatnagar and I'm a medical student at the Texas College of Osteopathic Medicine, and I'll be your host for today. We are delighted to introduce Dr. Shuhan He. He is an emergency medicine physician at Mass General Hospital. Dr. He is also an instructor at the lab of computer science at Mass General and a very prolific researcher who focuses on use of technology at scale. Hello and welcome Dr. He.

Dr. He: Thank you for having me. This is exciting to be here.
Bhatnagar: Yeah, absolutely. Thanks for taking time to join us. To get started, can you explain listeners a little bit how you're involved in the health IT space or any projects you're currently working on?

Dr. He: Sure. So basically, what I do, to keep it simple, essentially is to make things easy, open and accessible. So oftentimes when we think about health IT in medicine, we think about electronic medical records, right? So patient data, directly accessing the things that we are using to take care of patients. What I work on is, I think, everything that is not related to that. So, things that are such as remote work or websites for hospitals and the services that they offer. And what I think about a lot oftentimes is what is the architecture of those open accessible technologies that make it easy for people to find the information they need, right?

So, whether that's on Twitter or things like social media or Reddit, or even when you search for something like I need a procedure, how do you find the local hospital and the local institution that can provide you the service you need? And so, I'm making it easy to reach people oftentimes and I think about this almost like electronic circuits, right? A circuit is a... it shuttles around electrons. And what I think about of websites is how does the architecture of website move human attention and desire, and to get them the things they need? So, accessibility, openness and sharing of information.

Bhatnagar: Awesome. Yeah, it's really important when we're talking to patients and making sure that they understand what's going on with their health and things. So, you talked a little bit about the impact of your work. Can you talk about any challenges you may have faced along the way?

Dr. He: Yeah, absolutely. So oftentimes in medicine, number one priority is safety, security, right? So, we want to make sure that patient information is secure. We want to make sure that if we're talking about medical device, that if you make it more open, that it doesn't become more hackable, right? So absolutely, the number on top of what we're trying to do is make sure that if we're make things open, that it's all secure. And oftentimes how we do that is to make sure that frankly, no information ever enters the ecosystem if it's an open ecosystem.

So, we entirely divide it from very close systems like health electronic medical records entirely, right? That creates limitations of what we're doing, which is actually okay, because oftentimes what we're doing are things like showing around PPE during the PPE crisis or making sure that physicians who are working opioid disorder are getting their DEX waiver, right? A physician is oftentimes the best target when we're starting work in any of these spaces because they oftentimes are looking for information. So, whether that's medical education or learning or changing practice patterns, those are oftentimes very, very easy way that we can start in any sort of open accessible technology, right? But then moving towards patient, accessible information becomes much more difficult and challenging, and frankly, much more conservative around that kind work.
Bhatnagar: Yeah. This definitely seems to be a shared challenge that we've talked about with other interviews as well. You kind of touched on this with your answer but for our next question, we're going to ask about how COVID has impacted your work. You mentioned the PPE crisis.

Dr. He: Yeah. So, I think it's essentially turned all of society into the shared collective medical education on testing and surveillance rates, and just frankly, aware of the impact of human health and society, right? It integrates into everything we do. We are biological species and our health is so important to functioning. And we see that if society is not healthy, the society doesn't really function, right? So, in a lot of ways, my role has actually expanded because of that, because so much of more society has wanted and taken interest in their health, right? I give an example here, data and accessibility models. It used to be that the most frequent data that people looked at was the weather report. Every day you look at your weather and you say, "Okay, it's snowing outside. I should wear something, a nice warm jacket and snow boots," right?

