



Objectives

What data says about health-seeking consumers and patients, their conditions, and current treatments -- and how to accelerate the patient's journey

Panel

- Kimberly Khoury, RN, PhD
 Informatics at major health system
 & CEO of invenTech consulting
- Michelle Hamland, RN, PhD
 Informatics at major health system
 & CTO of invenTech consulting
- Daniel Edds
- Principal of Praxis Solutions, Strategic planning for healthcare organizations, & Author of Genetics of Leadership
- Mike Zangrilli
 Product Management & Strategy at 83bar

Mark: Welcome to this very special panel of experts. We're looking forward to talking about the patient journey, and especially about listening to the data along that patient journey and what we can learn, what the data analytics and health informatics tell us about the path to finding better health for patients. Together, all your perspectives and all your experiences in this area of data analytics and health informatics are really going to be great.

In the context of what we're going to explore today, we always call them patients, but long before they're patients, they're just consumers looking for a better health solution. So, we're going to talk about how data and informatics measure that journey and track that journey, and then most of all, how to better manage and accelerate that patient journey so the patients don't have to wait so long to get the care they need.

Focus Topic # 1 What about the Journey can be measured? Dr. Michelle Hamland

Mark: Michelle, I could start with you. When we think about the patient journey and all the elements from the health concern, all the way to the treatment and then perhaps the outcome -- what are some of the things that health informatics can track? What can we measure?

Michelle: I really appreciate that context. From a healthcare perspective, we always think of these as patients, but they're really people. Outside of the realm of healthcare, these are just consumers, they are people that are trying to manage their own care. From an informatics perspective, how we can really support this patient journey is helping to facilitate the management of their care through tracking diagnoses, tracking their treatment to that diagnosis, and how is the patient adhering to their treatment guidelines.

There are some conditions that a patient has for which we have very regimented guidelines and treatment protocols that facilitate best patient outcomes. And we know that because of the evidence. It supports treatment X for CHF or treatment Y for stroke-type patients. This is all data that we're constantly collecting in the healthcare arena and that is data that we can use in machine learning and AI to really support the patient's overall journey. Looking at their outcomes, are we achieving those outcomes that we're looking for?

I like the concept of proactive care. We shouldn't be waiting for the patient to get sick, or we shouldn't be waiting for the patient to have some sort of acute disease state. How can we use that data, that information, to really be more proactive in getting these patients the care that they need before they become acutely ill, and they end up in the hospital because that's an expensive bill. What can we do? How can we leverage patient's diagnostics, their laboratory testing? In some instances, genetics. Genetics, genomics is becoming a big thing in the healthcare arena. How can we leverage all of that information, the machine learning, the Al, to support more preventive care so that the patient's overall journey is a positive experience?



Mark: Does evidence-based medicine help be more proactive? Do the protocols guide the providers to be more proactive and less reactive?

Michelle: Definitely. There is some evidence that supports preventive type medicine; eating healthy, diet, exercise. Those are all preventive protocols that prevent cardiovascular disorders, strokes, those types of things, but unfortunately, we know that some patients don't adhere to those guidelines. So, we also must have protocols when patients slip through those cracks and end up becoming acutely ill. We know that those circumstances happen.

Mark: From the informatics, there is the issue of readmissions -- if the treatment doesn't go well and the patient must come back to the hospital, or even physician office repeat visits, or even worse, ER repeat visits, because some patients are still using the ER like an urgent care. What effect does that have?

Mark: We think about the patient journey in two different contexts, First, from the patient's perspective. We want to try and keep them out of the hospitals as much as we can. We certainly don't want them to get readmitted. Every time they're going into a healthcare setting, especially in a hospital setting, they're at an additional risk. We want to try to avoid that as much as we can.

Second, on the flip side is more of a health system perspective for readmissions. The readmissions are heavily regulated. CMS really scrutinizes how often our patients are readmitted into the facilities and then we get reduced reimbursements and then it's very costly to organizations.

What does the evidence tell us that really supports preventing these patients from getting readmitted? Again, are we following the treatment protocols in the hospitals to help prevent readmissions from occurring? Patient comes in with sepsis and part of the protocol is to provide as much IV fluids and hydration on this patient as possible, but at what risk and what detriment?

Some of these patients are getting readmitted because of heart failure complications, they had too much fluid

How do we pick up on those before they get discharged? How do we make sure that we didn't fluid overload them to treat one disease and then end up causing another disease that leads to their readmission? Trying to leverage that data to support best practices and managing these patients to avoid those readmissions.

