National Cancer Institute

caBIG® cancer Biomedical Informatics Grid®

# Leveraging the Power of Information to Help Conquer Cancer

## A Conversation with Aneesh Chopra, U.S. Chief Technology Officer

## caBIG® *Podcast Network*

### Moderator

Welcome to the caBIG® podcast network. In this podcast, we will discuss how the White House is working with the cancer community to bring the power of information to the challenge of conquering cancer in our time. Joining us today is Mr. Aneesh Chopra, the first ever U.S. Chief Technology Officer who was appointed by President Obama last year. Welcome, Mr. Chopra, and thank you for being with us.

### Aneesh Chopra

Well, thank you for having me.

### Moderator

Mr. Chopra, can you describe your role as the nation's Chief Technology Officer, and why it's important to have such a position today?

### Aneesh Chopra

Our role essentially is to help the President harness the power and potential of technology, data, and innovation—both to transform the nation's economy and to improve the lives of everyday Americans. We think this is an important position to have, because we find that in almost any aspect of our lives the technology around us is affecting nearly everything we do.

On a personal level, we're communicating via e-mail, we're tweeting, we're blogging, we're communicating using these new technologies in ways that we couldn't have imagined even three, four years ago.

In our professional lives, more and more of our private companies have taken advantage of these technologies to do the work that we see happening throughout our private sector, but for whatever reason our public sector has failed to properly embrace these capabilities and to incorporate them into the everyday practice of government. That's the problem the President was trying to solve, and it's an honor and privilege to serve as his advisor in this domain.

### Moderator

So Mr. Chopra, how does your role as CTO—with this harnessing—connect to the healthcare challenges we face as a nation, and specifically, why are you focused on cancer and information?

### Aneesh Chopra

I am focused on healthcare as part of our overall administration's commitment to spur innovation around this very important national priority. Historically, we've looked at cancer as an area for research and development investment, and—in addition to the stimulus package that put in some 10 billion dollars towards that endeavor in research and development in the National Institutes of Health, more broadly—we found an additional billion dollars even in this difficult budgetary environment for our proposed fiscal 2011 effort on top of the work we were doing within the NIH; a good portion of which we see going directly into the cancer efforts.

This conversation today, however, takes us down a second path, that is, how might we bring technology, data and innovation to help us improve our ability to manage cancer and to increase our understanding of cancer and therefore improve the quality of our medical interventions.

**Moderator**
So, what does information technology actually have to do with cancer? What is it you are trying to have happen in this arena?

**Aneesh Chopra**
Well, if you think about other industries first before we get into cancer, over the last decade we have seen dramatic investments in data to help firms—mostly in the private sector—better understand their customer base, their needs, so that they could sell them more products and services.

You cannot walk out of a store today and not have the corporation understand exactly what you've purchased, what motivated you to do that purchase, and how and in what manner could they spur more advertising and other tools to convince you to buy even more. That's part of the vibrancy and the dynamism that we face in our private sector.

Translate that into healthcare for a moment—we are having a similar challenge, but we lack the foundational elements of data. Today, you might go see a doctor and that doctor will record your experiences in his own or her own format, usually a paper chart. That information is not captured in some larger setting to help understand or analyze what it is that you're doing that works, and what it is that we're doing that doesn't work. We've not built the same data ecosystem that we've seen in other domains throughout the private sector, and it is to close that data and technology gap that we see some tremendous opportunities when thinking about healthcare in general and the cancer challenge more acutely.

**Moderator**
So, can you describe a little bit more about what a data ecosystem would look like in cancer?

**Aneesh Chopra**
Well, the great news is we already have a number of the foundational elements of this deployed. Dr. Ken Buetow has been spearheading the work around caBIG®, which essentially is a set of tools, policies, and programs to spur this data revolution to ensure clinicians, researchers, patients, and others can communicate with one another in ways to unlock the value of this data.

So, we have some of these building blocks and these foundational elements. Now we need to reach out into the communities and engage individual doctors, individual patients, those in the advocacy community so we can take full advantage of the raw material that's been laid before us by what's been probably a decade's worth of work.

**Moderator**
So, it sounds as if the White House is trying to mobilize the entire nation against cancer, is that feasible? How would that unfold?

