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**PATIENT CARE PROGRAM**

National Program Launch, National Press Club, Washington, D.C.

*Panel Discussion*

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**Mary Naylor, moderator:** Wow. What an extraordinary day. I am absolutely thrilled and honored to be joining each of you in this audience and those on the webcast and each of the panel members in welcoming you along with Steve and George to an extraordinary launch of a program that some of us have been waiting for, for a long, long time. I'm thrilled and honored to be joined on the panel by a group that will represent to you the multiple perspectives on patient

engagement, on family caregiver engagement, on systems change that need to be well integrated to realize the bold and courageous vision that we've heard about today. To my immediate left, I'm thrilled to welcome Mike Armstrong, who is Chairman and of Johns Hopkins Medicine Board of Trustees, Jim Guest, President and CEO of Consumer Reports, you've met George, and congratulations Peter and the Armstrong Institute, Nicole James who is a patient advocate, and my bookend on the other, Lew Sandy, Senior Vice President of Clinical Advancement at United Health Group.

Their detailed bios are in the briefing materials that you have. So, we wanted to really maximize on this opportunity to share first some perspectives from each of us on this program and then to open it up to you. Each of you near that yellow rose at the center of your table will find cards so as you're hearing more about the program and the ways that we believe it can be really implemented to accelerate the kind of change and realize the vision that you've heard about, you have the chance to ask us questions. Those on the webcast, welcome. You have a chance to type in questions and they will be gathered by teams and brought up so that we have a rich conversation about this opportunity.

Now, there's no one in this room that doesn't have some experience and you've already heard eloquently from Steve and George about the meaning of patient and family engagement. This is something that I've come to know in my work in the last couple of decades in ways that I hope to share with you my unbelievable excitement about the work that will be unleashed starting today but has already been underway by many of the teams and organizations represented here today. We know that patient-centered care, as the Institute of Medicine has told us, is a hallmark of quality. We know from the Center for Advancing Health that patient and caregiver engagement gives us the greatest opportunity to think about ways that people can be involved in the decisions that matter most to them. That family caregivers, when appropriate can be brought into that decision-making. That they can then take actions that enable them to maximize on the things that give them meaning and purpose. That gives them a sense of health. And, that's not always the way that we define it.

Many, many decades ago, I when a very young child, I launched with a multi-disciplinary team, a program of research that focuses on chronically ill older adults in this country that are arguably vast consumers of healthcare resources, but are not always getting the care that they deserve. And our team began a journey funded by the National Institute of Health to help us to understand how to create better safety nets for people and their families navigating a fragmented care system. We demonstrated early—very early—that we could get to better care, against the current way that we deliver care. We also followed what happened to these people over the long-haul, and found that our interventions did not stick. We could reduce readmissions for 30 days or 60 days or 90 days, but when we really tracked what was happening to people, we realized that these were not outcomes that were being sustained over time. So, what made the difference for us and our team?

Along the journey, we realized that it was because we were imposing on these patients and families what we thought was in their best interest. We were able to get some meaningful change, but not for a long time. It was their stories, *their* telling *us* what it was that was important to them that I think was a turning point for us.

There was a story in the Washington Post about a decade ago of Mr. Clifford Lynn. And he became emblematic to our team and to the many people who have supported our team over the years. Mr. Lynn's story was one of someone living in his home, unable to access the outside world except in an ambulance that took him to the emergency room or hospital. He lived with his loving wife in South Philadelphia, and he absolutely did not think that this was going to be the way that their golden years were spent. We became involved with Mr. Lynn and we found out that what would give him some sense of meaning and value was to get him back in a woodworking shop in his garage that gave him a sense of pleasure, a sense that I'm here to make a contribution and do something that gives me a pride. Mrs. Lynn's goal was to get Mr. Lynn out of the house. And in this way, for the first time patients and family caregiver's goals were aligned.

So that picture, now getting a little old, is what guides us in understanding what the pivotal role, *pivotal* of patients and family caregivers for sustained, long-term change. And that's what we need to get to higher value and to get to better improvements to focus on the things that Mr. Lynn cares about, that Mrs. Lynn cares about—improvements in function and quality of life. And when we do that, we get to affordable care. So that was part of our journey the second part was figuring out how it is we can move from a care delivery system to a system that made Mr. Lynn's experience the rule, and not the exception. And that may I say is a work in progress.

We've built a lot of tools to help systems figure out how to recreate, re-envision a sense of shared roles, shared responsibilities new sense of accountability. Built the kinds of quality monitoring and quality improvement systems that need to change the way that we structure our relationships with patients and families. But it is a path. It is not a completed journey. And so we are tremendously excited that the Gordon and Betty Moore Foundation has embarked on a vision that will help to accelerate all of the work of so many here, and so many throughout the country and the globe to dramatically think about a re-envisioned care system where patients and families are front and center. That path forward begins for us, and I have the great fortune to be a part of the national advisory group for this program begins today, renews itself again today in a

conversation with many extraordinary people who will share what it is that they think this kind of opportunity will bring. So let us begin where we should, with the patient's perspective on this program.