Mark: Let's bring in our other panelists. What other thoughts, questions, or insights do you all have?

Mike: At 83bar, a lot of our measurement is certainly around pre-visit. So, it's certainly interesting to learn about what to track in the hospital and in the care facilities. We focus a lot on the communication and tracking that communication.

Maybe one of my questions in keeping with patients on the protocols, what kind of advances in communications with the patients have you seen successfully keep them on track?

Michelle: Some of it has to do with the patient's accessibility to certain types of services. Not every organization or every state or city may have the resources to support communication efforts. And I find that having designated roles -- care coordinators, nursing coordinators -- are key to help maintain that communication, making sure that somebody is following up with these patients beyond that acute care or their visit, even in the clinics. Beyond just those moments in time where they're seeing a physician. Those programs tend to be a lot more successful.

Trying to build on some of our technologies that we must facilitate that communication. We're becoming a generation where we're dependent on technology. We like our devices, especially I'm a millennial. How do we meet the patient's needs? I'd go for text messaging, but my grandma may not. How do we make sure that we are establishing communication that meets the needs of the different populations that we're serving?



Kimberly: And we were having a conversation the other day about advocates for patients. I know I've been an advocate for my grandmother and my parents. And Michelle has been an advocate for me when I've been ill or had a surgery. We all need someone to be there to be that other set of eyes and ears and to relay information and to help follow up and understand education. I know that's not so much of an informatics perspective, but that could be accomplished, let's say, with your smart device, with your phone, with FaceTime, with the provider and the elderly patients, being there and being that extra set of ears.

Mark: Dan, when you've been doing strategic planning with the C-suite, how are we going to get every department to follow what is evidence-based, and how they balance that with also what feels good to the patient and what's going to keep everybody happy?

Daniel: To be perfectly frank, I have some real concerns when it comes to "the C-suite". And in this context, as our healthcare institutions get larger and larger and larger and larger, those in the C-suite, the executive leadership, get further and further and further away from the patient or the customer. That is an inherent challenge as well as danger.

You mentioned care coordinators; I have been involved with healthcare institutions that use those coordinators brilliantly. I've seen others where it's basically a call center. I'm thinking of my 96-year-old mother and a call center just is not going to work for her. The other thing that I'm thinking about from a strategic standpoint is where are the connections to the broader communities, because if we're going to bring people into a healthcare institution in a preventive mode, it seems to me that there must be intentional connections and relationships both from the institution as well as the informatics to the other institutions, non-profits, government agencies within the community.

Daniel: One simple example that I thought was brilliant: a small rural hospital that I know, they started noticing the number of falls coming into their emergency department from elderly people. When they got looking at the data, they realized a lot of these people did not have a relationship with a physician or the hospital. They reached out to the one institution that elderly people almost universally value, and that's the fire department and paramedics.

"After knowing the data and realizing that a lot of the elderly didn't have a relationship with their physicians, they set up an intentional relationship so that when the paramedic goes into a home or apartment, they will look for evidence, opportunities for an elderly person to fall and then they create that connection to a healthcare provider or to the hospital. It creates that caring, compassionate connection from the paramedic or the firefighter who we all just love to see. By the way, we start seeing victims of falls dropping and coming into the emergency department."

- Daniel Edds



Focus Topic # 2 How should informatics help accelerate the Journey? Dr. Kimberly Khoury

Mark: Kim, if we could continue and ask you about your experience with informatics. How might informatics help accelerate the patient's journey and speed up this path from looking for answers to a better outcome for the patient?

Kimberly: The major point is that we have the right patient with the right information treatment with the right provider at the right time. Informatics can support most of those touchpoints. Empowering patients to become the promoters or facilitators of their own healthcare journey is a great point. Just like Daniel was just speaking about having a relationship with not only your provider but your organization as well and being able to share that information across organizations.

We have two major healthcare organizations here where we are locally and it's difficult sometimes to share information on behalf of those patients who see providers at both systems. Informatics can support putting the patient in control and helping them lead their own experience and ultimately, their journey. A patient journey consists of many experiences. If we can make most of those positive, that will improve their outcomes and their journey overall.

Mark: And picking up on what you just said about the institutions and the various clinics and providers, I think about that referral pathway. Mike, you were talking about this communication, too. Many patients come in but how do they get from a primary care doctor to a specialist, and then they have to go to a diagnostic clinic then they have to come back? How is that pathway being managed and measured?

