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American Health Information Community
Consumer Empowerment Workgroup
Humphrey Building – Room 800
200 Independence Avenue, SW
Washington, DC 20201

September 18, 2009

REGARDING: Hearing on Personal Health Records

ATTENTION: Co-Chairs Nancy Davenport-Ennis and Rose Marie Robertson;

At the National Health Council¹, our goal is to normalize the practice of electronic personal health records (EPHRs) as a new standard of care. We believe that EPHRs will improve efficiency, effectiveness, timeliness and safety, and perhaps even more important, help people to play a more active role in promoting health, preventing disease and managing their own health care decisions. For approximately 100 million people with chronic disease and disabilities, EPHRs will not only help them to improve the quality of their lives, it may even save their lives.

Alpha-1 Antitrypsin Deficiency is a genetic disorder that can cause liver and lung disease. People with Alpha-1 can have episodes of severe breathing problems or liver failure. In the ER, they are often unable to communicate their diagnosis because of the severity of their condition, and they are often misdiagnosed as having acute asthma, smoking-related lung disease, or alcohol-related liver disease. These mistakes can prove fatal to a patient with Alpha-1 because the treatment of asthma or alcohol-related liver disease may be of no benefit or even harmful to an individuals suffering from Alpha-1 related disease.

The Alpha-1 patient presumed to have asthma may be intubated, placed on high-pressure mechanical ventilation and wind up blowing out one or both lungs. The Alpha-1 patient presumed to have alcoholic liver failure will be sedated to prevent

¹ The National Health Council is an independent, nonprofit organization representing more than 115 national, health-related organizations from all segments of the health care community, with a core constituency of 50 voluntary health agencies, such as the American Heart Association, American Cancer Society, Lupus Foundation of America, and March of Dimes Birth Defects Foundation. In addition, our members include professional and membership associations such as the American Academy of Family Physicians and American College of Cardiology, and other nonprofit agencies interested in health such as AARP and the National Council on Aging. And we also have industry members including pharmaceutical and biotech companies.

alcohol withdrawal symptoms and relegated to a distant corner of the ER where they rapidly slip into hepatic coma. Alpha-1 patients die needlessly every year in the ER and the intensive care unit because there was no way to identify that they had Alpha-1. An electronic record would completely eliminate this tragedy for people with Alpha-1 as well for many other people with chronic conditions who suffer needlessly every day.

The National Health Council represents a wide variety of stakeholders who come together to find common ground on issues that can improve the health of all people. The Council addresses issues of mutual concern to its members, such as the need for increased support for medical research, the need for fundamental reform of the health care delivery system, especially with regard to making it more patient-focused, and the need to engage patients and their families to be more active participants in their health and the health care system. Collectively our patient organization members represent about 100 million patients with chronic diseases and/or disabilities -- and representing patients' needs is our primary focus.

As part of our *Putting Patients First*® initiative, a major program of the Council that we established more than a decade ago, we have set a goal of empowering people to play an active role in promoting their own health, preventing disease and managing their own health care decisions. We believe that giving patients access to their own health information using principles of clear health communication is the logical starting point.

Electronic personal health records will provide an electronic source for patients to access, manage, and share their health information among providers in a secure and confidential manner. These kinds of records will allow patients to input important indicators, such as blood pressure readings, blood sugar levels, and levels of pain between doctor visits. In addition, patients can enter personal preferences that are relevant to their care -- and should be important to their providers -- such as complimentary and alternative therapies; homeopathic remedies; spiritual needs; medical directives; and caregiving authority. Patients will also see relevant information entered by their providers such as diagnosis, treatment, complete medical history, and test results.

Electronic personal health records will lay the foundation for many other health system changes that will benefit patients. EPHRs will not only improve patient care and medical outcomes, but will also catalyze other much needed changes such as the integration of care across time, across specialties, and across settings, and integration of alternative and complementary therapies with other therapies. EPHRs will focus information on managing the patient, not the disease or disability, providing a more holistic view that evidence has shown improves outcomes.