**Nicole James, panelist:** Good afternoon everybody. I'm Nicole James. I have sickle cell anemia, 37 years old. Sickle cell is a hereditary blood disorder. It causes red blood cells which are normally round to be shaped like a sickle, and they carry less oxygen throughout the body. As a sickle cell anemic, I experience episodes that are known as pain crises. And, it's excruciating pain that can range from a single joint or throughout your entire body. In 2008, I had a pain crisis that carried me to the hospital. And, it took me a little bit to be treated but after I was, I responded really well to the pain medications that I received and the IV fluids. I was up, walking around, joking with family like I usually do. And, I thought that I was going to be out of there in a day or so. In the background, my doctor was treating me, read my x-ray, my chest x-ray and diagnosed me with pneumonia. He proceeded to treat me for pneumonia without having any discussion with me.

Unfortunately, I responded negatively to the medication, and I ended up going back into crisis, one that was worse than the one I had originally come in to be treated for. If he chose to actually speak with me, he would have learned that I have scar tissue on my lungs, and what he was looking at wasn't actually pneumonia. So, what could have been a day or so in the hospital ended up being two weeks in the hospital. And it increases my costs for being in there in the first place, it increases the cost of my insurance company, and it takes me away from my life—the things that I like to do and the things that I value. And so it's really scary and you don't like to think about it on a daily basis but the truth is that every time I go to a hospital, there is a chance that I'm not coming out. And, you never want that to happen. So, I'm really, really thrilled to be a part of this today. I'm thrilled to know that there is a program like this, and from patients everywhere I'd like to say a huge thank you. Thank you for hearing us, thank you for caring, and thank you for making a difference.

**Mary Naylor, moderator:** Thank you, Nicole for sharing your story. This is the kind of story that we do need front and center to make sure that we're on a path in alignment with you and wanting to achieve what you want to achieve. Jim, you have the chance to hear the perspective from multiple consumers about the healthcare system and the path forward. So, your thoughts?

**Jim Guest, panelist:** I was going to say, the early remarks were truly inspiring and in some ways, I think you most of all reinforce what this is all about, so thank you. It's terrific what the Foundation is doing and I think the time is right. There's more attention being given to healthcare than ever before, and I like the goal that you [George] and Steve both articulated to eliminate all preventable patient harms. And I like the fact, Steve when you lead off, you said be ambitious, be transformative, and I think there's a real opportunity to do it.

Was it, 1999 the Institute of Medicine came out with its report *To Err is Human*. In Consumer Reports, we did a ten-year update in 2009 entitled *To Err is Human, to Delay is Deadly*, because by our analysis and actually, it's a conservative estimate, a million lives have been lost unnecessarily during that decade. I think what the Foundation is doing here, is saying, finally, that's not acceptable and working with a number of outlets that are engaged in this issue, and doing something about it. From the consumer perspective, it's kind of interesting; you had some

statistics about when people are not told about their medications or aren't consulted on different things, we did a couple of surveys of interest. One is, in a survey we did recently, 57%; nearly 6 out of 10, a random sample of the adult population, said that they believe that errors are likely or somewhat likely in a hospital. 62% said that they fear that a family member will be a victim of a medical error, and so there's not trust in the system. And in fact, there's not the prevention in the system that both of you have talked about. We also, and it's kind of interesting—we did a survey of what drives consumer satisfaction. And I think we're seeing more and more that the healthcare industry needs to pay attention to patient satisfaction. The number one driver is, "my provider explains things to me clearly," and the number two driver is, "my provider listens to me." And the notion of explaining and listening goes to the things you we're talking about. It goes to costs, it goes to preventing medical errors, and other harms and so forth, I think it's really crucial and I think by the way, that having that kind of engagement is going to number one, deliver on the promise that's been made—people have been talking about patient-centered care. It's not a reality. This is to deliver on what's been held there is what people are looking for. Clearly, it will improve outcomes and reduce harm. And I actually make the case that it's good for business as well.

As healthcare is changing and the delivery is changing, providers need to pay attention to what patients are doing and saying, and pay attention to what those numbers that I mentioned have to do with it. So, in terms of the communication and we can talk about it later—there's a tendency for those of us in the medical field to think "I know what patients want." They don't. You said, don't presume, ensure. You don't know what patients want unless you really, truly ask and listen, and listen with an open mind. In some ways it's almost as simple as that. I don't want to overstate it, but the notion of really paying attention and listening without preconceived notions. And also to realize that all patients are different. You can't categorize by demographics, or ethnicity, or anything else like that. Every patient is different and needs to be listened to.

My optimism is that I think with what people are doing here, what the Foundation is doing here, there really is the opportunity—I think you're going to achieve success; we will achieve success eventually on it. And I really applaud the Foundation in seeking the consumer perspective, because all too often, folks in the medical field say "yes of course the patient comes first," then assume what the patient wants, and don't really get the consumer perspective, and that's one thing the Foundation is doing.