**Aneesh Chopra**
Well, in a sense, that's the spirit by which this President took office. He has been calling for an all-hands-on-deck approach in almost every major domain. We acknowledge, especially in today's fiscally challenged environment, that in order for us to tackle the big issues of the day we're going to have to rely more heavily on everyone coming to the table.

And what that means in information technology as it relates to cancer is that we've got to find a way for the entrepreneur, for the corporation who's been involved in cancer care for many years, for the hospital system or the physician practice, or the patient to ask themselves what it is that we can do to share information in a secure way with respect to patient privacy, but to do so in a manner that will unlock this value.

And so, there are these conversations that are taking place but they all speak to the same question: If we took an all-hands-on-deck approach, how much more could we learn sooner around the real challenges and opportunities to improve upon those struggling with cancer today.

### Moderator
Mr. Chopra, how does the national commitment to adoption of Electronic Health Records that's now underway tie to this effort you're now describing?

### Aneesh Chopra
Well, you need to have a foundational capability of digitizing that which sits in the paper chart, the clipboard, when you and I visit our physician. That clipboard contains valuable data that needs to be digitized, and preferably in a manner that can allow for analysis and for improvements in care quality.

The work the President has asked us to direct—to build out a national movement towards the adoption of health information technology capable of achieving a variety of policy objectives—is absolutely critical for us to be able to execute on this plan for unlocking the value of data in cancer care.

So if I may, just to give you an example, one of the criteria by which we wish to dispense the funds out to physician practices is that they should be able to provide a patient an electronic copy of their medical record and their encounter summary within 48 hours of seeing the provider.

If you think about that in the cancer context, the work that we're doing around unlocking the value of data in the area of cancer care is essentially putting a story line around that requirement. So, a cancer patient visiting a provider under the President's program for healthcare information technology would be entitled to an electronic copy of their medical record within 48 hours of seeing the provider.

If it's done so in a manner that conforms to this broader set of tools and capabilities that we're building out to unlock the value of data in cancer care, we could actually start to see a whole new ecosystem of applications meant to help the patient navigate through this very difficult experience, to share in what others are doing so that they could understand. If I'm going through this challenge and I've been asked to take these medications or to deal with this type of treatment plan, that I can essentially start to understand how others have gone through similar experiences and to help to understand to what extent are we looking for results in these areas that can be shared across, so if something works well with me and perhaps people with my genetic disposition, might that be translated faster through this collaboration to those who might benefit from that knowledge.

### Moderator
So do you envision that these data as they're unlocked would be available online to any consumer with a computer?

### Aneesh Chopra
The ultimate ambition in the work we're doing in Healthcare Information Technology (HIT) is to empower the individual patient, the provider, and the variety of stakeholders in the healthcare system who need clinical information in order to better our shared healthcare capabilities—that we have the right foundation of technologies, of policies around security and privacy, so that anyone can benefit from this movement towards the digitization of healthcare.

**Moderator**
So is this initiative right now, or does some giant new leap forward invention have to be created?

**Aneesh Chopra**
This is right now. This is right now but for the spirit of imagination. We have the raw infrastructure already in place to collect patient information in a standardized way, to be able to engage the research community in having to understand what they can learn out of that information, to begin conversations around how we can extend that discussion to include genomics information as that comes into line. A lot of those capabilities have been prototyped and tested over the last several years. What's really changing now is that we can spur entrepreneurial activity and innovation in the marketplace by thinking more creatively about how to push this capability out.

I'm not envisioning a big government program of funding and resources—there won't be some big national spending plan, if you will, to gather all this data. It's really about building the right capabilities that would encourage volunteers to participate usually on their own dime.

**Moderator**
So, if patients and consumers and doctors and researchers can participate, can companies participate? Is there a role for small and large members of industry?

**Aneesh Chopra**
Oh, absolutely. And you can see this throughout the information supply chain. There are companies who speak on behalf of thousands of physicians that are in their practice management capability. So, corporations that speak on behalf of physicians, as an example, might build out some of the technology capabilities on their own and have them made available for physicians on the ground to access without a lot of extra investment or implementation difficulties.

You can imagine employers, who are keen on strategies to improve prevention or wellness programs, or frankly, to help their employees live healthier lives with cancer, to find ways to participate. You could see technology companies grab some of these capabilities and basically commercialize them in new and stunning ways.

