John Whyte, MD, MPH: Welcome, everyone, to Medscape Masters. We're excited to have you here for our debate: Should patients have immediate access to cancer test results via electronic health records (EHRs)?

We're joined by Dr Aaron Goodman and Dr Mark Lewis. I'm Dr John Whyte, WebMD's chief medical officer; I'm going to serve as tonight's or today's — depending on your time zone — moderator. We will have time for questions and answers at the end of today's event, so be sure to enter any questions you might have that you want Mark or Aaron to answer into the question box. That's to the right of your screen.

Let's get started. I'd like to introduce our experts. Dr Aaron Goodman is a hematologist who specializes in treating a variety of blood cancers at UC San Diego. Dr Mark Lewis is director of gastrointestinal oncology at Intermountain Healthcare in Utah. Doctors, I want to thank you both for joining me today.

Mark A. Lewis, MD: Thank you, John.

Aaron Goodman, MD: Thanks.

Whyte: Let's set the groundwork, so to speak. And let's keep in mind that in 2021, the 21st Century Cures Act requires healthcare providers to give patients access to all of our health information and our electronic medical records without delay. That's the phrase; without delay. In 2022, the requirement was expanded to include electronic protected health information (PHI). Now, the intention clearly is good: Patients should have access to the records. But in practice, how is this working? You know our patients are getting their test results and are misunderstanding them. They're panicking; it's creating anxiety. That's perhaps one perspective vs knowledge and information is power and that people should be able to have control over their own lives.

And let's be realistic: There are workload issues associated with this — responding to many of those emails, those phone calls. Oncologists spend 17.6 hours per week on paperwork and administration, including EHRs. It's the fifth highest among specialties surveyed by Medscape, and that's in our 2023 Medscape Medical Oncologist Compensation Report. We all know that bureaucratic tasks and EHR work were the first and fourth highest reported contributors to burnout among oncologists. And at Vanderbilt University, the number of patient messages via EHR doubled after implementing open notes. So, it really raises the issue here of whether we're meeting goals in getting people access to their records via EHR at the same time as clinicians. Is this a good thing, or is this a bad thing? The doctors today have different opinions.

So we should do a coin toss? Aaron, do you want to say heads or tails?

Goodman: Tails never fails.

Framing the Debate

Whyte: Indeed, you're right. So let's start with Aaron. Your position is that, of course, we should give patients immediate access without delay to their oncology [information]. Let's remember that we're talking about oncology here, which is a little different to me than in internal medicine. You say that's a good thing, and we need to do it? Why?

Goodman: I think the debate here is that we need to frame what the question is, and the question is, "Do patients deserve rights to their records immediately?" The question is not "Do physicians or oncologists prefer that the records not be made available?" That's not the question. The question is from the patients, and we'll start with the obvious: A patient's health information — you know, if anyone should be able to have control and say over it, it should be the patient. So that's number one.

Number two — and I think this is where the argument just kind of goes away — patients don't have to look at it. They can just wait to see Dr Lewis or myself. Sometimes that's a long wait, unfortunately, given access to healthcare, but they can just choose to wait and that basically gives everyone happiness. It gives that patient right away immediate access to their medical records, and it gives the ones who really want to wait so they can discuss it with their doctor time to wait.

I'm sure Dr Lewis will go over the many issues that [access to records] causes in terms of anxiety for patients and extra workload for physicians. But again, this is my experience, so we can't broadly give this to every physician practicing. The patient's results come back. They're not seen in my clinic the next day. They're usually seen, hopefully, within a week if it's a major result, but not always. And patients can have access to the records, and they can read it. They can let it sink in. They can read about it. They can Google it. We make fun of Dr Google, but Dr Google is pretty useful sometimes. They can ask their family members. A lot of patients know physicians or people in healthcare and get all this added opinion and data. Then they see me.

If they don't have any access to that or don't know, and then I say, "You know, your cancer has come back," even though I'll do it in a compassionate manner, they're stunned and they don't freaking hear anything else I have to say for the rest of that visit, rightfully so, and then they leave the clinic. And a minute later, they're MyCharting with all these questions. Let's remember, this used to happen all the time.

I'll let Mark talk a little bit, but those points are the main thesis. I still think this is the patient's own body. They should have a say as to whether they want to see the results or not. And we are in the business of making patients live longer and feel better, and if this makes some patients feel better, then they should have access to it.

Whyte: Even if they have to wait a week or two to see you, that's OK.

Goodman: They will reach out to our office, as we've discussed with the increase in MyChart messages. Which maybe is not a bad thing. It's a bad thing for physicians and workload, but it's more doctor-patient communication, which is what we should be spending our time on. I mean, we complain about that, but that's why we went into medicine: to communicate with our patients, not to do the other stuff. So they have fair warning. This is staying whether Dr Lewis likes this or not. I already won. [We cannot] focus on "this sucks for physicians" and this increase in workload. We need to make this better for patients and ourselves. I won't talk anymore, but I definitely think we'll have solutions on how to address them.

Whyte: All right, Mark, you don't completely agree with all of that, do you?

