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HIT Policy Committee
Meaningful Use Workgroup
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PANEL: Meaningful Use of HIT in the Real Lives of Patients & Families

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My name is M. Chris Gibbons and I am an Associate Director at the Johns Hopkins Urban Health Institute. Thank you for the opportunity to share my knowledge, experience and convictions regarding “Meaningful Use of HIT in the Real Lives of Patients & Families” here today. I am extremely delighted to know that the meaningful use matrix recommended by the HIT policy committee includes the overall health outcome policy priorities of 1) reducing health disparities and 2) engaging patients and families in their health and healthcare. The Meaningful use standards have been carefully crafted to encourage progressive utilization of HIT by healthcare providers in order to improve efficiency, quality and effectiveness of care. It is clear that it will take more than simply making patient records or healthcare processes electronic, to improve healthcare quality and patient health outcomes.

As our healthcare system continues to move towards shorter hospital lengths of stay an increased focus on self management, “aging in place” and patient centered processes, more “care” will inevitably be provided in the home by patients themselves or informal caregivers who need decision support and technical assistance with care processes and medical devices. Yet the Meaningful Use criteria seem predominately focused on healthcare provider needs and goals with only an implicit or indirect (via the provider) focus on patients and caregivers. The one exception to this observation is found in Stage 3 (beginning 2015) when meaningful use will include patient access to self management tools. However no guidance is provided as to what these are or need to be.

Even as HIT without technical, functional and performance standards would yield little benefit for providers, the same is likely to be true for patients’ electronic tools. The design of patient self management tools without the credible, iterative involvement of actual patients, will likely lead to lower than desired utilization rates or patient engagement. A reliance on such tools could actually increase healthcare disparities because of potential differential utilization patterns and therefore patient benefit across user population groups. Seeking simple solutions for these challenges would not be wise. In my opinion, **a staged implementation of meaningful patient use standards for patient self management and decision support tools included in Qualified, Complete or Certified EHR’s, or stand alone patient self management modules, should be developed and employed.** Where the evidence does not exist, it should be evaluated and obtained prior to recommending specific standards. In the interim, ONC can engage relevant expertise to provide informed guidance. The available evidence regarding the following six questions can provide some preliminary guidance along these lines.

1. What are consumers’ health information needs in the context of their real lives?

Even as providers needs differ, so to do patients health information needs. However patients often articulate a need to connect to emotional support and practical help for dealing with their health issues. Patient self management tools needs to help patients and caregivers keep up with the latest information and health news. There is an increasing interest in wellness and healthy lifestyle activities, information and resources in addition to disease oriented information and resources. (1)

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2. How do results of ethnographic studies of individuals with chronic health conditions inform our understanding of how HIT can improve their use of health information and connectivity with their providers to improve their health? Racial, ethnic and cultural differences impact technology utilization in complex, nuanced and multifaceted ways. The underlying causes of these impacts cannot be fully explained by socioeconomic and geographic factors. Much more research is needed to provide a more complete understanding of the determinants of utilization, the implications of differential utilization patterns and most importantly, how we can build upon this knowledge to ensure equitable utilization and maximize beneficial health outcomes. (1)

3. What is the evidence base for patient benefit from their direct use of PHRs and other HIT that interacts with EHRs? There is growing evidence that suggests patients can benefit from the use of electronic tools. Patients themselves report that when seeking for health information and resources on the internet they have generally been able to find what they are looking for and fully one third indicate that they have been positively helped by the information they found. In addition a recent evidence report indicates that the available literature suggests that select Consumer Health Informatics applications may effectively engage consumers, enhance traditional clinical interventions, and improve both intermediate and clinical health outcomes. (2)

4. What is the role of mobile applications in improving health of individuals? Is there a specific role for underserved populations? Many applications can be delivered across several types of platforms including mobile technologies. Any value that a patient may derive should be attributed to the platform, the content, usability and effectiveness of the application. In the same way that some drugs work better than others for different patients, we should not assume a one size fits all approach for the development, utilization or implementation of patient tools and applications. Mobile applications then may have particular utility among some patient groups while less utility among others.

5. How can we use HIT to make information and knowledge actionable for patients? We must first understand patient articulated health information and health technology needs and desires. Giving patient's data that is useful for providers will not prove valuable for most patients. Patients must see the information as relevant and helpful in order for them to use that information to make actionable decisions regarding their health and care. Asking patients what they want and need their electronic tools to do, will prove more helpful than developing tools based only on provider or expert insights.

6. How does HIT enhance collaboration between patients and their providers and change how the patient's health is managed? Generally HIT can inform an empower patients, resulting in significant shifts in patient health practices and habits. Because health information is increasingly available to patients, it is in some cases disrupting historic doctor-patient power differentials and impacting patient-provider communication in ways that can be uncomfortable for patients and providers. Paradoxically in some cases this can lead to poorer quality interactions which potentially affect care and outcomes particularly among underserved populations.

Let me close with the words of Michelangelo, "The greater danger for most of us lies not in setting our aim too high and falling short; but in setting our aim too low, and achieving our mark." While the challenges of engaging all patients in the meaningful use of HIT are real, the potential benefits of achieving the goal are even more substantial.

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