I'm going to hold out a vision of what the future could be. This is a letter that a woman in Maine who's been involved as a patient advocate said before she went into the hospital for a significant procedure. She sent this letter to everybody in the hospital that she could anticipate was going to be involved in her care. And here's what she said, "be patient with my questions, because if I ask, I don't know the answers. Listen to my concerns and my husband's. Remember that although he is not medically trained, after 40 years of marriage, he knows a whole lot better than any of you do. Once I'm in my room, please don't ask him, my lifeline, to leave my side. He will take a load off your nursing staff and help keep me safe." And that's the vision I see for the future.

**Mary Naylor, moderator:** Lew—huge, important expectations from Nicole and from Jim representing the consumer perspective, how well are we positioned as a system to take advantage

and make sure that this patient's plea and Nicole's compelling story help inform a very different healthcare system going forward.

**Lewis Sandy, panelist:** Well, thanks Mary. I, like you, have been on the national advisory committee for this program and I am also thrilled and privileged to have been a part of it. I think we all know that the time is now for all the reasons that George said. I've been a primary care physician, practiced for over 20 years; I now work at United Health Group, a diversified healthcare company that is trying to apply technology and advanced care management to care for over 70 million Americans. And we know the problems. I think from my perspective there are two sets of issues. The first is, we know improvement is possible—everybody has a story. My wife needed emergency surgery for a spinal cord compression. I actually found her a very good neurosurgeon, found her a terrific academic health center. Not Hopkins, but almost just as good. I was a little worried about her, given her condition and my father said “Lew, you should feel very good. You found her the best specialist, found her the best institution, she's going in for surgery in the morning, you can now relax and let the system do what it does.” And I said, “Dad, you don't understand how hospitals work.” And we know that it is a target-rich environment for all the reasons that George and Peter said, and yet the improvements are done one at a time, I think you said it perfectly. And then on the other hand, we all know it's important to engage—it's critical to engage patients and families in their perspective, and many of you in this room have been working, have been toiling in this vineyard for decades. And the problem, I think that the Moore Foundation has identified is that this is good, but it is not connected to a supportive healthcare system, that theory of change.

So the things that I'm most excited about this program are really, first the idea of the big tent, the idea that we have to collaborate and work together. Second, this idea of design; the engineering disciplines. Why should you have to be heroic to make it happen, why doesn't it happen automatically? And the third, this idea of innovation. We need this kind of innovation to apply the best minds, the best technology to basically, in a nutshell, have the care delivered to us—to us as patients, to our families—that we would like. The kind that Nicole deserves, the kind of thing that would prevent, in the future, anyone having to go through what she went through. So again, I'm thrilled, excited, I applaud the Foundation and I'm privileged to have been part of the advisory committee.

**Mary Naylor, moderator:** Thanks Lew. Well, Mike, this all says to me—leadership. This is going to be about unbelievable leadership within systems, across systems, to realize this vision. I'm wondering if you can share some perspectives as the head of the board of trustees at a big system, how do we get there? What's the path forward?

**Mike Armstrong, panelist:** Thank you, Mary. May I share first an observation, that I'm not the youngest member of the panel. And that permits me to go back and reflect that many years ago, when I was with the IBM Company, we invested with Intel and I had the opportunity to meet with Gordon Moore. And I know that he would be very proud today of what's being done. And I congratulate the Foundation, and I thank them for their commitment, to not getting rid of most of the infections, or not some curb on the infections, or not some preventable harm someday, but all preventable harm is your objective. And your approach of taking a systems view with a focus on patients and family is extraordinary. And we at Hopkins and at the Institute are 100% aligned with you. There are two reasons for that commitment, that is, if I may, Mary, call it a passion.



First, like Nicole, I had a personal experience with preventable harm that almost cost me my life. Back in the 1990s, when I took on a new career path at Hughes, I got a physical exam phone call from, the doctor of, not Hopkins but an academic medical center where I had my annual physicals like I'm sure many people who are nodding in the audience. And it started with a strange beginning. The doc said, "Mike. I am so sorry. We apologize. We made an awful mistake. A year ago your blood counts precipitously declined and we missed it. Today, they are dangerously low and you must immediately take action." What actions are you talking about, some pills, some shots? No, he said, "you have Leukemia, and I suggest you go to the best on the west coast which is the UCLA Cancer Medical Center and Dr. Bob Gale will see you." Long story short, I had Leukemia, and I was put on a clinical trial. I was the 100<sup>th</sup> person on a 100 person clinical trial. And after the chemotherapy was completed, they took it all out, I went home, went to bed. Blood count is about zero, and I woke up at about 10 o'clock with a 104 degree temperature. So, I called up Dr. Gale, and I said, "I think something's gone haywire, I have a 104 degree temperature." And he said, "you've got to get immediately to the ICU. But we can't come get you." And I said, "What do you mean, you can't come get me?" He says, "Well, the riots!" I said, "What riots? I've been asleep." He said, "The Rodney King riots are tearing up Los Angeles and there's no way we can get an ambulance to you. You've got to get in your car, go through the riots and get to the ICU."

So you talk about a complication to start with! So we maneuvered through the riots, and that's another story and we got there. And if you've never visited or spent any time in a Leukemia ICU, the adult and the children's... there's only one word for it—and that's 'terrifying.' Because you've got a race going on, your blood count is zero, you've obviously got a bad infection. And these antibiotics we hope will work. Seven days later—because it's a short battle—you're either up or down, I was the only patient on both floors to walk out and go home. And it didn't have to happen.