Another Perspective

Lewis: I don't agree with all of it, John, but I have to say that in the debate setting, I will concede right from the get-go that Aaron has won. He's won in the sense that this is what is happening now. And he's also won — and I have to acknowledge this because you're absolutely right, Aaron — in that this is about the patients. You have won in the court of public opinion. If you ask patients, many of them — in fact, most of them — will say that they want immediate access to the results. So I think what we're actually talking about tonight is, what are the implications? What are we not doing right in this system? I think that's where Aaron and I are going to converge — of course we have our patients' best interests at heart.

I'm going to do what magicians do: I'm going to tell you I'm going to do a trick, and then how you do it. I'm going to be using some anecdotes. I'm going to appeal to emotion, and I'm going to use some figurative language, and Aaron can tell me whether or not the analogies are applicable or not. He's absolutely correct that this comes down to use of the word "communication." But this has dramatically changed in a manner that I don't think we were entirely prepared for. And that's part of the problem: It's dramatically changed the timing of our communication with our patients.

I think it's important to say at the outset, these gaps between when the tests happen and when the patients see us in person — that's not a bug, most of the time it's a feature. What I mean by saying that is that there is a need for me, at least as an oncologist, to synthesize all the different information that a patient is acquiring through their tests, and that's not just labs. It's not just the pathology. Our job, and I think Aaron will agree with this, is to put it all together in a manner that is comprehensible to the patient and actually helps them understand their condition. I think that's the spirit of shared decision-making.

I know one of the words that's going to come up here, because it already came up online, is "paternalism." The way I see it, and I don't want to step on Aaron's toes here, is that it's almost like a pendulum. On the on the one side, we have paternalism, which I agree is an outdated model; it should never have really been the dominant paradigm of patient interaction. In the center, which is I think what we're aiming for, is true shared

decision-making. But I think the overcorrection is what I'll call à la carte oncology: We give all the information to the patients and put the onus of responsibility (I would argue unfairly) on them to interpret that and make decisions about their own care, sometimes before they've had the opportunity — and this is the crux of it — to sit down with us and talk about it. And my role is to be a counselor. My role is not to tell other people what to do; my role is to give them recommendations, and I think maybe that's where we've overshot the mark.

Whyte: So your position might be — and don't let me speak for you — is that this is the cart, and the horse is gone. So, we're not bringing it back in; patients are entitled to this information. But it may not be the best way to communicate results in oncology, given what can be the gravity of the test results or misinterpretation. What responsibility do doctors have, to Aaron's point, to MyChart it right and answer all these questions now? We're busy, we do it in between things, and we answer very quickly, and it may not be the most detailed, compassionate, emotionally sensitive response that we might do in the office, or on the phone in the old days.

I remember when I would call people with concerning test results, particularly around oncology, and tell them to come in. And I remember one day, one of them said to me — I had asked them how they felt after I delivered the results —"I knew it was bad, because you asked me to come in." I want to ask both of you, Mark and Aaron: Do we miss that? And then we're involved in an e-mail exchange with patients over test results, particularly when they're abnormal, how do you manage that?

Lewis: I'm actually going to invoke here a picture of my father. He's the very reason I went into oncology. I can't think about the word "paternalism" and not think about my dad, and the reason I'm going to use him right now is that I told you I was going to appeal to emotion and use anecdotes. He found out he had cancer over the phone from someone who was not even a physician.

To set the stage, this was 1987, my family was moving to America, and my father was a university professor. He was offered a position in Texas. We moved from Scotland. And the reason I'm bringing this up is when you move to this country — and this is still true as a public health policy — you're required to get a chest x-ray. It has nothing to do with COVID; it actually has to do with tuberculosis. And so my dad got a call from the embassy saying, "Good news and bad news, Mr Lewis. The good news is, you don't have tuberculosis; you can move to America. The bad news is we think you have lung cancer." And then they hung up.

At the time, I remember thinking that this is perhaps the most impersonal way that someone can find out that they have a life-changing diagnosis and indeed a malignancy, and the reason I'm raising it now is that decades later, I think we are still doing this, but in a different way.

Another thing I wanted to point out is, my dad was a really smart guy. He was a scholar. He wasn't medically savvy, and he did not have access to the internet. And I

know Aaron's going to say, and he's right, that our patients have the ability now most of them to look things up, and that's a huge shift in sort of the information asymmetry, if you will. But here's my point: My dad, as intelligent as he was, anchored on that phrase "lung cancer" — it was the first thing he heard, and that was not the right diagnosis.

I guess what I would say to you, John, is that there are some bells that we can't unring. So in the rush — and I'm going to use that word deliberately — the rush to get people, the information as soon as it's available, I think we're losing a little bit of quality control. Again, the reason I invoke my dad's x-ray is I think this is particularly a problem when it comes to radiology; it is not a coincidence that Medscape chose two oncologists to talk about this. Because number one, everybody knows that cancer is a diagnosis with a lot of gravity. And number two, in terms of information streams, there are multiple different sources. There's labs; there's tissue that we look under the microscope; and then there's the scans, and I'll elaborate more after Aaron gets to respond. I think it's the scans in particular where I have a lot of reservations about making immediately available a synoptic report of a set of images.

