National Cancer Institute

caBIG® cancer Biomedical Informatics Grid®

caBIG® and Health 2.0: A Conversation with Ken Buetow

Moderator

Welcome to the caBIG® Podcast Network. In this podcast, we will discuss how the National Cancer Institute is applying caBIG® and the emerging generation of Internet capabilities known as Web 2.0 to speed the nation's shift to digital medicine and to what some people are calling "Health 2.0."

Joining us today is Dr. Ken Buetow, a geneticist and head of the National Cancer Institute's bioinformatics program. Welcome, Dr. Buetow.

Dr. Buetow

Thank you very much for having me—look forward to our conversation.

Moderator

Dr. Buetow, let's start with the big picture of what's happening around us. What are the trends you see in health care and in our society today that you believe are important?

Dr. Buetow

Well, I think the biggest trend that's emerging in health care today is a shift in direction and a shift in momentum toward consumer-oriented and patient-centric activities. Partially, this is being driven by the whole Web 2.0 revolution that results in consumers having instantaneous access to information. Doctors talk all the time about how a common encounter now occurs with a patient showing up with volumes of material that they've pulled from the Internet.

But more importantly, what we're seeing is that there's real information that supports decision making, real information that allows consumers and patients to choose between different types of care based on their personal characteristics, as well as their personal cultural and choices associated with their lifestyles that really is making all of health care tailored to the individual's background and the individual's desires.

Moderator

As consumers look for more individualized treatment, what impact do you think advances in genomics will have on health care?

Dr. Buetow

What's clearly emerging is the capacity to really see individuals at a molecular level completely individualized in terms of the care they would receive, as well as how they will respond to the care that is delivered to them. This explosion in

genetics, genomics, molecular biology, minimally will result in us being able to deliver what I believe is being called stratified or personalized medicine—where we can appropriately tailor the right treatment to the right individual at the right time, but also allow us to design next-generation types of interventions that leverage that information so that we don't have to look at one-size-fits-all as we move forward.

Moderator

So, with all those macro-trends as background, what have you seen happening in Health Information Technology in recent months as the nation moves towards this new generation of “digital medicine”?

Dr. Buetow

Well, we're literally living through a revolution. I think we will look back on this time 10-15 years from now as a watershed moment. Part of this has been driven by the U.S.'s investment through the American Recovery and Reinvestment Act's engagement in the development and promotion of electronic health records. But it's also accompanied by tremendous trends across biomedicine even before this stimulus resulted in the drive for this activity.

This investment in having electronic representation of health information promises to just be absolutely transformational—transformational partially because for the first time, we'll have the resources necessary to make this a reality.

There's estimated to be over 40 billion dollars going to be spent by the U.S. government over the next three to five years to put this infrastructure in place. Then we will be able to actually view health fundamentally differently. We'll be able to have information liquidity: the ability for consumers, providers, and researchers to be able to access information in ways that are almost unimaginable today.

Moderator

Dr. Buetow, let me pick up another thread into the conversation. While the Health IT process is unfolding at the national level, what changes have been happening with the NCI caBIG® initiative?

Dr. Buetow

I think the caBIG® initiative, interestingly, almost anticipated what was going to be happening. In many ways, caBIG® has been a pioneer in the exploration of how one deploys electronic infrastructure in biomedicine. There's unfortunately been a very slow adoption of information technology across most of biomedicine.

While information technology has transformed other portions of the economy—whether it be finance, banking, commerce—it's actually still very behind the curve in the broader universe of biomedicine and health care.

caBIG® continues its efforts to wire together our NCI designated cancer centers, our standing infrastructures through the cooperative groups, and our translational program—the SPORE program–and are continuing to have deep penetration in these areas.

We're excited that we continue to have success with our NCI communities and also are expanding this, not just in our traditional communities but now in community settings. For instance, the NCI has recently launched a community cancer center program that will touch the 85 percent of cancer patients that aren't seen in our traditional NCI-designated centers.

Moderator

Can you talk a little bit about how the NCI-designated cancer centers, community centers, and other groups are using caBIG® to achieve their goals?

Dr. Buetow

These groups are rapidly deploying many of the caBIG® tools and infrastructures that we believe, are on the leading edge of transforming biomedicine—tools that allow us to capture molecular information, to create virtual biobanks such as our caTissue tools, support the conduct of clinical trials, and create and support our collection of information and the regulatory submission of that information to the FDA.

More recently, the caBIG® program has been partnering with the American Society of Clinical Oncology to extend our services-oriented architecture to not only support the research endeavor, but also to support electronic health records in an oncology setting. The effort with ASCO has created a series of specifications that define what one would need to extend an electronic health record to support the specialized care of oncology—an oncology extended health record.

More pragmatically, we are then working with the vendors and communities to see to it that those standards can then be captured in reference implementations using the caBIG® services-oriented architecture to support the rapid development and deployment of electronic health records across the oncology community.