But there's another experience out of the west coast that really got my attention. At Hughes we built a couple of things. One was Tomahawk missiles. The other was satellites. When Mary says "all preventable harm is going to be eliminated" that's perfection. That's zero defects, that's Six Sigma, there's a lot of words for it. But it's perfection. Now, one of the things you don't want a Tomahawk missile to do is be errant. Or have a mistake in it. Second, we provide electronics and radars for the Boeings and the Lockheeds for professional aircraft. You and I step aboard an airplane today. We expect, and they deliver perfection. At Hopkins a few years ago, in the medication area, we looked in the mirror because we had hundreds of medication errors every year. Although we issued millions of medication orders from docs, and we said "let's systematize this." And we flow-charted it. And it turned out, from the time the doc wrote the prescription, until the nurse stuck the needle in; there were 100 manual steps. Each one could cause preventable harm. And they did. And we systematized it, we automated it, we integrated it, we standardized it and today, it is Six Sigma. And so, in teaming up with the Moore Foundation to deliver perfection and eliminate all preventable harm, we are very proud.

**Mary Naylor, moderator:** Wow, these stories are what I think everyone in this audience will leave with. I am really torn between how to start and I want you all to start raising your questions, but both Mike and Nicole—and Nicole, if we could start with you. I was really blown

away in George's introduction in language around dignity and respect and you have reinforced this, this sense of who I am, my uniqueness as a human being. I'm wondering if you could share some of the ways in which those of us on the clinical team could be more responsive to that, could really leave you at the end of each encounter with a sense that you are the most respected person that we are meeting today.

**Nicole James, panelist:** I would say to ask questions. When I got to Hopkins, the first doctor that I did meet with there, we sat down and had a conversation about who I am and what I do, and the history of my medical background before we even got to treatment. And, finding out what my goals are, what's important to me, what I value, and giving me permission to speak, and letting me know that you want to know what I have to say is very important. And all that takes is to ask.

**Mary Naylor, moderator:** Jim, this is going to be changing, I think rather dramatically consumers' expectations. On the one hand, can you give some thought and share with us how you think we can get consumers engaged in changing those expectations? And once we do, how do we spread this so that the millions of people that our system serve are really coming to us with Nicole's sense of "you should be asking me questions. We should be talking to each other about our plan."

**Jim Guest, panelist**

I'm going to answer that, but as you were speaking it occurred to me a conversation I had with Don Berwick a couple of years ago. He told me what he did in the first several months when he set out to start the Institute for Healthcare Improvement. He went and spent several weeks at NASA trying to figure out how they went about, in a systems way, preventing errors. So this notion that the Foundation has on linking patient family engagement with systems, I think makes a lot of sense, and that really is something different than what's happened before.

In terms of how to engage patients, in some ways, let me talk a little on the individual way, and then on the systemic way. In the individual way, it goes back to listening and paying attention, and communicating. And I would urge, especially as some of the early work is being done with hospitals, a couple of things. Especially those who have had medical errors, or medical harm—bring them in, and talk to them and ask them how they think we could change what we're doing so that what happened to you wouldn't happen or could be prevented, or how your experience in the hospital could have been better. Bring people in, especially those who've had a problem. In any industry they talk about that the dissatisfied customer is your best source of information for how to improve.

And then I'm thinking in kind of a systemic way, some of you may be aware that the last couple of years, most recently in August, Consumer Reports put out hospital ratings. I think we had something in the neighborhood of 1,500-2,000 hospitals maybe even more than that. That have had to do with, among other things, patient engagement, hospital acquired infections, and so forth. And what we've learned, several hospitals have come to us, and—you've had some experience also, Peter. We put the ratings out to help consumers make choices but I think the real impact is a hospital doesn't want to be at the low end of those ratings, and a board of directors/trustees of a hospital, doesn't want to have the hospital in that way. And I think this whole notion that, being transparent, not only transparent in the individual conversation, but transparent on how an institution is doing, can have profound impact.

**Mary Naylor, moderator:** So, these changing metrics, changing expectations, to me, Lew this is a cultural transformation on the clinical teams end. Not having ... as the goal, but the goal, preventing harms—all harms—for Nicole is the goal. How do we get a new workforce prepared for this?

**Lewis Sandy, panelist:** Well, I think you're right. I think it's a cultural transformation and yet I'm very optimistic because if you actually talk to nurses and doctors about what it is they want to do—they want to deliver the care that works for the patient, but—Peter made the point in his remarks—but they, themselves are under constraints, pressures, and things from, frankly poorly designed systems. Whether the operational systems in hospitals or even the organization financing system broadly in healthcare. So, all of this is going to require a cultural transformation and what we see today is well-meaning clinicians working in poorly designed systems. What they feel is, they feel like they don't have time to really engage with the patient and the family. But really, they don't have time not to if they really want to achieve these kinds of goals. But we can just exhort them to do it. We really have to engineer the system that makes it easy for them to do it, and makes it easy for the patients and families to engage as well.