And so, there's a very clear action and that's very clear open data that people are interfacing with every single day. But now that data is COVID. So, what is the instance rate in my community? Should I meet make sure that I'm wearing a mask indoors if there's no mandate? Where do I get my local vaccine? How do I make sure that my provider, accessing infusion centers, things like that, right? So, this has become a much more prevalent and actually, I think, expectation among both health care providers and patients that technology, that open, accessible data and that easy to use interface. That is the expectation of people and is no longer okay to say that it's going to be very, very hard to access or you need to be in person to access some sort of health care related resource. It's the expectation that you get that at the tip of your fingertips, basically.

Bhatnagar: Yeah. And that's really empowering to patients too, if they can access it on their own without having to rely on us.

Dr. He: Absolutely.

Bhatnagar: And regarding the pandemic, back in 2020, you co-authored a number of articles about changes that were happening within the residency application process and the Match, which were unfortunate side effects of the pandemic itself. Could you give us a summary of what you found or any recommendations that you gathered from that?

Dr. He: Yeah. Basically, number one, remote work and remote communication is a really amazing thing. It turns out that even before COVID in organizations, tech companies, there was a whole host of companies that were no longer even ... They had people in the organization never met before. And these were publicly pre-traded companies that were entirely made of engineers that were entirely remote, right? And so this became, I think, much more relevant in the residency application process where you no longer needed a fly around, spend tens of thousands, twenty of thousands of dollars on...
every single site that you went to, that you could get to know a residency actually sometimes better because you get more access, right? In theory, if you go to a location and a site, you are able to see the facilities, right?

But you're limited by time and geography and cost, what is the tradeoff there? And we would see a lot oftentimes that by fully embracing this remote technology and remote work, I think culture, we would have more creativity in the ways that we would allow people to get to know residency programs. So in our local residency, we would have much more social media and the residents would do takeovers all the time and let the people see what is life like as a resident, right? Those kind really, really creative solutions would actually let people know what it's like to be a resident much more than going to a dinner and asking them, "What is it like to be a resident?" Right? When you can see the first hand in the social media. So, by embracing those technologies and by really us thinking creatively, we can really, really create a better and more accessible interview processes, and actually interview selections around residence.

Bhatnagar: Awesome. Yeah. And as a fourth year who just wrapped up residency interviews and is waiting for the Match results, definitely eager to see how this will impact things for my underclassmen and moving forward. Do you have any estimate for what changes might stay for upcoming applicants or maybe in a future when the pandemic might be over?

Dr. He: Yeah. I would say that is up to the decision makers and the ACGME, and what I call purely educational folks, right? I used to think of myself as a consultant to say that "Yes, you shouldn't be scared of these really amazing technologies and that there are really, really creative things we can do with them." But whether people embrace them long term, I think is ultimately up to the decision makers and residency, right? I personally, my view is you absolutely should because it makes things so much more easy and accessible. And that having is, again, that example of an Instagram takeover by residents.

Please keep that because not only are perspective students able to see better and truthfully able to see what are being residents like, right? And I am able to see how the residents are doing in my residency program to really make sure that their health and well-being is taken care of. I get to know them better through, an asynchronous way, even if I'm not there physically working with them on a day-to-day basis, right? So, I really appreciate that those additional channels to get to know people. And I certainly think those are and I hope those are here to stay.

Bhatnagar: Absolutely. I really love seeing how creative people got with YouTube and doing virtual tours, as well, and the Instagram takeovers were really fun to watch too.

Dr. He: Exactly. Fun, right?

Bhatnagar: Yeah, exactly. Kind of pivoting to another one of your more recent papers focused on the

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right to repair in health care settings. For any listeners who may not be familiar with that phrase or what the problem is, could you explain that for them?

**Dr. He:** Yeah. So, during the COVID pandemic, we became, in medicine, very aware of this issue called right to repair. In the sense of most consumers were very aware of it because of things like their phones, where in order to repair their phone, they would have to go to the person who sold it to them, whether that's Samsung or Apple. And they were the only authorized people who were able to make changes, right? So, this presents a problem in medicine when it's no longer a phone but it's a ventilator, right? And you only have so many ventilators and you need to make sure that they're all working. And one ventilator that is not working, if there's a six month wait to have it repaired, can cause a lot of issues, especially when there's supply chain shortages.