Whyte: I like this issue of quality control. Aaron, do you agree with that, that we're missing out? People are waiting. The results might not be exactly right. We've all seen instances where reports change a little bit. And there's clearly interpretation. What are your thoughts on that? Do you acknowledge upfront it's going to be a wait — do you tell patients that ahead of time so they know you're not going to be immediately available? How do you manage the issues that Mark brought up?

Communication Is Key

Goodman: Let me unpack these one by one. So yes, that story that Mark told it's unfortunate. No, it's not ideal to find out about cancer that way, but you could turn the argument around completely and say that for all those patients who get the scans, whether it's their cancer scan to see if it's in remission or to see whether they relapsed, it gets done but I've got to wait a week? You can't argue that there's not some anxiety component to that whole week. And which anxiety, though, it's not measurable, is worse? I don't know, but you can play that angle both ways with test results.

Quality control? This could be something we could get to, but I'm pretty sure at UCSD here — don't quote me — that the reads for radiographs and pathology are not made available till the read is final.

They might find some unfortunate news a little bit early and not have someone immediately available to provide that compassion, which us physicians do so well. Sounds like they're not going to get that, right? They're going to get it when we see them. Now, they have a whole week to have had that news. But they're going to get that compassion, and guess what? If I have a patient who finds out they have cancer and they MyChart me that they found out — they're not waiting. It makes my life worse; I will bend over backward to talk with them, and I think most of us will. We will not leave our patients with the diagnosis of lung cancer a week or two to meet with the physician.

We will bend over backward to find time in our day. Maybe not within a minute, but within 24 hours, I would say, most of us do. I fit them in on the car ride home. I do it on a walk. I make it work, because that's my duty, because I think of myself and that particular scenario being like, *Oh my God, I need some context to this*. Fortunately — not that this is a money thing — with the advent of telehealth, all these things can now be reimbursed. Patients have much more access to me now with results, and we schedule telephone calls, and they can happen whenever.

So I think it's a win-win. Patients are getting their data faster, getting their answers faster. I don't know if I answered all the questions. Anything I missed there?

Whyte: What's the downside, Mark? Aaron makes it seem...complicated.

Goodman: We have ways around it. The downside is that physicians have to work harder, and maybe we need to be paid more or whatever, or understand what we're getting into. But what we go into this job for is those talks, for patient-physician communication. We complain that we spend hours doing all this stupid-a** paperwork. But you know, this is what we go into the field to do: consult patients.

Whyte: I don't think it's just about working harder, because they're getting the test results better, I think. And correct me Mark, you're also saying that that might not necessarily always be the best scenario, and the best time to look over something.

Lewis: I like the fact that Aaron brought up why we went into this field in particular. You know, people have asked me, why on earth would you choose oncology? Well, I told you the origin story was my dad, and I have to say that once he connected with an oncologist, he received incredibly compassionate care, and it was such that it was actually a stark difference from how he learned about the diagnosis. That's one of the reasons I wanted to do this. I wanted to be the type of doctor that Dr Goodman is — the type of doctor he's describing, someone that will literally meet you where you are.

I think what's problematic is the asynchronous nature of people finding out not just that they have cancer — let's pretend for a moment that the diagnosis is established, because I agree with Aaron — I think what we're really going to talk about here is, how does this affect longitudinal care of people that are already in our practices?

I'll now invoke a true anecdote. I'm going to deliberately strip away some of the personal health information, but this is what changed my entire opinion on the immediate release of results. I had a patient, and he had had his scan about a week before I had seen him in clinic. I walked into the exam room, and it was an era without masking, so he could see my face, and there's lots of nonverbal cues, right? Aaron and I are human; newsflash, oncologists are human beings. I like to telegraph to the patient — just like you were saying, John, it's a phone call and come in and let's talk — I like to telegraph if it's going to be good news or bad news. So I walked in with a smile on my face because I knew that this patient's scan was encouraging and he had response [to treatment]. And he looked at me and before I even said a word, he said, "What are you

smiling about?" I said, "Oh, Mr. Smith, you've got good news on your scan." He said, "No, I don't." And it turned out what had happened is that the verbal transcription software that our radiologist was using — again, in an effort to dictate the result as quickly as possible — had misheard and mistranscribed millimeters as centimeters.

So this gentleman had been laboring under the misapprehension that his cancer had not just doubled in size but had grown by an order of magnitude. And here's what he said to me that I found so chilling. Aaron, you can absolutely rebut this and say, this is Mark's anecdote, you're choosing your example, but he said to me, "Dr Lewis, when I read that report, I went outside and I put a gun in my mouth." And I realized that without some serious quality control — not just at the radiology level but at the oncology level (and I'll explain what I mean by that in a minute) — we have to be very, very careful with releasing information, before appropriate measures have been taken with finalization of results, as Aaron was also mentioning. We have to be very careful in thinking about the audience of these reports. Because that's the other thing: It makes sense that you guys at Medscape chose oncologists to talk about this, but actually I think the missing partners in the dialogue here are the radiologists and the pathologists, without whom actually Aaron and I can't do our jobs.