**Peter Pronovost, panelist:** Mary, we did a study that shows that a nurse answers a false-positive alarm every 90 seconds. How on earth can they deliver—have any time to do any meaningful care when they're running around answering these alarms, and all these new devices have new alarms, and none of them talk, and ... we really are just setting clinicians up for dissatisfaction, and for patients to not get the care that they deserve.

**Mary Naylor, moderator:** So Peter, we talked a little bit last evening about—you're talking about starting in the ICU with the kind of systems change that enables everyone served in that ICU to walk out with no harm. And, yet we know that system change is going to require all of those patients as they move to the next unit, and as they move from the hospital back into the community. Can you talk a little about, how do we have this multiplier effect in building longitudinal systems that can accomplish?

**Peter Pronovost, panelist:** You're right, Mary. There's no shortage of places to start this work. This could have started with chronic diseases. When we were planning this approach, we got clinicians together to list all the harms patients suffer in the ICU and all the therapies that they'd need to prevent them, where we got our 200 things. At that meeting we had a number of primary care doctors and geriatricians that deal with chronically ill patients as you do. And they said, Peter this is the exact same thing for patients with chronic diseases, they're probably at risk for a dozen or more harms, they probably have to do 200 things a day, no one's ever listed them, we don't automate them, we don't even know if they're capable of doing it. And so, there's a lot of places.

We started in the ICU and in some sense, Mary we're sadistic because that's the hardest. I mean, if we could get respectful and dignified care in an ICU, we hopefully should be able to expand upon that anywhere. And, there's data sources there so it's a technology-rich place that our engineering colleagues could link up and we could learn in a controlled way, how to integrate these devices and spread it, hopefully both to in-patient and out-patient. But the principles that



will guide us about transparency and data and integration and patients as the North Star, I think are the same.

**Mary Naylor, moderator:** I want to get to this notion of; as you describe this...this is a shared responsibility. A unit to unit, shared responsibility among clinical team members and patients, and this whole notion of accountability. So Mike, how do you create, within a system the sense that we're all going to be working together to accomplish this? How do we set the expectations so people understand, if you want to be part of our system, here's what we're holding you up to accomplish?

**Mike Armstrong, panelist:** That's a key word—accountability. And, you have to do, whether you're talking about the nurses, or the interns, or the residents, or the doctors, or the Board of Trustees, a commitment and a passion to solve this problem. And so, by bringing together the facts, or the analytics, or the research, as to what does it mean when we say preventable harm, and how much harm is really going on? Your number was quite alarming—a decade and a million deaths due to preventable harm. Now, where's it sourced? Is it in the ... surgical procedures? Is it blood infections only? Is it in bacterial infections, bad hand-offs, poor communication, bad assumptions? Whether you're at this level or you're at the Board level, if you don't understand the source of the problem, it's pretty hard to get people accountable to solve the problem.

Once you've got that work done, whether it's for the hospital or the system, then you've got to enable the forum to bring all the providers together. Because nothing works by itself, whether it's the ICU or the regular hospital room. Those who've been patients and I bet there's not a hand that won't go up of who's not been a patient in this room. We expect perfection. At our level, when the patient is a person that we expect to walk out and we don't expect to be harmed. And that means, anything that goes into that room, both people and products must be systematized, and so once the people understand the problem, their contribution to the problem, the design on the system, products, interfaces, standards, protocols, productivity, integration, has to take place to deliver the perfection we're talking about.

#### –Q&A–

**Mary Naylor, moderator:** So, there are a number of questions and some of them are on the Hopkins program going forward. So the questions specific to the Hopkins program are, how will patients be directly involved in the implementation? Will they be involved in the steering committee, beyond being recipients of care?

**Peter Pronovost, panelist:** Sure, absolutely. So, the patients will help design this system. So as we're planning this, my engineering colleagues have really schooled me on ... healthcare has never defined the goals it wants. How could you set up a system without explicit, prioritized goals? So in this case, our goals are eliminate preventable harms, because harm will never be respectful, optimize experience and outcomes, and reduce costs, in that order. We have patients on our committee designing what that looks like. So, what does it mean to optimize experience? What do they really want to do?

In addition to designing it, we believe deeply that patients need to be actively involved in the care process. So we use this term “patient engagement,” but if we're ambiguous about the

expected behaviors, it will never happen. So in this case, we've at least articulated initially three very clear behaviors 1) that patients will actively participate in their care to the extent that they want. 2) that we will meet their needs. As Nicole said, we first have to ask them what their needs are, but that we will meet their needs. And 3) that we will ensure that they leave knowing how to self-care and being comfortable in that self-care. As a starting point, that's part of the engagement that the patients that were on our initial planning really wanted to make sure that we do these things. So, it's a journey that we will be holding hands together on, and iterating and correcting us, and no doubt we'll make those courses. But I think that if the patient stays as a North Star, we'll get to the right place.

**Mike Armstrong, panelist:** I'm not supposed to be a part of this, but to add to Peter's comment, Hopkins about 7-8 years ago, we redesigned the medical education curriculum and in about 3 years, we introduced it. If I had to use two words of the curriculum that goes back 99 years in the American education of our docs, today it's called "personalized medicine." That's the underpinning of it. Whether its genealogy, our molecular makeup, heredity, our obesity, our diet, our exercise, our stress—but docs today are not only being trained in the science of caring, but on the patient care.