This patient-centered focus in health IT may seem like a nuance, or simply an "add-on" to the architecture of a system well underway, but we believe that integrating this patient focus now is central to the success of health IT. We and our members know from extensive consumer research that people are often confused and frustrated by a system they do not understand, while decisions that affect their health are made every day

without their direct involvement. As a result, people do not comply with medication regimens; they don't schedule necessary follow-up visits; information about previous tests and treatments is lost; terminally ill people are often denied appropriate end-of-life care; emergency room doctors are forced to make life-altering decisions without access to complete information; and a host of other problems arise. We believe that patient focused EPHRs that incorporate principles of clear health communications will improve health literacy, compliance with health regimens, clinical outcomes, safety, and satisfaction rates and will reduce costs.

Social marketing – the use of marketing and communications techniques to achieve positive social change - has a long and successful history of changing consumer behavior and promoting better health outcomes through community based activities and dialogue. While tobacco prevention and seat belt utilization are among the better-known examples of successful social marketing campaigns, similar efforts have focused on the use of sunscreen, vaccination of children, drunk driving, teen pregnancy, blood pressure screening and the prevention of sexually transmitted diseases. We believe that such models could be adapted to normalize EPHRs as a new standard of care.

Communications aimed at changing social behavior goes through three stages – public awareness, increased saliency and motivating action. The first stage, raising awareness, places the issue on the public's radar screen. People learn that there is a problem and are made aware that it needs to be fixed. The core question the communications need to answer is: "Why should I care?" Why should people care about EPHRs?

Once awareness is raised, the saliency of the issue needs to be heightened. The message needs to address: "Why is it my responsibility to do something?" Once people get beyond their initial outrage, concern can fade into resignation. There is a long litany of social ills that Americans face as they listen to the news each day. What will make them feel they have a responsibility to promote the acceptance and adoption of EPHRs? The core question that needs to be addressed is: "Why do I have to get involved with something that does not directly influence my life?"

Once the issue is salient, people are willing to take action. At this point we need to identify actions the public can take to promote the adoption of EPHRs. The core question that needs to be addressed is: "What do I have to do to help fix this?" This "ask" as it is commonly called requires identifying two activities – a believable and doable solution to the problem and a series of actions that people can take that they are both willing to do and believe will help bring about the solution. These questions provide the basic framework for assessing the state of messages and message development that will promote the acceptance and widespread adoption of EPHRs.

To answer these critical questions, the Council has commissioned extensive research in several phases among patients, especially those with chronic diseases and/or disabilities. We began with a literature review and environmental scan to identify various efforts and programs aimed at promoting electronic records, look at how they were being promoted, and how consumers were or were not being engaged. A second phase involved

exploratory focus groups with patients who have chronic conditions, to identify what issues regarding health care delivery and information interest and concern them, and to guide the development of messages that will engage them on their own terms. From these groups, we developed message concepts and detailed messages and tested them in individual, in-depth interviews

Overall, our research shows that while patients are eager: to have better access to their own records, to have their providers more aware of their health data, and to see systems streamlined, coordinated and integrated. But, it is important to note that they have serious concerns about privacy, security, accuracy and the user-friendliness of the information.

Quite early in the research we learned that brief “sound bite” explanations will not engage people. Research participants immediately perceived that “the devil is in the details” and wanted thorough explanations about access, security, and privacy. We learned that people have natural curiosity about how EPHRs would work, and did not get impatient with detailed information. This may run contrary to our society’s seeming assumption that everything must be simplified to appeal to supposedly ever-shrinking attention spans. But when you think about it, we know that people are willing to spend lots of time online and elsewhere researching health information, and learning about EPHRs was no exception. We adapted the description of EPHRs in later stages of testing to provide this kind of thorough detail, and it was well received.