A Role for Radiologists

Lewis: Yes, I picked an extreme example on purpose; of course I did. But the radiology workflow here and their throughput is really important to my entire premise. So quickly, and this is not just going to be me being an apologist for radiologists: Radiologists have an interesting job and it's very different from the one Aaron and I do. It's seldom the case that a non–interventional radiologist will have direct patient contact. Most radiologists, throughout their day, are reading many scans, dozens of scans; by some estimates, they have under 10 minutes, say, to read a CT scan and in reading it, they also have to write a report. And maybe my biggest take away from this other than the potential for catastrophic error, like the mistranscription I mentioned, is that our radiologist did not train to write the reports for a patient audience. I know that Aaron mentioned that there's maybe some potential technological remedies to this, which we should invoke. They're still writing the reports for us, by which I mean healthcare professionals, the ordering physicians.

We should acknowledge that yes, patients can absolutely google things. But when they google things, they are going to run into a bewildering number of mere synonyms, for instance.

Whyte: But you could argue, is that their job? That's why they have a doctor. Should they have to be googling something? That's why they have this engagement with the clinician? That's why they have insurance. That's what we want to say, when we're talking about oncology?

Lewis: I can let Aaron respond to that, John. The radiologists are the ones that are generating the synopsis of the images —remember, they're looking at the scan with

expert eyes and then they are translating for us what they see — but very few of them went through their training and entered practice thinking that the patients are going to be reading this not just eventually, but immediately. So I see very few [if any] synopses of reports that are in plain language. And I think that that is, unfortunately, a real hotbed for a misunderstanding.

Whyte: I'm trying to read Aaron's face. I'm not sure what he's going to say. What's your response to that?

Goodman: Well, he brings up an unfortunate case, and that was horrible for that patient, but you could have said the same thing if you had read that error yourself and hadn't looked at the scan. Not everyone always looks at the images themselves, and you could very well have called the patient told and the same thing. The fact is that they got the information a little bit sooner without you. I could come up with numerous examples where it would be horrible for a patient to get those results or wrong results, but it still doesn't take with the fact that they shouldn't have the ability to make their own decision — the autonomy to say "I want to look at this when it comes down to it." They don't need to see it if they don't want to.

Again, solution-wise, radiologists do maybe need to start changing their reports. I don't know about you, Dr Lewis, but when patients started knowing that they were reading my notes, they definitely changed.

Whyte: I was going to ask you that. In terms of censoring notes, has the advent of open notes changed how you write?

Goodman: I changed how I write. I can't speak for everyone

Whyte: How has it changed? What do you do differently?

Goodman: Sometimes we don't tell them right away about the bad prognosis that they may have because as an oncologist, it's our job to integrate that in a stepwise fashion. I know from experience and learning and doing this now long enough that on that first day, you don't maybe hit them with it all. It's not trying to hide stuff in them. There's a way I used to write my notes: you know, AML/TP53. This is really bad. Now I'll keep those things away. And there's certainly inflammatory words that might have used before — an intro like "morbidly obese," for example. I don't need to write that anymore. I don't need my patient reading that. It's not going to make them feel good. It doesn't help anyone.

So that's how things have changed with my notes. And I do try to write more concisely and exactly; I'm very transparent with what my thought process is with the clinical decisions that I'm making. I literally write my plans in that stepwise thought process of how I arrived at making a certain clinical decision, so hopefully patients and others can see it. It's made me more self-conscious about my notes, which is probably a good

thing, although it's made it harder. It makes me think more about what I'm writing, as opposed to just copy forward and all that other stuff.

Whyte: Mark, has it changed the way you write your notes?

Lewis: Well, it's interesting. In my training, I had a really important and influential attending physician who told me at the time, "Write your note as if the patient is going to read it." So that was of inculcated in me even before the open notes movement. But I agree with Aaron wholeheartedly that the Hawthorne effect says that we act differently if we know we're being observed. I think the difference here is that he and I signed up for this; we signed up for being right at the interface between clinician and patient, And let's be honest, patients who are literally facing life-and-death decisions are the ultimate stakeholders. I think Aaron said it best just a minute ago, that what hasn't changed yet but probably needs to is how our colleagues — again, please understand the furthest thing I'm trying to do here is denigrate radiologists or pathologists; I'm literally blind without them — but if they are now in the business of generating the raw data that our patients are going to be consuming without us in the middle as a filter, that I think is maybe the number-one call to action I have coming out of this debate. There is so much room for misinterpretation — and yes, I chose an extreme example to illustrate that — but I think what we're moving toward is some form of plain-language summary to relay these findings in a manner that doesn't come across as condescending, but meets the patients where they are.

Lastly, I want to say one other thing about my training. I was taught — and I get the sense that Aaron does this too — that an oncologist who doesn't look at the scans and just goes by what the radiologist says is not doing their job. The analogy I would use is the difference between looking at the Mona Lisa [for yourself] vs having it described to you as a woman that's kind of smiling. You get so much more information from actually looking at it. John, you'd mentioned before we started that some healthcare systems are now sophisticated enough that they can offer patients the option of looking at their own scans — and many patients, even with that rather remarkable capacity, will opt not to do that.