So, this became an issue nationally actually because even if a hospital individually would have enough ventilators, it became an issue to nationally where we wanted to make sure at that this was not a threat where the inability to repair something because of a third-party vendor or a primary vendor was limiting factor to make sure that a patient did have their ventilator that they needed, right? And so, this is something that is frequently brought up as is this something that we should allow? And actually, it's a very complicated topic. It's not as easy as it may seem because one, there's a lot of factors, right? It's not just the open accessibility. It's going back to that previous point of security and safety.

If you make it easier to repair something, does it also make it easier to hack? And you can imagine the danger of hacking a ventilator, right? And how potentially catastrophic that can be. So, we want to make sure that we're very, very careful in this idea of this openness accessibility to hardware devices, right? So, what we did was we really just wrote a letter saying, "This should be considered, this is a problem around the hardware space, the need to repair." But what we were very, very clear about is that this should be something that is very carefully debated. That is very clearly thought out, right?

Because it is such a special protected space, and that a safety and security need to be top of mind. In addition to other considerations like environmental sustainability, right? How does it make the hospital more environmentally sustainable if we are able to repair more devices rather than throwing them away, right? So, this is something that I think is a future topic of discussion that require certain amount of research, right? Especially to make sure that for every change that we make that's open and makes things more accessible to repair, that we also make it an opportunity to make things more safe and secure.

**Bhatnagar:** Yeah, definitely sounds very complex and multifaceted. Are there any other barriers that have made this very difficult to address so far?

**Dr. He:** Well, I think it's a very multifaceted problem, right? It's not just a medical problem. It is an engineering problem. It is a political problem. It is an environmental problem. It is a fiscal problem,
right? So, all of these things have to be taken account. When you think about, I give of the example of an ultrasound device, right? A very, very small ultrasound device that is incredibly compact, that becomes real tradeoffs when you are thinking about making a device smaller, right?

And you want it to be smaller because you want these devices to be easier and more portable but that means that you are making basically circuits that are pushing the limits of physics to basically make sure that electrons can hop from one part to another in a very efficient way. And if you're creating legislation that says they must be interchangeable in its parts, there becomes an upper limit to how small you can make these devices. And we really want those to make them more mini, more portable and have the innovation that we've seen in things like phones, right? So, there is a very, very complicated dynamic in this space and we just want to make sure that things are very carefully considered.

Bhatnagar: Sure. Yeah. I'm eager to see if they make any progress with this moving forward.

Dr. He: Yeah.

Bhatnagar: And now backtracking to a time before COVID. A couple years ago, you founded a company called Maze Engineers and you're also a founder of Conduct Science. Can you tell us a bit more about those projects?

Dr. He: Yeah. This is kind of one of my first loves, and actually something I did in med school, so I would always encourage medicine students to really seek their passions, right? Because you can make so much of impact in science and medicine. And this really kind of gets to the greater theme that in medicine we are becoming much more multi-disciplined and especially around technology, right? And the ability and the desire for doctors to build, not only take care patients but also build things that fix things a more systematic basis, right? So, in this particular instance, I was really passionate about mass mazes.

I was working in a neuroscience lab, and it turns out that one of the biggest and more persistent problems in neuroscience is that you can figure out exactly how the brain works but the brain doesn't have a marker for its health other than behavior, right? Your ability to perform better, to love more, to learn better, to take care of your family, to build the relationships, to basically do the things that you should do in life, right? That is what we define as behavior. And it turns out that in mice, we did not have a very good way to measure how does a mouse behave when you feed it a new candidate drug, right?