Kimberly: That's a great question. We are using a system. With that maintenance becomes referrals for colonoscopies, mammograms, chest X-rays for smokers, those kinds of things. All of those things have to have a referral, so we support that through the maintenance portion with informatics and getting those patients to the right place at the right time before something acute almost happens.

"We are using a system that supports health maintenance. It is reminding providers and clinicians to talk to patients about maintenance and prevention, which keeps them out of the acute care setting."

- Dr. Kimberly Khoury

Mark: In a system like yours, especially as EMRs and things have evolved, are you able to track and measure how many people did ask for a referral to a gastroenterologist? How many people went to three cardiologists before they got the answer they wanted? Whatever the case might be, or this doctor-hopping that we hear a lot about. Are you able to track and measure and sort of document that as an overall thing, not just an individual patient basis?

Kimberly: We do look at multiple factors, especially with referrals and outcomes and what those outcomes were. Or if there is a poor outcome, we can go back and look and see where can we improve in our process. We get them the care that they need.

We have a large oncology center at our institution and they're very good about tracking and following up with patients and creating that continual mode of care that leads the patient down every single path that they need to go for a better outcome.

Mark: And then do the clinics get that feedback? Like, "Look, you're the fourth doctor that they've seen." I don't know if that's helpful to the providers or not.

Kimberly: I have not heard of that information being shared.

Michelle: : Not necessarily in a clinic setting. We see it a lot in our ER settings. The ERs, that's one of the big data points that our ER settings look to to see how often we're seeing patients go through many different ERs. Well, what it shows is that these patients are falling through the cracks.



Michelle: We are not setting them up with their primary care providers like we should. Or we're referring them to primary care, but then nobody tracks, or nobody supports them after they leave the ER. How do we make sure and ensure that those patients are getting set up to be successful outside of the ED?

That is a data point that EDs definitely monitor because as you said, patients are using EDs like primary care rather than going to a primary care facility. From that perspective, it's leveraged heavily. In terms of the clinics using it, I have not personally seen clinics use that sort of information as widely presumably because they're not dealt with an ER cost as EDs are and overflow and making sure that you have enough capacity in your EDs. A little different perspective from the clinic side.

Kimberly: We see a lot of patients at least in the areas I have worked as a clinician. We see a lot of patients that decline a primary care provider, a PCP. They don't understand the need for having preventive healthcare. They only go to a provider or the ED if there is an urgent need. Once again, speaking to that relationship and building trust with your organization and your provider so that you can understand that you do need health maintenance. That's what it's about now, prevention for these patients on their journey.

"We don't want anybody to have cancer or heart disease. Starting with that piece, and that has a lot to do with education, pushing education to patients when they're ready to see it and when they can digest it and helping support that relationship."

Daniel: One of the areas that I get asked about a lot is institutional learning. For Kim and Michelle, I'm curious about your perspective on you have data. How do we take data and intentionally embed it into organizational learning? One of the healthcare organizations that researched for my book, I thought they did a brilliant job of taking the data, improving processes, building those process changes directly back into their operations. But I've seen several healthcare organizations where I asked about improving processes, embedding everyday learning, and it's like, "Oh yeah, we have this library of courses over here that's online," which, to me, just doesn't make that connection

Kimberly: At least at the organizations I have been employed with, we do take every opportunity to learn. We do an audit and we do pull data to see where are we missing, what can we do to improve our patient experience, what can we do to improve outcomes, what evidencebased practice can we implement to improve outcomes and quality and safety. Some organizations are not doing that as well or have challenges with that. The organizational framework is really burdened by all the regulations and compliance and trying to get reimbursed, or if they have a very busy ED or a very busy inpatient setting. It's hard to focus on learning and implementing institutionalized education based on our own experiences if they have those many challenges.

It really goes back to your C-suite, your executives, your operations, and your leadership to say, "We need to look at our outcomes and we need to improve." Regulatory compliance, especially with Joint Commission and CMS, really helps to foster that because we're going to lose reimbursement if we don't improve.

Daniel: Yes. Do you see that as much of a cultural issue that the institution needs to embed that cultural DNA into their operations and their mindsets?

"Having a culture of transparency really supports that learning. I have to say that every time there is an outcome that may be... I don't want to say a poor outcome, but an outcome that wasn't the desired outcome, I do see our institution and our operational leadership looking at why that happened and how can we improve, and how will that never happen again."

