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Written Testimony to the Certification/Adoption Workgroup  
Panel 2: Consumer Perspective  
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## **Introduction**

The National Partnership is a non-profit, non-partisan consumer organization with almost 40 years of experience working to make life better for women and families by promoting access to quality health care, fairness in the workplace and policies that help women and men meet the dual demands of work and family. As you know, health care is central to the well-being of all individuals – it is a key determinant of their quality of life, their economic security, and their ability to thrive, prosper and participate in our society.

We are privileged to lead two important coalitions of consumer organizations dedicated to changing the way health care is organized, financed and delivered. The Consumer Partnership for eHealth (CPeH) and the Campaign for Better Care together include more than 150 consumer and patient groups working to ensure that implementation of both the HITECH Act and the health reform law result in higher quality, more patient-centered care, fewer disparities and better outcomes for everyone.

Health information technology (IT) plays a critical role in achieving these goals, and I am honored to be with you today to discuss issues related to usability of health IT and how they affect patients and their families.

*To what extent has usability of EHRs helped in providing patients access to their health information and engaging patients in their care? Particularly in:*

*Getting an electronic copy of their health information upon request*

*Getting an electronic copy of discharge instructions*

*Getting a clinical summary*

*Getting electronic access to their health information*

*Being provided educational resources specific to their care needs*

*To what extent is usability of health information technology, by care providers, an issue for health care consumers? Has it supported better interactions with the care providers?*

It's important to be clear about the differences between the usability of an EHR (a provider issue) and the usability of information that comes from an EHR (both a patient and a provider issue), and about whether that information is used in ways that are meaningful to patients. Usability from a consumer/patient perspective is equivalent to the degree to which it enables and fosters effective collaboration between patients and providers to make better health care decisions. To that end, it must help support patients and their caregivers in the roles they play in health and health care. In other words, how well does it support provider **and patient** workflows – through better communication and coordination – as they work in partnership?

## **Consumer Roles in Health and Health Care**

Patients and their caregivers play four distinct roles in a true partnership with their providers:

- (1) They act as agents of change by being vocal about priorities and goals, and by giving feedback on their experiences of care;

- (2) They act as informed decision makers at numerous points when interacting with the health care system – many of which occur before they have ever even seen a provider;
- (3) They verify facts and provide necessary context for ensuring the care they receive is right for them; and
- (4) Most importantly – and this is critical to achieving the goals of the National Quality Strategy – they integrate health and health care into the full context of their lives.

However it is designed, health IT must support patient and caregiver engagement by providing the information and tools they need to be successful in the roles above. For effective self-management, patients – like providers – need information to be available at the point of decision-making, whether that involves taking a medication, considering a complex, invasive procedure, or making changes to their diet or activity.

### **Context is Important**

Information and tools offered in a clinical context, such as during an office visit or as part of the discharge process, provide the significant benefit of initiating a collaborative process that is much more than just a record of what happened. Providing information to patients in the clinical setting offers patients and their caregivers the opportunity to identify errors in the medical record and request that changes be made. This approach also provides a unique opportunity for them to ask questions, for clinicians to assess understanding, and for patients and providers to work together to resolve identified issues. This collaborative process is at the heart of shared decision-making, but is also a basic requirement for establishing an effective relationship.

Yet patients spend the vast majority of their time outside of the clinical setting, so information must be just as readily available to them when they are at home or on the go. Further, research shows that patients remember as little as 11%<sup>1</sup> of what is told to them in the course of a clinical encounter, so real-time, or near real-time access to discharge summaries, care summaries and educational resources tailored to a patient's situation is essential to the success of any plan of care. In addition, the information must be easy to understand, portable and available in common languages.

Making information available to patients and their caregivers in both the clinical setting and in real-time from outside the clinical setting is essential to fostering and maintaining the relationship between patient and provider, and it's hard to imagine how the goals of the National Quality Strategy will be met without this longitudinal, collaborative approach to care. The use of health IT to support self-management beyond the walls of the traditional health care system has significant implications for the effectiveness of interventions, reduction of Emergency Department visits and reduction of readmissions.

### **Functionalities Valued by Patients Produce Value for Providers**

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<sup>1</sup> Flocke, SA and Stange, KC. *Prev Med.* 2004 Mar;38(3):343-9.