We also learned – emphatically – that patients’ security and privacy worries cannot be skimmed over. They must be answered, so it is better to raise the issues up front. Many were skeptical that any system could be truly secure, and they pointed to widely publicized, large security breaches of supposedly secure credit card information, but other people found it fairly easy to overcome this concern.

Our research also revealed the need to clearly list benefits to the patient. We found that the more we explained how patients directly benefit from electronic records, such as increasing safety by reducing mistakes, helping alert providers to medication conflicts, or helping various specialists share test results, the more they liked what they heard. Not surprisingly, we found that real life examples help convey the importance of the issue. We created a message concept that referenced weather, fire, burst pipes and hurricane Katrina, and it strongly resonated with everyone.

We also learned -- and were perhaps a bit surprised -- that people disliked anything that sounded like a slogan or sounded too promotional. For example, our “disaster” message ended with the phrase...”because when a natural disaster or other emergency strikes, you have enough to worry about.” Many people singled out this phrase as sounding like “advertising hype” and thought it would make people think that someone was trying to sell them something. Several people guessed that EPHRs are being promoted by the “computer industry” for profit.

Another important finding for us was the complexity of our task. It will be a challenge to get patients actively engaged on this topic, because it seemed technical to some people, and they are skeptical that they can make a difference, and that their voices will be heard. But as usual, a few activists can stir up others, and that phenomenon played out in our research groups. Motivating patients to get involved will be a challenge, but we believe it is a challenge we can overcome.

Consumers emphatically did not like one message we tested -- based on an analogy with the banking industry -- in which we likened EPHRs to the convenience of electronic banking and ATMs. They thought the comparison was irrelevant, and made them think that EPHRs were an effort to reduce human contact with providers.

As in almost every research project we have conducted, patients perceived voluntary health agencies -- nonprofit patient advocacy and education organizations such as the American Diabetes Association and the Spina Bifida Association of America -- as credible and caring sources of messages on this topic. Consistently, we find that people trust their personal doctor and these organizations more than any other sources.

Through our voluntary health agency members, the Council has access to an active network of grassroots activists -- people who have one or more chronic disease or disability, and therefore have regular interaction with the health care system -- and who are eager for a role to help make fundamental improvements. A massive army of motivated patients and their families can drive demand for EPHRs that will speed their use and acceptance. In fact, a futures study by the Robert Wood Johnson Foundation found that only a national patient and family movement can significantly influence the speed and quality of improvements to the nation's health care system.

We are currently in the planning stages of a pilot program with America's Health Insurance Plans that we will run in two states -- northern California and Massachusetts -- to motivate grassroots activists to get involved in advocating for EPHRs. Together, we are developing the believable and doable "asks" that will ensure that EPHRs become the new standard of care. Such action may include: asking current providers and provider systems or networks to use EPHR systems, selecting new providers based on whether they use EPHR systems, advocating in support of EPHR systems, including writing letters to policymakers and to newspaper editors and making use of EPHR systems as they become available to be more active participants in their own care.

While we believe a public-private partnership should be explored -- especially the provision of resources to community-based programs and the coordination of such initiatives -- further research should be conducted before the precise role of government can be determined. We need to ensure that such partnerships do not undermine public confidence in EPHR systems. Furthermore, all activities must promote community-based dialogue and education about the personal and societal benefits of EPHRs.

We also believe that while issues of privacy and system security may not yet be resolved to perfection, we should move forward immediately to put EPHRs in operation. From

what we learned in our research, we are convinced that we can strike a balance between offering patients the many benefits of EPHRs, and allaying their concerns over the security and privacy of information. People are dying every day from lack of critical information and other inefficiencies in the system; we cannot wait any longer for the perfect, fine-tuned product. We can solve the security issues while the new technology is saving lives. This is a classic situation of the saying, "the perfect is the worst enemy of the good." We have the technology now. Let's use it and get on with the business of saving lives, and perfect the technology as we go along.

Sincerely,

Marc M. Boutin
Executive Vice President