So, I started building these because I felt like that was the best and easiest way to fix this really massive problem in neuroscience. And I was doing it as a med student. I was doing it as a resident and that actually kept my, I think a lot of my engineering chops, right? For background here, I learned computer science, basically informally when I was a child. My dad was a computer scientist growing...
up and I basically grew up in the computer science lab, University of Illinois, Champaign, working in the sea terminal, building websites. And actually, and through the years, I think it's almost been 20, 25 years now, language has changed, right?

The tools you have to build things change but architectures in general, principles stick around. And really the only way to keep up is to continue to build, right? So, having a real project that is working with real neuroscientists and working with real problems on the ground was really the best way to continue to stay really relevant, right? Because it meant that I would not say, out of date, and there were real problems I had to solve in very short time limited fashion, right? Especially as a busy medicine and as a resident, but basically to this day, we're one of the largest mouse-based companies where we distribute mouse bases throughout the country. Hundreds of institutions, thousands of labs across the world, making better behavioral science apparatuses and actually we've really grown and expanded to even we're doing things like virtual reality for humans.

It turns out that in mice, we know exactly how the mice brain works but we don't do the same rigor in humans. And we can put those same humans into those very mazes that we put rodents in. And a lot of the same mechanisms exist. And it turns out that for a lot of the drugs that we have in medicine, right? We first figure out that they work and then we figure out the mechanism, right? So, the perfect example is benzodiazepines. We knew that they worked because mice would spend more time in an open area of the maze where there was less dark space, right? Because that means that you have more exploration. Mice tend to want to stay in closed, dark locations, right? But when you fed them this drug, color benzodiazepines, they would spend more time in this open area.

No one really knew how it worked but it did. And that's what translated into this amazing drug that we use all the time called benzodiazepines, right? And it's very useful for so many different things. We figured out the mechanism later, and it turns out that we can do the same thing for a lot of other different neurological drugs, is find the things that help us in outcomes, right? In patient report outcomes first. And then once we know that there is a difference, we can figure out how it works. And oftentimes that can be a very efficient way to do drug discovery. And that's something that I've been always really passionate about. And it actually goes to the next ... a lot of my other work in emojis.

Bhatnagar: Yeah. And I'm glad that you brought up the fact that these mazes can be used for human trials as well because when I clicked on the species tab on your website, I was surprised to see that humans were listed too.

Dr. He: Yeah.

Bhatnagar: Can you also explain a little bit more about how these VR mazes compared to the analog versions that have been used in the past?

Dr. He: Yeah. Oftentimes they're exactly the same because we know the exact parts of the brain that
are being tested with specific task and skills. I'll give you example. There's something that's very famous called the Morris water maze. This is a maze where you put a mouse into a tank of water, oftentimes milk because you can't see underneath. And you'll want to find this hidden platform, right? And so, it's a very circular arena, and you're looking outside of this arena and you're looking for small cues. And so, you're actually activating basically the parts of your brain that work on spatial navigation specific like ... There's very specific types of allocentric navigation that are very important for this behavior.

It turns out that we weren't doing the same rigor in humans that we were on mice, which is for very odd because ultimately what we're trying to do is treat people, right? And to make sure that if someone has Alzheimer's or dementia or a stroke that's very subtle, or even a large stroke that they're able to regain their function and navigate their home or go to the grocery store or recognize that the people that they are in their families, right? So, we knew that there is literature and literature and literature on mice and rats around navigation but we weren't doing the same tests on people.

So, the solution was why don't we do the exact same tests on people, right? And that actually has a lot of, and to make sure that we are testing basically what I call the bench to bedside road, right? So, we want to make sure that drugs that are working in mice are also working in humans. And why don't we put them in the exact same thing? But I guess you can make the maze 10 times the size of a mouse or you can put them in virtual reality environment and you collect very fine navigation data and how efficiently they're navigating in a virtual reality space. And there's a lot of basic translational clinical utility to that in drug development.

Bhatnagar: Awesome. That's really neat. And you kind of touched on this with your last answer, but we wanted to talk to you about your passion for emojis as well. So, you are an author or co-author of the anatomical heart and lung emojis that we see in our keyboards. Is that correct?

