

Thank you very much for inviting me to be on this panel. I thought I'd start by disclosing the relationships our foundation has had with ONC and some of the others in this room.

First, we have partnered with ONC – in the form of co-funding – on the issue of measuring the adoption of health information technology. ONC has provided support for an expert consensus panel on measuring HIT adoption and we've provided support for publication of the panel's reports.

I am a member of the AHIC's Consumer Empowerment workgroup and John Lumpkin, a senior VP at the Foundation, is one of the co-chairs of the workgroup on Population Health and Clinical Care Connections.

We've also provided support to some of the stakeholders in these processes:

(as Carol mentioned?) we've invested in the Connecting for Health efforts over the past few years and we also gave grants to HL7 to support strengthening of that organization and a modernization of their processes.

I should also disclose that I'm a close collaborator with Patti Brennan on Project HealthDesign, a program, of which I'll speak later, that she runs on behalf of both Robert Wood Johnson Foundation and Sam's folks at the California HealthCare Foundation.

With that, I'd like to give you some context for the Foundation's interest in HIT. Our mission is to improve health and health care of all Americans. We focus on the pressing challenges of our time: like reversing the epidemic of childhood obesity; improving the quality of care; raising the visibility, effectiveness and readiness of the public health system; and ensuring that everyone in America has stable, affordable health care coverage. Health IT per se is not a major focus for us, except that it has such potential to influence so many things we care about:

- it is an essential ingredient in our efforts to improve the quality of both health care but also of the public health system that protects us all

- we have rich legacy and central role in health services research, and we're very excited about the potential that access to electronic records has to transforming that field (ref Carol?)

- looking forward, we are convinced that consumers will need to become far more engaged in their health, and believe that health IT offers tremendous opportunities to support them in doing so

So with that context, let me turn to ONC and I have to start by saying that ONC is playing a vital leadership role. By focusing so much attention on the issues, engaging so many of the key players, and really sparking the whole industry to turn its attention to health IT, their effort has been so important.

And it's impressive how much the office has created – through HITSP, CCHIT, the NHIN prototypes, and many other efforts, they're clearly tackling some of the key issues – and not in a scattershot way – the efforts seem very well coordinated. From our perspective, we're very pleased to see the attention being paid to areas such as consumer empowerment, quality, and public health.

When you look up close, it's an impressive body of work and even more impressive when you consider the relatively short time ONC's been in existence. I thought for today, though, it would be

helpful to step back a bit and offer some observations from some more distance.

It almost goes without saying that ONC, in coordinating activities to meet the President's 2014 goal, has a mammoth task. It's a major engineering challenge, but more importantly, it's a major social change challenge. While there might be myriad technical details to sort out, the bigger challenges lie in areas such as health care financing policy, business models, organizational behavior, and human behavior. In complexity theory terms, this is not a complicated problem – such as putting a man on the moon – this is a complex problem. From a systems perspective, health care as an industry behaves more like an organism than a machine.

With that in mind, the first observation I'd make is the complexity of the challenge suggests the need for a strategy that explores and recognizes the potential for multiple scenarios. By this I mean that over the next ten years there will be economic, political, technological and market developments well beyond the control of ONC, and a key question is whether the current strategy would be robust in the face of wide-ranging scenarios of possible developments. For example, what if RHIOs or HIEs fail to be viable? What if disruptive innovations or new market entrants

significantly change consumer expectations and demands? What if the cost of EHRs consistently exceeds the value that can be attributed? What if we shift more of our resources and energy toward prevention?

I don't want to suggest that ONC's strategies aren't well thought through, but I do think it worthwhile to examine the assumptions that underlie them. While there is much to be said for offering a clear vision, it is equally important to recognize and acknowledge the uncertainty that goes with it. One of the federal government's greatest contributions to shaping the development of the Internet was its restraint – it largely refrained from shaping it directly. In the case of NHIN and the related activities, there's a balance to be struck between having a vision that specific enough to impel action, but open enough to allow solutions to emerge. I think there's room to explore alternative visions and focus most on the building blocks that will be valuable in many possible scenarios.