**Mary Naylor, moderator:** So this builds directly on a question that says, it's not just about docs anymore, it's about clinical teams. How do we prepare nurses, physicians, and other health professionals to work in a context of teams with patients and family caregivers at the center? So, George or others want to talk about your vision on how the training or preparation of teams, inter-professional work is central to you?

**George Bo-Linn, panelist:** I appreciate that question. As Steve McCormick has said, the Foundation has started its work with the Betty Irene Moore Nursing Initiative and the Betty Irene Moore School of Nursing at the University of California, Davis. I'm a physician. I didn't know about nursing. However, a lot of nurses very patiently explained to me what it is to be a nurse. What is the profession. What is the sense of obligation that a nurse has that supports and aligns with a physician, but is different. And so for me, that was an education. A real education, and a real moment of appreciation. And from that, I'm so pleased that we have some of our sister foundations here. The Jonas Foundation, and the Hartford Foundation who are working with us to build a sense of inter-professional team care.

One of the things that Betty Moore told to us, is she said, "I want all of you...I want all of you to work together. I don't want to talk to a nurse, and then talk to another nurse who doesn't know what the other nurse is talking about, who doesn't know where the doctor is." Now, that seems just imminently reasonable.

So, we are working with others to develop a sense of inter-professional team-based care. Both at the level of education as Mike described—graduate and medical education—even before going into medical school. That's one of the things that University of California Davis School of Nursing is developing is inter-professional team-based care. But also in practice, and I'm glad that Joe Selby of the Patient Centered Outcomes Research Institute is here because there's a lot of research that needs to be done and will be done in understanding how do we address research questions around inter-professional team-based care. I think it goes back to what Mike was saying. And what Nicole was saying—Keep clear what it is that we want, we do not want to hurt

patients. Whether it's bodily harm, or loss of dignity and respect. Second, give me feedback that I can understand, and I can take action on. Don't feed me data I don't understand. Help me understand what I need to do, and if need be, help me use the words, help me use the phrases. Help me be a better nurse, pharmacist, x-ray technician, whoever it is. We are so dedicated, those of us in healthcare. We want to do the very best. Help us learn. And I think it begins with that. Both the humility of "I want to learn," and the respect of "I want to help you learn."

**Peter Pronovost, panelist:** Mary, one comment on this, because it's a crucial point. Medicine has grown up with the belief that the only domain of wisdom is how many years you've trained. So the senior doctor has more wisdom than the junior doctor and so on, and we fail to realize that experiential wisdom or "tacit wisdom," time with the disease or the patient is as important, if not more an important domain of knowledge as formal book learning. And those hierarchies are completely inverse. So, on the tacit wisdom, it's the family and the patient, and the nurse, and me as a physician—I'm on the bottom of that hierarchy and I have to be humble enough to say that there's wisdom from others, and put those together and we are likely to arrive at a better decision. And I know in my medical school or our nursing school really encouraging people to appreciate this second epistemology.

The other concrete example is, we started a course called, "The Hospital" and in it, our medical students work as a nurse, within their roles, they work as a physical therapist, no lectures, they work as a dietician, they work as a hospital administrator to roll up their sleeves and say what is it that these people do because I'm going to be working with them as a team, but they have no context for what these other people really do. And, every one of them, its eye-opening to see, "well, I just thought that a nurse is a nurse is a nurse," and well no, there are very different levels of an NP, and a senior nurse, and a new nurse, just like there are with doctors, and they need to appreciate that.

**Mary Naylor, moderator:** Well, music to my ears. This is—there are so many rich questions here, so let me try to frame some that have to do with how you create a culture, of no harm, and yet an environment in which there is a just culture orientation, and I'm wondering, Mike—if that's, you know how do you set these expectations if that's perfection and at the same time realize the human parts of our system?

**Mike Armstrong, panelist:** Well, it gets back to a thing that you put forward and Peter spoke to. That awareness, understanding, and insight will lead to responsibility and accountability. Many people in the system—Peter was talking about all the levels and the grades and the seniority and the juniors—need to understand that they are responsible for the wellbeing, the outcome, and the care of the patient. The patient is a person, and if as a team they take responsibility and accountability, and you have to reinforce that. Normally, culture change either happens because of great leadership that just pounds, pounds, pounds, pounds, pounds, or some event, like what happened to Hopkins that Peter was describing in his talk where we all stepped back and said, "That could never, never happen to us! How could that little girl Josie King die as she died at Hopkins hospital?!"

So today, when we have a million deaths in a decade, an underestimate, I think we're at the point where we need to combine the shock of what we're doing to patients and drive the accountability with analytics, with training, with education, and with responsibility.

**Mary Naylor, moderator:** This is very, very important and related to this. Lew I want to turn to you because someone has written that harm, the harm that we're talking about, is absolutely the result of the delay of the application of evidence. So we heard about what it takes to produce rigorous evidence, and what it takes to get it into systems. And, to get people positioned as Mike has described, with the tools and the resources requires rapid movement. So how are we going to get to a fifteen-year implementation?

