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Well, thank you everybody. It's a pleasure to get to speak a bit to the President's Cancer Panel and other participants. I wish I could be there in person. I greatly respect the work that's going on in this group and care deeply about it, so perhaps some other opportunity will arise to be there with you in person.

Like most people, I have direct connections to the problem of cancer and cancer care. When I was 15 years old, my mother died of cancer and I remember it well, the heroic efforts of people who tried to help her and the drama and tragedy of her loss. One of my closest friends more recently, just in the past five years, developed multiple myeloma, and the story is quite different there. He received, I think, the world's best possible care for his myeloma. He is now going on three years disease-free, and we have great hopes that he actually has been cured—a modern medical miracle.

In my field, which is quality of care, I have 35 or 40 years of experience trying to help make care better. Cancer care has always been central. Most of you know the turning point in the work of the Institute of Medicine—in 1999 the report *To Err Is Human* and in 2001 the report *Crossing the Quality Chasm*, which are well cited in the President's Cancer Panel work. These turned the attention of American healthcare, and eventually worldwide healthcare, to working on better care as the best route to both excellence and outcomes and sustainability and cost.

What most people may not know is that the Institute of Medicine work was preceded in the later part of the 1990s by the work of the President's Advisory Council on Consumer Protection and Quality in the Healthcare Industry, a panel on which I served, but also the National Cancer Policy Board report—I think it was in 1997. These two bellwether reports, one on healthcare in general and one on cancer care, alerted the Institute of Medicine and others to relatively high rates of defect in care that previously had not been so clearly elucidated. So cancer care was on the screen early in the days of the modern momentum toward better care.

In my field, in quality improvement, it was the Institute of Medicine reports that turned the corner, with *To Err Is Human* showing us how much error there is in care and *Crossing the Quality Chasm* broadening the attention to a whole list of qualities, six in particular: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity—the six so-called aims for improvement that the Institute of Medicine, the committee on which I served, articulated in *Crossing the Quality Chasm*. Those reports documented very high rates of defect in American healthcare, far beyond what the public and most professionals knew were there. It's highly evidence based. There's very little doubt about the margins for improvement.

And they began to link these defects to another urgent American healthcare problem, and that's cost. The costs of care in our country have become a great burden on the economy and on the well-being of individuals, with the highest cost by far in the world. And the evidence is that those costs are not necessary to produce value—that through improvement of care, not through rationing or withholding care but through the improvement of care, we have the best possible tools for reduction of costs to a level which the society can maintain and which will allow resources, public and private resources, to be devoted to other efforts.

My own organization, the Institute for Healthcare Improvement, articulated in the mid-2000s the triple aim—broadening the Institute of Medicine's six aims to three large aims. One is better care—that includes the six aims: safe, effective, patient-centered, timely, efficient, equitable care; better health, moving upstream to prevention; and lower cost per capita achieved through improvement. And the triple aim now has been embraced really globally as a vector of goals that any modern healthcare system can and should embrace.

The problem has been the delivery system we have. Although it supports in many ways the efforts of a heroic healthcare workforce, one we can really be proud of, and has not been bad at its approach to high-tech care, the technical care that people want and need when they're very sick, the triple aim has not been within reach, nor have been the six aims of the Institute of Medicine. And this was articulated quite famously

in the roundtable that preceded the Institute of Medicine's work in the late 1990s, a roundtable that included Dr. David Lawrence, who at that time was head of Kaiser Permanente. David famously said the words, "The chasse is broken." That phrase, "The chasse is broken," appears in the Institute of Medicine reports, and it refers to the problem of design—that the way we've built healthcare and healthcare delivery for a century is not today up to the task of achieving the Institute of Medicine aims or the triple aim. It can't do it. It's like asking a tank to fly.

And, so, those of us interested in improvement of care have inevitably become extremely interested in the redesign of care. We have to have a different care system. That's not just a wonky statement; that's right at the sharp end. That has to do with the day-to-day experiences of those who get care—patients, families, and communities—and those who give care—doctors, nurses, other health professionals, pharmacists, and managers. We need a different care system.