The second observation I'd make is that the technology considerations appear to be getting more attention than the policy considerations. Carol discussed this and I believe that *Connecting for Health* has been exemplary in showing how these paths are should be intertwined. As Lawrence Lessig would say, “code is

law.” The technological choices we make constrain our policy options. My favorite example comes from the old Bell System, where the network was not designed to allow for competition. Having multiple long-distance carriers just wasn’t one of the design goals. So when the courts come along and try to open up the network, we got decades of legal wrangling about retrofitting costs. So many of the technical details that are being worked out through the ONC and AHIC’s various processes have policy implications and it’s not clear to me that we have a policy consensus that guides those decisions.

The third observation I’d like to offer is that looking at the body of work it seems as if the emphasis is much more on the “how” and less on the “what.” It’s quite clear that there’s a goal of greater adoption of EHRs and PHRs but less clear that we’ve thought through what sort of EHRs and PHRs should be adopted. I know that this is a struggle now for some of my colleagues who work to improve health care quality – they see the necessity of using technology more effectively in health care practice, but they’re also concerned that health IT, without significant changes in practice, isn’t likely to improve much. And I’ve talked with a number of clinicians who believe that EHRs as we know them miss the point – that technology tools that help close process loops,

such as following up after a positive test result, or registries, that enable better population-based care, offer more potential. We funded a study at the Center for Information Technology Leadership that looked at the value proposition for the use of various information technologies in the care of diabetes. Registries were the only clear winners. I really don't have doubt that greater adoption of EHRs will lead to improvements in care, but I wonder if there's been enough critical examination of how IT might enable major changes in care practices that could lead to dramatic improvements.

Now I'd like to move on to some of the specific areas in which we work and I'll start with public health. As I mentioned before, we're pleased with the visibility and attention for that issue. The only concern I'd raise here is the inherent challenge in getting meaningful participation from public health agencies in voluntary standards setting and other committee processes. I know that this committee reached out Dave Ross, of the Public Health Informatics Institute, and this was a point he raised with me – that the people on the ground in public health agencies who are the ones solving the day-to-day practical problems of how to obtain and manage vital public health information – face real barriers to participation. Their agencies have limited travel budgets, they

frequently face restrictions on out-of-state travel, and they often don't have the organizational depth to sacrifice their time to volunteer efforts. I also recognize that this problem is not unique to public health – you certainly hear this in respect to consumer groups as well, but it's a concern nonetheless.

I mentioned earlier that we're supporting *Project HealthDesign*, which is an effort to stimulate innovation in the area of personal health records. In essence, the program asks, "if we can all have access to a consolidated personal health record, what could we do with it to improve our health?" The vision that we've offered sees the medical record as a platform on top of which a whole industry of application developers can build tools for people to manage their health. This brings me back to my first observation – about the need for multiple scenarios and the need to be open to different visions. PHRs are in a time of emergence, with many different types currently on the market and on the drawing board, new players poised to enter the market, and we've had precious little consumer experience with any of them. I'd also add that it doesn't seem as if we need an NHIN to provide people with access to a consolidated medical record. So this is a time where we don't need clarity on what constitutes a suitable PHR, but rather progress on the building blocks that can support a wide range of approaches.

One of those building blocks is an exchange standard that would make it very simple for a consumer to have her medical records exported to a service that will hold those records on her behalf. I'm certainly pleased to see the progress that HL7, ASTM, HITSP, and CCHIT have made on developing and popularizing the CCD as a standard. But I also see this as a good example of my second observation – that the technology and policy work needs to be intertwined. Until anyone who holds my medical records of any kind is required to provide them to me, or to my agent, in a standard electronic format, upon my request, it's hard to imagine that we'll make much progress on PHRs. The standards work is certainly helpful – that's the engineering work – but the social change work – developing the right incentives – is absolutely essential.

Our experience in *Project HealthDesign* also highlights my third observation – that we ought to focus on *the what as much as the how*. It's not clear that in the push to drive greater adoption of PHRs there's been enough discussion of what characteristics of a PHR will yield the greatest health benefits. Without that exploration, I'm not sure we have a sound basis for defining a PHR and developing strategies to increase its adoption.

So to conclude, I want to emphasize that ONC is playing a vital role and making significant progress in meeting an enormous and complex challenge. At the same time, the complexity of the challenge and the *significance of the opportunity*, suggest that it's worthwhile to step back,

- examine the assumptions underpinning the strategy and test them against different scenarios to see how well they hold up,

- make sure the policy efforts are well aligned, and

- make sure that we don't lock ourselves in to our current practices, but rather use technology to enable new and innovative ways of helping people stay healthy.

Thank you.