Whyte: I wanted to bring that up. We know nationally, in terms of the data for all patients and all specialties, that looking at lab results is very low: 20%-25%, on average. Despite the fact that patients say they want access to it, they often don't access it. Do you think in oncology, given the gravitas of an oncology diagnosis, it's a higher percentage of patients? What do you find in your individual practices? Do you find that the majority of the patients look at their test results online are not? Aaron, what do you find in yours?

How Many Patients Are Looking at Their Data?

Goodman: I don't have a direct measurement of it, but what I do know is the patients that are asking me — like the example you brought up, like median platelet volumes elevated or some useless lab value — those patients that are sending me those

MyCharts, even if they didn't have labs, would be sending me MyCharts about something else. You know what I mean? There's a selected group of patients, and I'm not trying to be mean; you know, we're doctors, we know those types of patients. I know I do, they look at the results and just don't do anything with it.

Whyte: Because you can look on MyChart to see if patients have looked [at the information. But nationally, for non-oncology patients, it's a fourth or a fifth of all patients [who] look at the record. Do you think it's different, Mark, in oncology?

Lewis: I've actually looked at this in my own practice. One of things I wanted to say is that I was really interested in this even before the Final Rule of the 21st Century Cures Act. Internally at my institution, we were having lots of discussion about whether some results are (I don't like this phrase) "too hot to handle" — that is, sensitive and where a time release made sense and what we had brokered before the federal mandate

Whyte: We used to do that for sexually transmitted diseases (STDs) a while back, until the doctor viewed the results.

Lewis: Yes, exactly. What we had brokered was that it was immediately released to the patient once the ordering physician had seen the result and/or there was a time limit — no more than, I think, 5 business days can elapse, and then it would just autorelease. Personally, I thought that that was fair. I completely grant to Aaron that what we've done here is a little bit of a shell game of anxiety — where before the apprehension, which maybe was worse, was the uncertainty of knowing what we were going to say. Now I think we've shifted the anxiety a little bit to looking up results that are flagged as abnormal, some of which we know are clinically insignificant, but the patients don't have the benefit upfront of knowing that.

But to answer your question, John, when we did this survey before the federal mandate, almost exactly half of our patients were accessing results. That's on the oncology site.

When Al Steps In

Whyte: What do you think the role of chatbots are? We see in other spaces that they actually give responses that are considered more empathic. Clearly, they can write more. I've seen some of these in a report. Say the person swallowed a toothpick, as an example. And the chatbot is like, toothpicks are made of materials that typically don't puncture the intestinal tract; you should be fine, but look out for any blood. And they compare that with the doctors response, which is typically, oh, you're fine, no need to worry.

Is there a role here for AI and chatbots? You're talking about workload burden. Right now, you have to answer all these emails, and let's be honest, they often precipitate more email exchanges, right? It's not as if the person emails you about their lab results,

and then you answer it, and then it's done. It often leads to more emails around it, both good and bad. Do chatbots help here, Aaron?

Goodman: Actually, our group, including myself, we looked at this question. It was published in *JAMA Internal Medicine*. What we found was that chatbots are likely more accurate and even more empathetic.

Whyte: I just said that!

Goodman: Yeah. I'm all for artificial intelligence. I think how most people envision it [being used] — I'm not taking credit for this original idea — is that the chatbot sees [the information], responds, and formulates some nice response. Then a physician spends X amount of seconds reviewing it and being, like, OK, I'm cool with this response and clicks a mark. I still think it needs, at this point, a human review.

Whyte: Mark?

Lewis: I agree with that. And I am far from an expert on OpenAI. I've dipped my toe into the waters of ChatGPT. It was frankly a little bit eye-opening, and a little bit disappointing, that we can have chatbots that come across as more empathetic than human beings. But I think it's like Aaron said himself: What we're actually changing here is when people find out.

Aaron has said this very compassionately on Twitter: Patients would love to have our worst days. Aaron and I both know this. When we are in a busy clinic, behind every door we go to is someone that's nervous. There's no such thing as a routine visit to oncology. We know that. And I know he and I feel that. But I think what's happening is that it's shifting the timing of when people are finding out about both things that are inconsequential — that, frankly, they shouldn't need to be worried about but now are — and also things that are that are truly life-changing. Again, maybe I am being overbearing here, and I'm not there to help them.

In our training — John, I actually I'm curious to know if you received this as a non-oncologist — I was taught this protocol, this acronym, called SPIKES. At, first when I heard it, I was like, gosh, there's a mnemonic for breaking bad news? So we're going to mechanize everything? But the first "S" in that mnemonic is "setting." And just like you said, where you sent a shot across the bow by calling that patient and saying, why don't you come in so we can talk about this? — that is a very clever indirect way of saying listen, there's something serious, that is of sufficient importance, that you need to come in. What I'm getting at is I worry, I really do worry, about my patients receiving life-changing information when they're alone.

Physician Burnout, Patient 'Scanxiety,' and More

Whyte: That's the reason why I did it. I didn't want that person to be alone, and we're going to have time for questions [from the audience]. And there's a bunch of great

questions in there. But I also wanted to address the fact that we've all talked about burnout in the profession. Aaron, you talked about you're going to find time in the day, you're doing phone calls on the way home; even if you can bill for things under telehealth, it's still lengthening your day in terms of addressing many of these issues. Is this contributing more to burnout?