Now, this has been worked on in the United States for decades now, with some progress. But in any effort of social change like that, I think there tend to be leading arms, leading streams of work. These tend to be areas that are particularly symptomatic, particularly important to people, and particularly amenable to change because of structures of leadership and public awareness and science, and they've become the prototypes, the ways in which we work on redesign, and evidence that across the field we can achieve redesigns. I personally think that cancer care is exactly that kind of lead area.

My wife is in the environmental community. She's a specialist on energy, and she has talked to me about charismatic species. These are animals, which if threatened in the environment, raise public awareness and are a way to get attention. If a type of animal people love—whales or gorillas or grizzly bears—is threatened, it gets a lot more attention than if something nobody ever heard of is threatened. Well, in a way, I think cancer is a charismatic species. It's the area of healthcare reform, which if we were to achieve it successfully, could really show people in a way they understand how good care could get and how the triple aim could be achieved.

Cancer care is charismatic because of the personal experiences that almost everybody has with cancer in dramatic ways in their lives, like in my life with my mother. It's a charismatic area because it stresses the system; it requires the ultimate in team-based care, in patient-centeredness, in proper use of modern technologies, with proper attention to the hazards and risks that those involve. It's because of that—it's charismatic because it's vulnerable; it's vulnerable to rupture. Any frailty in a system is going to be reflected in the way that system deals with cancer care. Cancer care is not alone in these properties, but it certainly is high on the list of the kinds of care that if we got right would teach us the redesigns that could help all people with all conditions. So, there couldn't be a more important topic than the work that the President's Cancer Panel is about to attack.

So, what do I mean by redesign? In any production system, whether they are explicit or not, there are fundamental underlying principles about how the production occurs, how the work occurs. These principles of design infuse the decisions that everyone makes—workers, people who allocate resources, leaders, consumers. They are underlying principles. You can see such a principle, for example, as a change in the world of banking. In most of my life, from youth until most of my adulthood, the way you dealt with a bank was you went to the teller. I haven't seen a bank teller in three years. I go to an ATM. And that simple shift from a system that uses a person to distribute a service to a system that successfully pushes service out to the hands of the consumer is what I mean by a design principle.

Now, in healthcare, when the *Crossing the Quality Chasm* report came out, it included ten principles of design. They're right there in the report, and I hope the Council takes a close look at them again. They articulate what kind of system, what basic rules of process, will achieve the six aims for improvement: safe, effective, patient-centered, timely, efficient, equitable care. I think they stand still on solid ground. I helped write them. They emerged in 2001. What those principles lack in redesign are exactly the kinds of ideas that the President's Cancer Panel now is addressing through the four priority dimensions in its work on connectivity. We didn't have the connectivity then. We couldn't think about the use of technology and

communication. And I don't think we actually had the depth of understanding that we've arrived at in the 14 years since then about what patient-centeredness or person-centeredness means. That whole wonderful branch of improvement has blossomed through courageous leadership, vocal consumers, and an alert and interested workforce. And we understand what person-centeredness looks like. Nor did we have a national strategy for sharing information; that wasn't there. We had a cottage industry information system largely—not that it didn't have gems. In my work as a pediatrician for 20 years, I always practiced with an electronic medical record. I never saw a patient without the record, and I had the benefits of instant access that few others did. But a national plan for information was not around, and now we are migrating toward it. In the arena of technological development, we have had enormous breakthroughs.

The question is: What are the underlying design principles that are going to allow us to change cancer care and, as a charismatic species of care, cancer care as a whole? The Institute for Healthcare Improvement, the organization that I'm now back at as a Senior Fellow and that I led for 19 years, has formed something called the IHI Leadership Alliance. It's a group of about 40 organizations that are trying to do what we're talking about—to break through to new levels of performance across the board, not just in cancer care. And they've articulated 11 principles for redesign, which I'd be happy to share with the Panel. I think they represent a try; they represent a draft of the underlying principles. They include ideas like: change the balance of power. Just like with ATM machines now, we have a chance in healthcare to move decision-making control right into the hands of the people that are being helped. The best possible answers lie in the hands of the people that get the help. How can we equip them better to actually control the shape and the flow and the emphases in the care that they receive?

There is a strong emphasis in these design principles on cooperation. Instead of superspecialization and individual excellence, as important as that is, being the mainstay of superb care, we now know that it is all about teamwork. It has to be about cooperation and working together. We are in an interdependent system. That's a design principle—that cooperation trumps individual heroism.