Certain functionalities are particularly appealing to patients and their caregivers, and have been shown to lead to robust usage of “patient portals.” Reaching out to consumers through the use of such portals makes the usability of health IT particularly relevant to consumers, but only if this function is used as an integral part of the care process, rather than simply a repository for information. Access to test results, appointment scheduling, prescription refills, ability to pay bills and secure messaging with their providers are all features patients say they want<sup>2</sup> and evidence shows they actually will use, even to the point of changing providers in order to get it.<sup>134</sup> Portability and full access to health information round out these features by providing transparency and choice to consumers. These functionalities support **patients’ workflow**, support their partnership with providers, and therefore provide value.

When implemented and embedded thoughtfully into new models of care, such as the Patient Centered Medical Home, health IT can produce value to other stakeholders in the form of reduced burn-out and reduced costs. For example, Group Health Cooperative in Washington state, found in its medical home pilot that its staff exhibited less burn-out after 12 months. Patients in the medical home pilot had 29% fewer emergency visits and six percent fewer office visits than patients served by clinics not participating in the pilot. Interestingly, in spite of fewer in-person visits, use of secure messaging among pilot clinic patients was 80% higher than other patients, suggesting that it is possible to decrease utilization (and ultimately costs) **and** increase communication if technology is employed effectively and in the context of redesigned care processes and workflows.<sup>5</sup>

Usability of technology to support more effective interactions between patients and providers depends also on office design and placement of the technology. In other words, systems should be set up in such a way that they are not a physical barrier between patients and their providers, but rather are a central focus of both patient and provider attention. This promotes transparency and the collaborative process described above, by enabling both provider and patient to see information, especially in visual formats like charts and graphs, and to discuss it relative to health and outcome goals.

Current health IT tools have largely been designed without input from patients. Patient input should be included in the design of systems to ensure they are effective tools for supporting the patient/provider partnership. This should include a means of continuously assessing patients’ information needs and how they are using the information provided to them. For example, the HIT CAHPS module of the CAHPS patient experience of care survey could be evolved to fulfill this function. The VA’s 200,000 individual users of the newly installed “download button” represent other opportunities for assessment, as they could be asked how they are actually using their newly-available information.

*Do consumers believe that health IT is safe? How does usability factor into that perception?*

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<sup>2</sup> Intuit Health Survey by Decipher Research, January 2011.

<sup>3</sup> Weingart et al. *J Am Med Inform Assoc.* 2006 Sep-Oct;13(5):579.

<sup>4</sup> Halamka et al. *J Am Med Inform Assoc.* 2008 Jan-Feb;15(1):1-7.

<sup>5</sup> Reid, et al. *Health Affairs.* 2010 May;29(5):835-843.

To my knowledge, there are no public opinion surveys that address consumer beliefs about the safety of health IT. I do know that – according to patient responses in our field research – health IT plays a role in improving safety by addressing the problems with communication and coordination they experience over and over again in the health care system. Of course the systems themselves have to be safe. When consumers see evidence that their providers are more effectively communicating with each other and coordinating their care, their belief in the safety of health IT will be enhanced. Offering a means by which consumers can identify and request changes to incorrect information in their medical record would also foster belief in its positive impact on safety.

When health IT is used as I've described above, it can also contribute to safety by opening up conversation that might reveal information or trigger questions a clinician might not otherwise ask, but that nonetheless have significant impact on care.

### *What aspects of health IT usability would consumers like to see improved?*

The best way to improve usability of health IT is to shift away from the notion that health IT used in provider settings should be designed exclusively for provider purposes. Rather, health IT should be considered and designed to support effective partnerships between patients and their providers by enabling better, more patient-centered decisions based on better use of information. Specifically, the following capabilities should be included in health IT products:

- Easy, secure access for patients to health information in real time (or near real time).
- Health IT tools that make this information meaningful and useful to patients based on their specific health needs.
- Ability to have two-way communication between patients and their providers.
- Ability of patients to contribute key information to their health record (flagged as patient-contributed).
- Familiar functionality, such as online appointment-making, prescription refills, and secure messaging for questions and screening.
- Linkages to reliable resources for additional information and/or help.

### **Summary Points:**

1. Usability of health IT, from the consumer perspective, means that the technology supports an effective partnership between patients and their providers by enabling better, more patient-centered decisions.
2. Health IT can support more effective patient/provider partnerships by improving communication and coordination through increased transparency, bidirectional flow of information and interactive features that meet patients' needs for integrating health care into the workflow of their everyday lives, wherever they are.
3. Specific, familiar services are good starting points for engaging patients, and then can and should be followed by more advanced engagement strategies, such as individualization and tailored experiences and solicitation of patient contributed data.