- Dr. Kimberly Khoury



Focus Topic # 3 What does 83Bar Data Analysis say about gaps? Mike Zangrilli

Mark: Mike, let's bring in the patient's viewpoint and what you've learned from 83bar's work. In terms of the gaps that your data might show, the dissatisfaction with current treatments, the desire and motivation for something new, maybe even enrolling in a clinical trial.

Mike: At 83bar, we're putting our surveys and educational material in front of patients a lot of times before they're even searching for something. We get a lot of people who raise their hand and say, "Yeah, I've been suffering from this. I didn't know there was a different way. I didn't know there was different care."

We deal with several chronic disease areas such as overactive bladder or GERD. We see a large percentage of people who have been suffering for 5, 10, 15 years. They're very excited about the opportunity to get a second opinion or learn more. They're certainly active healthcare consumers. At some point, their current treatment is not getting them the results that they want, they're looking for something different. They're acting as a consumer would, as we do with anything else.

"We build our campaigns very focused from what is that consumer service standpoint. We try to reduce the friction, be clear and transparent in the communications, and then ultimately connect them."

Mike: Obviously, we're running these campaigns because we think we've got a better solution or at least an alternative that we want to offer them, whether it's a specialist in that area or a new diagnostic kit that might be able to screen for something.

Mike: All the materials we build are around that. We see people, certainly, of varying levels of interest in health still engaged with us. Our plus-factor is a call center versus a care coordinator. And to toot 83bar's horn a little bit, our call center is made up of nurses, so it's our clinical contact center. Having a dialogue with the patient, someone who's empathetic and used to taking care of the patient as a nurse really provides a better level of customer service to that patient who's frustrated, then able to make that empathetic connection and navigate that patient to where they're looking to go.

To throw a couple of stats out there, for example with our bladder control patients, we've had a very long-running bladder control campaign with tens of thousands of people that had completed our survey and 58% of them were either very dissatisfied or dissatisfied with their current bladder control treatment. Before I started 83bar, I would've thought, well, how could so many people be dissatisfied? Go to your doctor and say this isn't working, it's not satisfying, what's happening? But obviously, they're not getting taken care of, so they need to take that more active role.

Mark: If I could drill down on that "navigate" word that you used, this cross between a call center and a nurse care coordinator -- is the nurse able to do some of that navigation? Obviously, as Kim mentioned, compliance and regulatory and things like that that you need to be mindful of, I'm sure.

Mike: Sure. I'll clarify a couple of those things. Even though our clinical contact center nurses are medically trained, we're not actually giving the medical advice over the phone because they haven't really engaged with us as a provider of healthcare. They've given us some information about a survey, we're having an empathetic conversation, which makes it easier for us to ask the right questions but also not overstep our bounds.

Then on the navigation side we say, here's a list of doctors in your area, or here's some information to take to your doctor. One thing, Mark, you asked was how many people want to seek a second opinion. It's a good percentage depending on how frustrated they are. Might be as high as 50 to 60 percent, but sometimes they just want to take the information to their own doctor. They do trust their doctor, but they didn't even know what to ask or didn't even know to ask about something else.



Mike: We'll say, let us give you a PDF or a doctor discussion guide. A lot of times, it speaks to information overload. We have so much information. You could probably Google about your condition and read about it for the next three weeks and you still don't know which way is up. Hopefully, you're not just reading Facebook posts about medical advice, you're getting it from a good source.

"Our nurses are able to distill it down and help somebody focus and then when you do see your doctor and get some feedback from them as they're very happy that our patients come in properly educated rather than coming in with a notebook full of 150 pages they printed out, asking 10 million questions. Doctors are limited with their time. The others here will know. If the patient comes in focus, has fewer questions, it takes some burden off the front office staff, it takes some burden off the doctor, to have a more efficient patient encounter, which hopefully leads to a faster successful outcome for the patient."

Kimberly: It sounds like you're really prepping your patients well for their experience and you're educating them before they go in. I was wondering, having that education you may be providing that education to providers too for a treatment that maybe they didn't know about. Have you heard that from any of your providers or is this known information usually?

Mike: I don't have specific feedback from the providers, but certainly from our clients who are hiring us to develop the campaigns. A lot of times, we discover a ton of information about their patient population that they just didn't know about. They didn't know what the barriers were, or they didn't get the feedback when the patient did go into the office. When we do have, what we call an "activation," if someone's successfully moving forward and wanting to move forward after they talked to our nurses, we'll do a two-week or a 30-day follow-up, "How was your appointment?" Maybe a follow-up survey to gather some more info.