Dr. He: Correct. I encourage everyone to use them.

Bhatnagar: Yeah. What is the importance of having accurate emojis and what drew you to that side of the field?
Dr. He: Yeah. So, two things. First is linking back to the last question of we are trying to answer this question of, "Do you make people feel better?" Right? Well, it turns out we do this thing with emojis every single day in the hospital all the time called the Wong Baker scale, right? So those things that are asking patients, "How is your pain today?" Scales 0 to 10 or looking at smiley face meter on a pediatric clinic, how was your pain for a child, right? Because there's something called the patient report outcome that was basically really introduced into medicine after the Affordable Care Act. In 2009 in the Affordable Care Act, we wanted to shift payment models in medicine from fee for service, AKA, doing more. So, replacing your knee with payment models, compensation models to physicians by making people feel better, right?

But that meant that you had this really large outstanding question. What does it mean to make someone feel better? Right? How do you measure that objectively? So basically, there was an institute called the Patient-centered Outcome Research Institute that was spun out from the Affordable Care Act to basically create and measure these tools that would ask people, "How do you feel?" So, papers and papers, and hundreds of different types of smiley face meters have been created in order to ask patients, "How do you feel? Are you less depressed today? Is your depression getting better or worse? Is your stomach pain that's chronic getting better or worse?" Because the alternative is you're coming to the doctor's office once every six months, right? That doesn't actually tell you much information because when it comes to these very fine grain measurements of behavior, right? Looking back to the mouse mazes, you're really thinking about a day-to-day existence.

What is your happiness in the morning? What is your happiness after lunch? What is your happiness when you pick up your daughter from school? This kind of internal mass data is really, really critical. And it turns out that a lot of the scales we had to ask patients how you feel are not digital, they're based on paper scales, right? Well, it turns out that there happens to be this smiley face meter on everyone's phones, all computers worldwide and even electronic medical records say based on this common code called Unicode, right? And they are the basis for emoji. And to give you a sense of this, this code analyze not just emoji but the Chinese language, the Arabic language, visual languages that are also characters just like emoji, right? So, if you actually look at the Chinese character for heart, Xin, it is looks actually just like a heart. It's amazing.
And this has been with us in human history for as long as we remember. Emoji are basically a way to visually communicate with other people and that's why it's so important to think about. How can we use this tool to answer this very important question of how do you feel today, right? Can you build this emoji scale into an application that asks you every single day, multiple times a day after your knee procedure, "How are you walking? Do you feel better?" Right. So, we're doing a lot of research around using these visual analog scales that are ... So, everyone worldwide, billions of people, "How do you feel?" Right. So that's kind of part one, is visual analog scales, AKA, emoji as a standard patient report outcome.

Now there's a second part of this that's frankly I just think it should exist. The fact that there is not, right now, a liver, a stomach, an intestine, a kidney emoji is something that really strikes me as fundamentally unfair, okay? And I'll give you an example of this. In the emoji, a consortiums called the Unicode Consortium that decides every year what emojis should exist. In 2018, the anatomical brain emoji was introduced. I had actually nothing to do with this but this created this whole category that said that medical emoji should be a thing, right? There are entire categories right now to food. There are emoji for beer, for clinking beer glass, for champagne, for sake, for matcha but there is no liver emoji that actually digests the alcohol that comes in with all of that category of alcohol, right?

And that to me is really fundamentally unfair. Is that if I imagine a child whose father is on the liver transplant list or if you are a child with nephrotic syndrome and to not have a kidney emoji, I just fundamentally think that's about representation and inclusion, right? That we should have that ability to represent it among these anatomical emoji because these are, one, universal. Everyone has these organs, right? And two, if the emoji exists, more people know what they look like, and become more and more usable and accessible, right? There's actually an amazing movie trailer about this.