Goodman: Again, I can only speak to how I do it, I. My time has shifted. If I do more patient stuff, I'm doing less of whatever else I used to do. Somehow it all gets done. I'm forced to reprioritize and put emphasis on the things that matter, which is communication with our patients. And, again I've adapted to this, like most of us, will, or already have. When I get a CT scan result back and I read it, I send the nurse I work with a quick message that this is fine. Just let them know that this is fine, I'm not concerned, and we'll talk about it later. I do that now, even with routine labs. I'm fortunate. I have a dedicated nurse coordinator that works with me in the transplant clinic. And every time I come across a result, I just say, please notify the patient of this, and I've changed the way I do things.

Mark, I'll ask you a question. Your wife gets a scan, and God forbid, and there's concern for cancer. Do you want to wait a week? Are you going to look at it yourself? You're a doctor, but that doesn't count. You want those results, like we all do, or at least want the options to look at them.

Whyte: There's a good question in here that I want to ask you. In your experience, which is a greater psychological stress: the wait to hear the results from the doctor, or getting the results and waiting to hear from the doctor to explain them?

Goodman: I have heard numerous times, "Gosh, I'm so relieved. I've been thinking about that all week." For the patients who are now getting the results early, they're freaking out, but guess what? They are notifying me, and that eats maybe into the burnout, but I'm finding out their reaction. Maybe a few kept it internally. But Mark, how many times have you heard the patient say, "Thank God, I've been thinking about, you know..." "Scanxiety" is a real thing.

Whyte: Scanxiety — I had not heard that. I'm going to use it.

Goodman: It's a real thing. Patients, especially those with solid tumors, get scans every 3 months, and that time between scan and visiting for results is a time of.... I mean, I would be freaking out and thinking about it nonstop.

Whyte: Do you agree with that, Mark? Or do you feel that there's a greater stress waiting?

Lewis: This is exactly the sort of qualitative comparison that's really hard for us to answer. What we're all seeing is it's really stressful to be a patient with cancer; there's no technological solution to that. I think what we're doing, though, is shifting the timing and the nature of the apprehension. And we have to be honest that we've actually

introduced some new anxiety. So to Aaron's point, "scanxiety" is a beautiful portmanteau; I felt it myself, as a patient. I see it in my patients. When they get a good scan result, that's one thing.

What I find unnerving is — I think this is going to go back to the nature of radiologists — radiologists are human beings, too, and the interobserver reproducibility between radiologists can be wildly variable. What I find interesting is, from my patients who are getting good news — meaning their scan doesn't show cancer — they start anchoring on findings that to me at least (and again, I'm not the patient, it's not my body) are trivial or incidental. They also get very concerned, and I understand why, that the last radiologist didn't mention, say, a thyroid nodule, and they start to then question the integrity of the whole process. Again, that's why at the beginning, I was saying there's a big difference between the raw materials of imaging and the subjective interpretation of that in context.

Whyte: Also, it's not just radiology; it's blood tests, et cetera, for the blood cancers.

A question came up: Do we feel this is a generational issue? Is it different for patients born before 1990 (their words, not mine). Do you see a difference in how patients behave kind of generationally, or is that more a stereotype?

Goodman: Young patients are definitely more tech savvy. My 89-year-olds aren't on their iPhones getting their results, for the most part. But I haven't noticed a generational thing. Have you, Mark?

Lewis: I take care of a lot of young people here in Utah; the average age is 30, so my practice skews young. One thing I will say very briefly on that, John, is that somewhat counterintuitively, during COVID, when we were doing telehealth, some of these young adult patients were actually the most nervous *not* to come into clinic. I know this is addressing a separate issue, but even the digital natives still found it very reassuring that we would do a hands-on physical exam. I found that fascinating. So while I agree with Aaron that there's a certain demographic that is more facile with technology, I don't think we can automatically assume that 1990 is some magical bifurcator between people that like this and people that don't.

Whyte: Someone has asked to your point about whether EMRs can delay the results to patients? Clearly, that would violate the law on how things are set up. But someone else asked — and I think goes to what we're talking about — do you have any recommended scripting to provide to patients during visits that will help them understand upfront that viewing the results before they've talked to you has an inherent risk in terms of misinterpreting the information? Do you take that step ahead of time proactively?

Goodman: I tell all new patients whom I see in my clinic — usually toward the end of the visit, when we're telling them how to use MyChart — many times, you are going to see these results before I do. I'm busy. I'm either in clinic, or I'm not immediately by

computer. I go through examples of good and bad, as concrete as I can, and I say, you get to make this decision; I can't answer whether you should look at them before and not, but understand the potential negative consequences of it. I just started doing that in the past 6 months. I have that discussion with every patient, and I do it on the new patient visit.

Whyte: Mark, do you do that?

Lewis: Yes. In fact, when Aaron and I were talking about this issue beforehand, I think he and I kind of agree that there's a huge disclaimer that has to be attached to this system. I think the medium is the message. If patients are going to get the results through MyChart, which is what you guys have referenced, then I actually think that's also the venue through which they should submit their questions.