We can take that information back to our client and maybe they learn about the reimbursement issues or insurance issues or more steps that the patient might need to take. Mark: You're describing a situation where... And Kim, this is what you were asking, was the patient come into the office and say, "I've heard about," or "I've been told about," or "I have this discussion guide about," and wouldn't that be better than "I saw a TV commercial and I sure like the drug that one actor was on." It seemed like a little bit more educated patient is a good thing for all around.

Kimberly: Right. Definitely makes for a more efficient and effective visit for the provider because it's such a limited time that they have.

Focus Topic # 4 How do "The Numbers" Inform Health System Leadership? Daniel Edds

Mark: Dan, to come back around to you on this implication for leadership. We've been talking about better outcomes and also a more educated or satisfied patient with their treatment. If they'd gone from dissatisfied to satisfied, that's a good thing. But as leadership is often driven by these rankings, such as U.S. News & World Report? What is my number? Am I the number one in this specialty? How is all this blending together as they want to develop an approach and a strategy?

Daniel: From my observation, it's a big challenge. What I see is that executive leadership could put their attention in 100 different directions and that's just impossible. I'm thinking of a hospital from two perspectives. One, it's consistently ranked as one of the safest hospitals in the country. When I was writing my book, I did a case study on them. They're one of the first hospitals in the world to adopt the Toyota Production System; they teach LEAN all over the world. I'm also their patient, so I see it from both perspectives and it's actually kind of fun.

They start off everything with a core value of respect. Respect for the work, respect for the patient, respect for the worker. That drives a lens of respect for every decision. What I see them doing, in both for my interviews with them as well as just as a patient, is that they create an experience for the patient that's really driven off of respect.



Implications for "Patient Activation" along the Journey

Mark: I'd like to conclude by having you respond to a statement that often goes in these patient surveys on satisfaction and empowerment. I would just be curious based on your experience with both data and informatics and of course, living it in the real world of your jobs, how you would respond or how you think patients might respond to this statement:

"Taking an active role in my own healthcare is the most important factor in determining my treatment plan and quality of life."

Kimberly: I would respond to that and say it depends on the generation that's responding. Millennials, I would say yes. Baby boomers, maybe not so much. At least from my experience and what I see.

Daniel: From my experience, that sense of patient empowerment is absolutely vital, but I also think that becomes more of a challenge as people do age. I'm thinking of my 96-year-old mother. She's quite competent, she's quite capable of managing her own care, but it is a challenge. One of the other factors that makes it challenging is not just age but is the complexity of healthcare, the healthcare system in general.

Kimberly: I'm a little intrigued by the example that you were just telling, Daniel, about having that one person guide you through a particular visit, but if we take that story and apply it to the patient experience outside of the healthcare setting just in general, our patients don't have anything to support them in the real world outside of those hospital walls, outside of that clinic walls, and some patients are seeing three, four, five different specialists all from different organizations.

Kimberly: What can we use in terms of technology? What can we do to help support them in managing the complexity? We're reducing that complexity into much simpler, digestible steps that they can be more empowered to manage their own care.

Mike: And I was going to add to that from the patients we've talked to that this insurance and affordability is a big factor. They might want something, but their insurance doesn't cover this specialist or this procedure or they don't have insurance. This is America; we don't have 100% healthcare insurance coverage, between 10-20 percent don't, and those people respond to our surveys as well and they want healthcare but if it's something that's going to cost them out of pocket or even with a high deductible.

Kimberly: That adds to the complexity too, Mike, though is it's that the transparency and our cost, we're not very open about some of the costs and true story, I know some patients that are insured but they still don't use their insurance because it's actually cheaper to do it out of pocket rather than trying to meet their deductible.

How do we provide those options to our patients again in the real world when they're trying to figure out they have to do a colonoscopy? How do they figure out which one is more affordable but still has the best outcomes because cheaper healthcare doesn't necessarily mean it's good healthcare.

What can learn by Listening through Data

We've been talking about listening to the data and anyone who may have started with us who said, "Oh, it's a meeting about data. I guess I'm going to hear a lot of numbers," what I have enjoyed about this is you've been translating the numbers, you've listened to the numbers and then told us what it all means and how it's applied both for the patient and for the healthcare organization, and that's been very helpful. I really appreciate you all on the panel participating with us."

- Mark Stinson