**Lewis Sandy, panelist:** Well, the two things that come to my mind in this discussion, speaks to something that Mike grazed earlier around the issue of inertia, and the issue of incentives. I think one of the cultural features of health systems, from my experience and efforts over several decades and through other work in my career at another health foundation to try and stimulate improvement is just the tremendous inertia that exists within healthcare systems. Mary, your example—you showed it could be done, but you know, it hasn't happened and it's because we have so many inertial forces to overcome. One part of the solution, in addition to getting focused and having a movement really emerge out of programs like this is also the issue of incentives and aligned incentives. There's really, one reason that we have this problem in this country, is that there is no incentive not to have it, frankly. And that gets to Mike's comments about accountability, measurement, if there was a dashboard that let the Johns Hopkins system know where it was green, where it was yellow, and where it was red, you could bet they would take action. But there is no such dashboard. So that's what I think Peter and this program are intending to catalyze and stimulate. Starting in, on the one hand, the most technological rich from a scientific and clinical point of view, but among the most bewildering and hazardous from a system point of view, the Intensive Care Unit.

**George Bo-Linn, panelist:** I wanted to highlight, as Steve McCormick had described, the Gordon and Betty Moore Foundation, we are all about transformation and having collective impact. And the way that we intend to have collective impact, in all of our programs, but especially in the Patient Care Program, is to design systems, just as you said Mike. If you don't have a system, it's hard to know in fact, that innovation *will* spread. Many of you may have read recently, Atul Gawande's article in the *New Yorker* where he talked about The Cheesecake Factory, as applied to medicine. Now, we may not all agree with that. But, one thing he did say—it takes way too long to get a great idea into widespread adoption. And, one of the things that the Foundation is interested in and will support is, how to achieve large-scale adoption at scale. And we think that a systems approach is the way to do it. It's as though we want to communicate from this part of the room to that part of the room, and we hand Michael McGinnis a cup with a little string, going over here, that's how quickly communications spread. When an IM crosses the globe, thanks to AT&T at that rate, that's what we need—a system. A coherent, optimally designed system, so that receptivity of innovation is a reality, as it is everywhere else.

Remember the co-founder of the Gordon and Betty Moore Foundation, Gordon Moore—innovation, rapidly, at scale.

**Jim Guest, panelist:** This whole notion, it's been referenced as sort of the culture change, and part of what's been kind of happening is the culture from within as you've been describing, but I sort of talk about four myths that the public has, that it's going to take quite a lot of time to overturn.

One is that more is better. Another is that tests, that diagnostic tests have no downside. Another is that the more something costs, the better it is. And the final one is that docs and providers are making judgments based on evidence. And those are sort of four major myths. And, it's not going to be easy to overturn those. But, as part of the change to the healthcare system as we move, whether it's toward Accountable Care Organizations or whatever it may be, is that those myths need to be dispelled. Now, they may happen sort of one at a time. I'm struck that it was a specific incident, a specific story, that drove in a significant way what happened at Hopkins. Or, a story... think of a number of changes that have happened in public attitudes or institutional behaviors. And so this whole notion of building on stories and getting stories out there is going to be key.

And, I'll give you my favorite. It has to do with medical devices, those of you that are familiar with the federal law on medical devices. One of the provisions, we tried to get it changed this year but didn't, is that if a new medical device is similar to a medical device that had been approved previously by the FDA, it automatically gets approved even if the previous device had subsequently been found to be unsafe and harmful. I mean, something is wrong. Stories like that need to get out and the public needs to understand that it's not just fine the way things are.

**Mary Naylor, moderator:** Well, stories like that I think will be increasingly getting out as a result of this program. Nicole, someone from the webcast wanted you particularly to reflect on this question. Which is, what is your vision for including a patient and the family as a true member of the healthcare team?

**Nicole James, panelist:** Well, I can honestly say that I'm starting to see what that looks like a little bit. I have a doctor—I have a primary care physician now, and my primary care physician knows every single other doctor that treats me. And they know my family, which is also very important so when I am in the hospital or I am in a pain crisis and unable to communicate, they can still keep that communication with my family because they know what my body needs, and they know also because they've been right alongside me the whole time. So, having that whole network of collaborative care is incredibly important. And, it makes me as a patient feel really safe.

**Mary Naylor, moderator:** Can I pursue one question that is also related to this—and this is for anyone on the panel—but this issue of accountability, so someone has raised this question. Regarding accountability, what does the clinician do if they feel that the patient and family is not prepared to be a real partner in decisions? Who is accountable?

**George Bo-Linn, panelist:** Well, I think that's a great question. One of the principles of medicine and all the healthcare professions but certainly we hold it dear as physicians is above all, do no harm. So if we were to say, all patients have to come in and they have to do these things whether they like it or not. They have to do these things whether we explain it in a way that's understandable to their cultural or socio-economic status. And we create anxieties and guilt—that is creating harm. So, I would say first the accountability resides in understanding who each of us is. It means to understand the family dynamics, as you've described. It means to understand our role in the team-based, inter-professional care that we've described. It means that we understand the components of how we roll across those of us at the front line of providing



care and those of us at the Board of Trustees. I think its understanding that and having as Nicole said, a conversation that may be a courageous conversation, particularly at the end of life—who is your mom? Tell us about your grandma. What would she have wanted? What kind of care would she have preferred? And so the accountability is across everyone. But I think it always begins as Nicole said—ask, ask, and always bear in mind that our desire to do good but, always remember do not harm. The respect to the person who it is to begin as you said Nicole, ask.