There is a strong focus on working better with the community so that, now, we broaden the idea of what healthcare is right out to the resources in the community that we've not connected to in the traditional care system.

The two redesign principles that seem to be in contradiction with each other, but aren't, are, first, to standardize what is wise to standardize. The enormous variation in care—it doesn't make any sense at all. It has to do only with rather random effects of history and training and experience. They need to give way to standardization when standardization really matters, and you in cancer care know that better than anyone. Following protocols for proper chemotherapy, for example, has been a mainstay of progress in cancer care.

But the other principle related to that is to customize care to the individual, because we're now at a place in the technologies of healthcare where, actually, every single patient can be the only patient. Standardize what makes sense, but listen so carefully to every individual and maintain the capacity to respond to individuals' needs and capabilities so that care becomes a unique experience for every individual because of all the technologies and knowledge that we can bring to bear.

Perhaps the most relevant redesign principle is stated as, "Move knowledge, not people." There is now a worldwide collection of efforts that are showing how much we can leverage knowledge through the modern structures of the web and the Internet and other kinds of electronic connectivity so that, literally, the best knowledge in the world can reach everyone in the world at low cost and with no delay. That's a big vision, but I think it's achievable, and we're beginning to see it.

I'm a great admirer of Dr. Sanjeev Arora. Dr. Arora is a hepatologist at the University of New Mexico who reasoned that as an expert on hepatitis C management, he might in his career be able to take care of, say, 2 percent of the people with hepatitis C in New Mexico. But that wasn't enough for Dr. Arora. He wanted to be able to get the best possible care to everyone, and his project, called the Echo Project, has now achieved what he envisioned, which is access by literally everyone in that state to the best possible hepatitis C

care through electronic connectivity in which people don't move. They don't come to Albuquerque for their care; they get treated right on site by nurse practitioners and rural physicians who are supported by Dr. Arora's Echo Project to give the best possible care in situ, in the local environment. And his publications now show results the same or better than if those patients received care by moving to the medical center. Move knowledge, not people.

The themes of the President's Cancer Panel now focused on connectivity all revolve around this concept of redesign, as I read it. This is about the fundamental reforming of healthcare, with cancer care in the lead. Connectivity, the modern use of systems of connection, aids in all of the redesign principles that I've articulated, and more. Go back to the IHI website, <u>ihi.org</u>; look at the Leadership Alliance redesign principles, and you'll see echoes of the power of connectivity from beginning to end: personal health information and data sharing; the concept of giving people power over their own care; and the ability to actually exercise autonomy to modify the care to meet their individual needs, customized to the individual. The currency of that is information.

And the concept that we could actually begin to democratize access to personal health information, with appropriate attention to confidentiality, and share data for rapid learning, is fundamental to the vision of a shift in the balance of power and the better customization of care to the needs of every single individual. It's also, by the way, a front door to wise standardization. If we know what each other is doing, then we can much more effectively ask questions about why the variation is there and whether we want to agree to converge on proper, well-evidence-based standards for care.

Obviously, person- and family-centered care is equally connected to redesign. It is redesign. It's the concept that, as my colleague who now runs the Institute for Healthcare Improvement, Maureen Bisognano, says "We need to stop asking so much, 'What's the matter with you? The question needs to become, 'What matters to you?'" And person- and family-centered care is care that is shaped around the needs and resources of the individual. These include, by the way, community-based resources that individuals have access to. And the actual reorientation of care to meet individual needs is central to redesign. It's person-centered care.

Devices, sensors, apps—these are less familiar to me. I'm not a techie, but I can tell you that I've seen in my scanning around the world for better ways to give care remotely, to move knowledge and not people, for example, tremendous successes like Dr. Arora's success with Echo. I've stumbled on an English ophthalmology project called PEEK. Now, this is not in cancer care; this is ophthalmologic care, which is using cell-phone-based technologies to do retinal imaging and visual screening of children all over the world, thousands and thousands of miles from London with image quality and accuracy of screening that rivals what would happen if the same patients in Kenya or Pakistan would have gotten physically to London. And the sky is the limit.