Moderator

Let me explore with you a little bit more detail about extending caBIG® and EHRs. Why is it important for caBIG® to be helping health care providers, in addition to helping researchers?

Dr. Buetow

I think the extension of caBIG® into the health universe represents a rejoining of, conceivably, twins separated at birth. Health care and research are essentially different sides of the same coin.

The fact that we have separate universes that support clinical care and clinical trials, for instance, means that we don't have a simple way to recruit at point-of-care into clinical trials. It means that the information that is present at clinical encounter has to be manually re-entered into a separate infrastructure—at great cost and with great duplication of effort—into clinical research systems.

Moderator

So, what impact does this separation between research and care have on patients?

Dr. Buetow

Because we've separated these resources and defined these as completely separate environments, we don't have the capacity to leverage knowledge from each patient encounter in a health setting. We don't have a learning health system because we've separated those who can interpret the findings of individual patient encounters in an aggregated fashion that they can then translate into new observations.

The research environment doesn't directly connect with the care environment, and because they're not directly connected, if you want to have those findings in a care setting, you'd either have to duplicate the research infrastructure, or you'd have to wait for the diffusion of structured clinical research findings back into the community, and that diffusion is recognized to take anywhere from 10 to 15 years while people continue to die of cancer.

Moderator

So now let's return to the subject of Health 2.0, which sounds to me like a mix of the internet and medicine. How do you define Health 2.0, and how does it specifically relate to the work that NCI and caBIG® are doing?

Dr. Buetow

Well, Health 2.0 is an extension of emerging trends that are at the interface between Web 2.0 to Web 3.0 and this connection to the consumer and the investment into the consumer's health care delivery, as well as the use and reuse of their information. At the level of Web 2.0-3.0, there's a fundamental transformation of how we technically approach problems. We deal with services, not packaged software.

So, the caBIG® services oriented architecture then is a way that one can deliver technical capabilities, not through large, integrated electronic health records, but instead, through composite applications that interconnect services capabilities so that one can choose to customize their electronic infrastructure and use and reuse components. The data sources get richer because more people use them. They allow consumers, physicians, and other folks to continue to add to the data sources.

Moderator

Dr. Buetow, how will this movement toward Health 2.0 transform the way that consumers, physicians, and others access information?

Dr. Buetow

Clearly, as part of the Web 2.0-3.0 universe, we no longer are talking about computing in a single universe, but we actually are talking about using all sorts of platforms—personal computers personal PDA's, iPhones, iPods. So we actually surface the information in very consumer and/or provider-friendly interfaces.

This then empowers a whole new way of utilizing information that allows us to not have to guess how information would be used, but—using search engines such as Google or Bing—people can pull the customized information they want, and because it's community generated, the communities themselves can capture and accumulate knowledge in a manner that doesn't come in this more traditional hierarchical approach.

Moderator

So, we all know that the biomedical community is made up of many different stakeholders. If you were to think about all those different sectors, could you give us a very short description of what each of them might get from the kind of Health 2.0 capabilities you've been describing?

Dr. Buetow

The most transformational piece of Health 2.0 is the direct engagement of the consumers. So, in our growing collection of services and resources, consumers would be increasingly in control of the information and would be able to make much more effective decisions around their treatment and who they want to share information with. But it would be a mistake to suggest that this is only a benefit to the consumers.

The providers of health care have the ability now:

- To look at information on what's working and what's not working;
- To track how they are delivering care;
- To measure the quality of the care that they are delivering, as well as;
- To figure out how they can more effectively engage with patients and have an information-based dialogue

This has a benefit not just to the specific care encounter, it has value to hospital administrators, for instance, to be able to track patterns of care, what's working where quality is either lacking or could be improved, where there is unnecessary care that doesn't provide or drive a patient outcome and to be able to channel care encounters to those most efficacious in delivering results.

Moderator

Do the capabilities of Health 2.0 benefit any other stakeholders?

Dr. Buetow

The infrastructure also has tremendous value to the much broader biomedical community. It has value to the research community in allowing us to do unprecedented types of research investigations to more effectively recruit into clinical trials so that we don't have to redundantly identify and enter information. If you're an epidemiologist it allows you to have dynamic real-time cohorts of patients to track what happens over time, both in terms of healthy people developing disease and the outcomes of diseased individuals in different contexts.

For basic scientists, it allows us to have access to both clinical observations and biomaterials that allow us to do next generation clinical molecular characterizations. It has advantage for government agencies. It allows us to examine how we can most effectively, both reimburse for healthcare, as well as track how we can as a society, improve health outcomes.

Moderator

So, Dr. Buetow, we will be watching for announcements about caBIG® and Health 2.0 in coming weeks. For now, we'd like to thank you for all your time today for the caBIG® Podcast Network.

Dr. Buetow

Thank you very much.

Moderator

More information on caBIG® can be found online by visiting us at caBIG.cancer.gov.