The reason I'm bringing this up is that there are a lot of different ways — a bewildering number of ways, in fact — to communicate with a doctor's office. For one, it is the Year of Our Lord 2023, and I still have a fax machine. That aside, the phone tree is actually a problem. Let me bring up an example. To me, the most sacrosanct time I have with the patient is when they are literally in front of me; that is when I can do the best counseling, right? And especially if I am in with the patient in front of me, and if I am relaying life-changing news to them, I only want to be disturbed in case of emergency. And this is my final anecdote. I have been pulled from a room while telling someone that I was recommending they should go to hospice; they had a terminal diagnosis. I've been pulled from a room because a patient was on the phone panicking about a lab result that they had seen in their patient-facing portal. And I have to tell you, gentlemen, that lab result was of next to no consequence, and I couldn't be indignant with that patient because they are scared — they are not seeing me until next week to discuss that result. It made me think a lot about workflows.

Whyte: This is about office practices. This is about communicating to patients ahead of time what the boundaries are. It's interesting you bring that up because related to that, someone is asking Dr Goodman: You mentioned that patients should have the ability to access their data. Does that view change for patients who are cognitively compromised? Who gets to choose?

Goodman: Wow, if someone's cognitively compromised enough where they can't make their own decisions.... If there's someone who can make decisions for them, they should have access to that. But no, I haven't thought specifically on those more borderline cases of whether they should have access to it or not. Who am I to say they can't, you know? I'm no judge of what's competent, and that's a hard decision. But I stand by the thesis that everyone should have access to these immediately.

Whyte: Someone asked, do you ever suggest to patients they should opt out or not check? Have you ever explicitly said that to a patient?

Goodman: I just tell them what it is. I know [if it were] me, I would want them! But that's me. I never recommend. I say that there's pros and cons of both. Unlike when I make a medical recommendation, I don't say, "You need to do this." I say, "This is what I think you should do and here's why, and I would do it." Butin terms of looking at records, I discuss the pros and cons of both approaches, and I let them arrive at their own conclusions.

Whyte: What about you, Mark?

Lewis: I think it's underrecognized, and you have to read all the fine print, but the final rule of the 21st Century Cures Act says that patients can opt out, which is another exercise of autonomy. I think the reason that Aaron and I are largely in agreement is that the core principle of medical ethics, perhaps above all others, is that patients do get to exercise autonomy. I think what we're trying to get at today is: Have we actually moved closer to true autonomy by giving them access — I'm going to use the phrase again deliberately — to the "raw data"? Or are we actually confounding the issue? Again, Aaron's absolutely right, patients have the right to their own information. What I want very much, though, is for that information to be reliable.

I also don't want that volume of information. For instance, Aaron's a hematologist. Before we got on the call, I counted: When I order a CBC with differential, I get 24 different numbers back. Very few of them, if I'm honest as a solid tumor oncologist, matter that much to me, but those all come back. I don't want patients getting distracted. I know we've made fun of MPV. I've seen patients send me a message at 2 in the morning because their MCHC was out of range. These results get flagged in the record with an exclamation mark, because they're supposed to call our attention to it. We have, thankfully, the clinical acumen to know what's significant and what's not; patients don't have that ability.

Whyte: Dr Goodman was telling me that I order too many CBCs. Should we be changing how many results we report?

Goodman: We get the argument all the time that my creatinine's too low, you know. I order so many labs, I do bone marrow transplants, but I've got people coming in three times a week. Maybe someone should do some research on this, but it's not that common; I'm not getting 200 messages a day about my MCHC being low or whatever. I don't get that. I think we remember them because we get angry; there's that visceral response. But I don't think it's all that common, and maybe that's an area of research. I don't think it's important.

Whyte: What about the issues relating to health literacy? We talk a lot about that. You've referenced imaging reports, in terms of scans being positive vs negative meaning different things to us as doctors from what they may mean to patients. Do we need to revisit? You both alluded to how we report results. We all know a story of a patient who, when they hear the results are positive, thought that was OK when it's not, and that's not their fault. But they're not doctors; they're not pathologists. There's a fear

of finding out sometimes as well, and then not wanting to follow up on things. How do we address that in terms of the language of the reporting? Because you're right: You both referenced how these test results, these imaging results, are designed to be reported to physicians. And now we're saying to patients, you read them first, or it's OK if you do. Then we have to deal with the outcome. Should we be changing how we report things, or no?

Lewis: My whole thesis is that if this is the system that we are living in, and it is, we have to change the input. That means we need to start making sure that what goes in is quality, and we need to make sure that what comes out and is visible to the patient is as good as it can be and to help them. I agree, I don't have any technical expertise in it, but I do wonder about the ability of large language modeling to render radiology reports in particular comprehensible at an average level of health literacy. This is the hardest thing to say in the whole talk without sounding condescending. But the past couple of years have been a real exercise in public health messaging, and I think we've learned some real pitfalls. You're absolutely right, John: People can take things the wrong way.

Whyte: So what would you change, Mark? What would you change, and then we'll hear from Aaron whether he would change anything.