And we all experience, of course, in other domains in our lives the friendliness of modern application developments to make our lives easier. The same will apply in healthcare. This, of course, is going to involve a tremendous cultural change. As one of you quoted David Blumenthal, the adoption of electronic records and a modern information system is not a technical change; it's a cultural change. It's a sociologic change, because think of all the implications that happen as we develop truly person- and family-centered care. We understand that information should be democratized and that we really rely on the most modern forms of apps and devices that move capability out into the workforce. This is going to challenge our concepts of what role definitions are in healthcare, of the proper roles and capabilities of patients and families, of the crucial importance of teams, which will frankly trump autonomy; they'll trump professional autonomy sometimes. And we need to be sensitive to these cultural changes, but the sky is the limit.

And the national information infrastructure is there if we want to use it. We are a few fries short of a Happy Meal, as my kids used to say. In this case, the information infrastructure is not what it needs to be. The electronic record has become, in some ways, a burden as well as an asset because of ways we've approached it and implemented it. As appropriate perhap only to the adolescent phase, it's been more widely adopted, but it lacks forms of interconnectivity that it needs. It's being used, unfortunately, too much to shore up the status

quo instead of to change it. But that's just the beginning. The national health information infrastructure, to me, is ready to surge into adulthood, and with proper support, and maybe with the example in cancer care, we can get to a whole new level of interconnectivity.

But changes will be in store. I've mentioned the cultural changes that are going to be needed to democratize information and to give power to families and patients, and to rely on connectivity is going to threaten role boundaries, guild behaviors, and probably issues of licensure and accreditation. We're seeing that play out in the telemedicine sphere in which some environments for support of telehealth and telemedicine have not matured because of resistance from guilds and belief structures and economic interests that really become threatened by the idea that everyone can get access to the best knowledge instantly. But that's transitional, and we need to go there, and I hope cancer care leads the way.

A few pieces of advice: let's not replicate the status quo delivery system in digital form. That's not the point here. It's not to make the current system digital. It's to achieve the future system through better use of information technologies and modern technologies.

So, underlying the connectivity that's considered by the President's Cancer Panel lies, fundamentally, an image of better care, of a new care system, and a new way that people get help, even with something as serious and dire as cancer care. So, the new system should represent the new care, not the old care.

And one other piece of advice: at this stage in the evolution of American healthcare, it simply isn't responsible, in my view, to pursue just two arms of the triple aim. It's better care, yes: safe, effective, patient-centered, timely, efficient, equitable care. Better health—yes, much more focused on prevention, moving upstream, and, boy, there is no field more important than cancer care for that.

But it also has to be cost reduction—lower cost per capita. It just has to be on the screen. The reasons are perhaps too many to discuss in this short time I have with you, but I'll just tell you this. At the moment, at the level of cost in American healthcare, we're essentially confiscating resources from non-healthcare enterprises. Our schools suffer. Our roads suffer. Our housing suffers. Workers suffer. Our corrections system suffers. Investments in social justice and equality suffer. If healthcare continues to take a larger and larger share of the public and private economy, government budgets and private budgets—that just can't go on. If we needed it to go on in order to get proper cancer care or proper healthcare, I guess I could defend it, but we don't.

We know the levels of waste in healthcare. Good studies show that a third or more of the total expenditure of our \$3 billion in healthcare isn't buying value for anyone. It's coming out of the same defects in design of the care system that the Institute of Medicine addressed and that the triple aim is calling out. And so it is entirely responsible, entirely plausible, and entirely necessary for cost reduction to be on the screen for the goals of the new care system we need.

And I think that burden falls just as heavily on the shoulders of cancer care as it does on any other component of our system. We need better care, better health, and lower cost all at the same time. The keys are there. It's providing power and support to patients and families. It's using all of the resources the communities can bring to bear to achieve and grow their own health. It's the fundamental investment in transparency and the democratization of information. It's the modernization of the use of technologies not to support the status quo but to change it. And it's an investment in the kind of connectivity and teamwork that the President's Cancer Panel is here discussing.

So, again, thank you for the chance to join you. I'm thrilled by the work I've been reading about. I look forward to tracking this work much more closely in the future. And, as I say, I hope the time will come when I can join this important work, one way or another, in person.

Thanks a lot.