**Lewis Sandy, panelist:** Can I add onto what George said because I think he's right. And I think, everyone has a role to play, all the stakeholders. We're very active, United Health Group, in promoting consumer activation, and the word I wanted to highlight is engagement. If you just think about Nicole's story, what was really the gap? The gap was that there was no engagement, basically. There was kind of an assumption that if only people would have engaged with you, none of that would have happened. And there has to be...people basically get nervous when, "am I picking...am I being asked to do something that is beyond what I can really deliver?" It's not beyond anybody's capability to simply engage. Talk to people. And so that's what I think is really the place to start.

**Nicole James, panelist:** Can I add as well? I'm sorry—I think there's a reality that's there that all life comes to an end at some point. I've lost my mom to breast cancer, and my mom fought it out. But when you're in those final stages, if you've had this type of program in place, it's easier to swallow. It makes it more comforting. The road is what's important. It's not necessarily the outcome. When the road is making sure that everybody is being taken care of and the quality care is there, then some are able to thrive. But the truth is that there are some that won't. And that's a reality that also needs to be accepted.

**Mary Naylor, moderator:** Well this very much connects with one of the other questions that has to do with, starting this program in the ICU, a high-tech environment, but people's needs changing to not require in fact, often those high-tech interventions can be harmful. How do we—in this case—what's the greatest opportunities for technology, including the use of low-tech methods to best support patients and do we see a place for this in the evolution of this program?

**Peter Pronovost, panelist:** Yes, I'll take a stab at that and I'll give you a couple of examples. You, the taxpayers invested somewhere around \$2 billion studying this disease called Acute Lung Injury. About 200,000 people get it a year, it has around a 40-45% mortality. And, Michael Gropper knows this well. And after two decades and \$2 billion in research, the main finding that lowers mortality is if we give small breaths on the breathing machine. That's the main thing we learned from that. And we do that somewhere between 20-40% of the time. Now you could say, doc/nurse, work harder. But what we also know is that the ventilator doesn't know whether or not you have this disease because it doesn't communicate with the electronic health record that has that diagnosis. Again, in any other industry, they would talk and it would say, "you have this disease, set the ventilator to give you what the evidence says." We rely on heroism.

Another example is we know people suffer harm from lack of mobility and delirium. And we've now, very low-tech started engaging patients and families to help them walk, while they still have a breathing machine in. We've seen lower costs, lower length of stay, much better long-term outcomes by something as easy as getting them up and walking and engaging their families in helping them become ambulatory. So, I think there's just a wealth of things we can do. But it

all hinges on, as we've said, this culture that harm is inevitable, and we're going to work towards that goal.

**Jim Guest, panelist:** As I'm listening to these questions, both on an individual level and an institutional level, in favor of trust and transparency and respect, it's going to be somewhat of a foreign concept of humility, and I'm thinking of humility in two ways. Humility in that conversation where you're saying, what if the patient really doesn't want to engage or the family doesn't know how to engage, humility on the part of the person who's communicating with them can ease that conversation tremendously.

But you know, there's the other humility which I'm going to say is institutional. And as you develop ways and systems that can be replicated, and that's one of the goals here—make sure that something can be rolled out – there's going to be a real tendency for institutions other than UCSF and John's Hopkins, to say wait a minute, we didn't invent this; we've got to come up with our own. And some way to make it more palatable and more acceptable, so that if somebody else comes up with something good, for God sake, do it. Don't say, not invented here.

**Peter Pronovost, panelist:** If I could just add to that, because it's a key point. When we did our Michigan study, The Checklist, people asked me all the time, could their ICU use the Michigan Checklist. And, I'd chuckle and say there are 103 ICUs, there are 103 checklists. They are 98% the same, but that 2% difference is what made it work for them and every one of them believes their's is the best, and it absolutely is, for their context! Right, and so what we have to find this tension between standardizing it in one way, but then engaging others to make it flexible. I have no doubt that what Michael will do at UCSF will be better than what we did at Hopkins and it will change, and it needs to change. The principles and the boundaries will still be guiding us.

**George Bo-Linn, panelist:** That's why we're so excited to work with the Institute of Medicine and the National Academy of Engineering because they will bring together all of these great places, not only University of California San Francisco and Hopkins, but University of Pittsburgh, Vanderbilt, University of Michigan, Kaiser, Ascension, all of us that are working on this to come together and do exactly what Nicole says—don't hurt me, give me respect, understand the dignity that I deserve.

**Mary Naylor, moderator:** So, I'm just going to, before turning it back to Steve, read something that someone proposed. And this is, Moore's Law—that the number of patients in the US receiving perfect care every year doubles every quarter, the person also notes, I haven't done the math yet, but you get the idea.

Thank you! Thank this panel!