Room for Improvement

Lewis: If I had to pick one thing to change, it would be how we report scans. Again, I'm an oncologist, and it may sound strange that I wouldn't focus on labs. As Aaron said, there's ways around the lab issues, but to me, the biggest area of misunderstanding — and that's what I keep coming back to — is how we report out scans. Even leading up to this call, John, I took a straw poll among my colleagues, and, the people that have the most misgivings about this new system are the radiologists. They have not materially changed, most of them, how they write their reports, and I think this is forcing them to adapt very quickly. Again, do I have the panacea? No, I don't. But as you're alluding to, I've seen enough crucial misunderstanding about what a scan means even beyond the doublespeak of positive and negative. If I had to start at one place, I would think very seriously about plain-language summaries that are both accurate and as close to real time in this model as possible as we can achieve.

Whyte: Aaron, anything we need to change?

Goodman: It could definitely be better, but all that's going to require more work for likely the physicians, which leads to burnout-related issues. But ideally, just like sometimes with clinical trial reporting, now we'll put a two-sentence thing where it will explain [to someone who's not a physician/scientist], ideally at the end of every report, they'll have the patient impression — eg, your cancer is better — something very simple. These things are little incidentals; your coronary calcification doesn't matter OK? Ideally, we would have that. My dad's a radiologist — he's actually a breast radiologist and has quite a bit of patient interaction. He's the one who usually reads the mammogram results and tells them do a biopsy. So I think that's special to radiology.

But I actually think most radiologists — first of all, I don't know how many of them even know that their stuff's being read, because they're not talking with the patients, but they might embrace the fact that this is a way that they can connect further with the patients. I think with education and teaching, they would embrace this, I honestly don't know. I'm not speaking as a radiologist. And whether they can get a little bit more reimbursement, I don't know, But ideally, a one- to two-sentence thing would help, and AI can help with the whole lab-related thing. If a patient types in on the MyChart, "I'm freaked out by my median platelet value," AI should immediately spit back "don't worry about this." You know, that would be a nice use of AI.

Whyte: All right, we're just about at time. We gave Aaron the first word. So, Mark, let's hear from you first, your final thoughts about patients having immediate access to the cancer test results via EHR.

Lewis: I think you've learned, John, throughout this hour that although it was obviously framed as a debate, Aaron and I don't come at this as diametric opposites. We actually have way more in common than we do differences. I know on the face of it, when I accepted this side of the debate, that people said, "Oh, you're a paternalistic dinosaur." I realize that the federal government put a law in place, and this is literally the language they used — they put a law in place to prevent information blocking. That is extremely strong wording and almost sets up, which I think is unfortunate, an adversarial relationship between the doctor and the patient. That's the farthest thing from what I want in my therapeutic alliances. What I will say, though — and I think Aaron will admit this too — is that there are very few, if any, interventions in medicine that are entirely benign. And I think we just have to acknowledge that there are potential harms to immediate results. I think we're both saying that there is a better way of doing it.

The last thing I would say, as part of patient empowerment — which I think is really the message — use the same channel by which you're receiving the information, if it's upsetting to you, to communicate back to us. It's beautiful. It's like secure email, and that way, you're getting the answers straight from Aaron or I, and you're not actually going to some indirect source. And I think it's important for our clinics; we keep talking about workflow. I work in a team, and I can't do my job without a host of medical assistants or nurses. What I see happening already, and this is really unfortunate, is that calls are coming in to a system that's really designed to pick up urgency and emergency — calls that, frankly, should be answered directly by me through these MyChart mechanisms. So I encourage any patient listening who's in that gap between getting the results and waiting to see us in person: Please, please, please, if that technology is available to you, as it should be, use it. Because this is not Aaron and I complaining about our workload. We have to do this work. We enjoy serving our patients. It's just a matter of when we're doing it. And, again, patients should understand that the results they are receiving could be slightly premature, or even inaccurate, and that's a massive caveat emptor.

Whyte: Aaron, we'll give you the final word.

Goodman: After now debating this and thinking more clearly through all this, I'm even more favor of this than ever. I agree with Mark completely. You know, a lot of what we do, any intervention, when it comes to involving a patient, there's always harms. And we really need to be positive about our benefits. Ideally, this would have been rolled out with study. It can be studied. Just thinking about this is giving me ideas of how to study this. We should study this as a field. We owe it to our patients. Right now, it is what it is. But I will be the first to admit, if I'm shown well-presented data showing that the harms outweigh the benefits, or in specific groups, I'll be the first to change my mind. That would have been the ideal. I'm glad we discussed this, and I'm curious to see the feedback, maybe on Twitter. I had a good time talking about this with you guys.

Whyte: I want to thank you, Dr Goodman, Dr Lewis, for participating today. We really have had a great discussion. I want to thank our attendees as well, and we'd like to invite everyone to our next *Medscape Masters* event. It's going to be on November 8. It's titled "Al Is Here. Is Your Practice Ready?" We have alluded to it already. Our experts are going to be Dr Eric Topol, Dr Raj Manrai, and Dr Ted James, and I'll once again be moderating. We're putting the link in the chat, so you can click and register today.

I want to thank everyone again, especially our debaters, and I hope everyone will have a good rest of the day and a good evening. Thank you, everyone. Thank you, Mark. Thank you, Aaron.