Around the creation of the hijab emoji. This was a years long fight. At one point there were four mailbox emoji, right? One mailbox with a little flag up, down, left, right. But there was not a person wearing a hijab to represent the 500 million Muslims across the world. And that to me is fundamentally unfair, and we are doing basically the same thing in medicine where I am pushing for basically with a group of other physicians, the creation of the kidney emoji, the stomach emoji, the intestine emoji, spine, EKG. And actually, one of the most important ones, a white blood cell emoji, especially in the context of the recent pandemic.

**Bhatnagar:** Absolutely. I can totally see how this can be applied in many different situations, especially patient education, and that's awesome. I saw that you retweeted earlier today, someone talking about the need for a kidney emoji. And it reminded me that during my nephrology blocks that I always used a potato as a close alternative.

**Dr. He:** Right.
Bhatnagar: I want love to see an anatomic version sometime soon.

Dr. He: Yeah.

Bhatnagar: That'd be great.

Dr. He: Exactly. And quick plug on this, anyone who's listening should go to medicalemoji.org where you can participate in the campaign. What we're doing is we're getting letters from societies because the people create these emoji or actually it's a consensus setting organization, right? So, they listen to society consensus. So, when the AGA, American Gastroenterological Association puts out a letter that says there should be a stomach and intestine and liver emoji, they listen. When the ASLD for the liver puts out this formal letter that says this liver should exist, that actually really moves the needle on the creation of these emoji. So that's what we're for every single one of these. So, if you're passionate about the spine, we would love to have more people to help reach out to ANS and other societies, right? To help create basically more endorsement letters and more awareness for the need for, for example, the spine emoji or the white blood cell emoji.

Bhatnagar: Awesome. And as we're starting to wrap up, as a physician, how do you see the future of health IT in the next 10 to 5 years when Kris and I start practicing?

Dr. He: Yeah. So, I would say this, there is right now seen as this divide of health IT and medicine, right? That they're somehow different things, right? But I'll give you an example of this. At one point the stethoscope was seen as this very fancy new tool, and this technological tool called a stethoscope and where you would have to use a tool to listen to someone's heart and lung. That was a fancy tech at the time, right? Because if you look at the history back then, physicians were putting the ear directly onto patients. And this new stethoscope was seen as some divide or a tool that would take you away from patients.

But now fundamentally it is one of the most representative tools for medicine, right? And I think it's a very similar to what we're seeing in other technological tools, that they're different than how we're practicing, right? That there are just tools for the practice of medicine. And what we're trying to do at the end of the day is to take care of a patient in front of us and tools make it easier, more accessible and actually make us more capable of taking care of patients. And so, what I would really emphasize to kind of all the future med students is that that divide is really starting to close where we think about technology and health IT as a fundamental part of medicine. And that's what I would really push that as is really what we're trying to do is just take care of patients.

Bhatnagar: Great. And finally, do you have any channels where people can connect with you or follow your work?
Dr. He: Yeah. Twitter. So especially for the med students that are listening, we do a lot of research. It's all remote. Anyone can connect with us. We have a lot of different projects at any one time whether that's in the opioid disorder space, in the emoji space, in the patient report outcome space, in the remote workspace. But ultimately regardless of who it might be, follow me on Twitter. It's ShuhanHeMD on Twitter. But certainly, I think Twitter, especially in medicine Twitter, med Twitter is one of the most active communities, and something I love and embrace, and something that has really grown especially in the COVID pandemic for the representation of medicine in just larger society, right? So certainly, reach out to me on Twitter.

Bhatnagar: Great. Well, everyone, that's all for today. Thank you for listening and thank you for your time today, Dr. He. This has been Making the Rounds, a podcast by the American Medical Association. You can subscribe to Making the Rounds and other great AMA podcasts wherever you listen to yours or you can visit ama-assn.org/podcasts. Thank you for listening.

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