You know, I have on my iPhone apps that I can download that you never would've thought advanced a national policy objective, but actually do, but in a way that you wouldn't imagine. So, I've got a program on my cell phone called *Lose It*, which is a simple and easy way for me to track all the foods that I'm eating so that I can stay moderately healthy in my eating habits. Underneath that application, though, is a set of capabilities built out of the U.S. Department of Agriculture and the Agricultural Research Service to publish all the raw data on the most commonly eaten foods.

So, if you typed in 'bagel with cream cheese,' it has the ability to call up nutrition information. So, you may see activities out of caBIG® commercialized in the private sector without actually making reference to the government.

**Moderator**
Mr. Chopra, how big do you envision this data ecosystem to grow to? Is it something that could have millions of records of what happened with patient experience with cancer, or hundreds of millions?

**Aneesh Chopra**
Your imagination is really the rate-limiting step. In an ideal world, you would imagine that every patient encounter relating to cancer should be treated as a researchable moment so we can understand what works and what doesn't work.

There are a lot of limitations from ubiquitous universal encounter capturing all the way to the world of today where you've got very, very little. And those are very thoughtfully: How do we engage on patient privacy? How do we engage on the technical hurdles to provide a supply of that information? What are the ways in which we can instill confidence in the ecosystem—that the information, when captured, will be securely maintained?

My hope is that we get thousands of patients enrolled, if not tens of thousands. We want to have the capability for a million to join in, but acknowledge that with these very real and thoughtful constraints, that may be a long ways away.

### Moderator

So Mr. Chopra, we understand that the White House is the catalyst for this initiative in many ways. What do you and the President expect to see happen in coming months as this unfolds?

### Aneesh Chopra

I would suggest that there are essentially three things that we're looking for. Number one, first and foremost, we want to improve our ability to deliver high-quality care to those dealing with cancer today. Number two, we want to make sure that this adheres to the President's highest levels of commitment to openness and transparency—that we build out as much of these tools in an open format, in an open capacity, so everybody can participate. And that leads to the third point, which is this should really reflect the all-hands-on-deck philosophy.

Success here is going to be measured on our ability to mobilize volunteers in the community, corporations, academicians, patients, the provider community all really should find value in this program and if they don't that would suggest to us to go back to the drawing board and make sure we're getting it right. Demonstrating an ability to inspire the all-hands-on-deck call as the President has set out, would be a terrific manifestation of this program.

### Moderator

And what do you think will happen once the program is up and running? Does the way in which patients relate to the medical world and the way they view their own health—is that likely to change?

### Aneesh Chopra

You know, what is so exciting about innovation is that it's really hard to define what it will ultimately lead to. So, it's unclear to me what and how we will care for our health in the future. What I do know is that today, we are living much more in a world of opacity, rather than openness and transparency. We're living in a world where we have far little knowledge of what works and what doesn't, and we need a world where we do know what works and what doesn't. And we have an environment where patients and their loved ones and their family members are in many ways hungry for access to the information they need so that they can have the best approach to treating their loved ones who struggle with cancer, and we need to move to a world where they're empowered with all the information that they need so that they can be effective.

So, on all of these dimensions, you know that the current world is insufficient and we see an opportunity now to build out a new world that is, and it's really going to be the building of a new foundation for a healthcare system that's been modernized. It can improve quality. It can lower cost and improve our experiences as consumers when navigating the complexity of the system.

### Moderator

Mr. Chopra, you've been very gracious with your time today. Is there any other thought or idea you'd like to leave our podcast audience with?

## Aneesh Chopra

Yeah, I need your help! My hope is that there are those listening to this podcast who feel like they could contribute in some way, shape, or form to this collective vision. We want to make sure that we can hear from you—that we can work with you and address the questions and opportunities as you see them. So, this is not a passive podcast. This should be an active podcast, and we will absolutely have the right mechanisms to capture your information and ensure that we're all working together towards this very ambitious and bold agenda.

## Moderator

Thank you for joining us for this podcast on how the White House is working with the cancer community to bring the power of information to the challenge of conquering cancer in our time. More information on caBIG® can be found online by visiting us at caBIG.cancer.gov.