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**Consumer Perspective: to the Adoption/Certification Workgroup for the purpose of formulating recommendations to the HIT Policy Committee and the National Coordinator on usability of Electronic Health Records**

**By**

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**Introduction**

**AAPD** is the country's largest cross-disability membership organization with a mission to organize the disability community to be a powerful voice for change – politically, economically, and socially. AAPD was founded in 1995 to help unite the diverse community of people with disabilities, including their family, friends and supporters, and to be a national voice for change in implementing the civil rights of Americans with Disabilities. AAPD's Public Policy & Research division has initiatives that include a focus on health care and the growing use of health information technologies. This effort includes many projects, ranging from research, consumer education and awareness activities, and working with public policymakers. AAPD's approach is based on the fundamental principle of the need for accessibility, usability, and affordability of technologies for people with disabilities.

***Answer to the Following Specific Questions***

1. *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*
2. *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?*
  - *Do consumers believe that health IT is safe? How does usability factor into that perception?*
  - *What aspects of health IT usability would consumers like to see improved?*
  - *How has HIT affected the provider/patient relationship?*

We are unaware of any data or studies that have specifically addressed in depth the usability perspectives and needs of consumers/patients with disabilities and their family members,

including caregivers, in regard to Electronic Health Records (EHRs). For us at AAPD, usability also includes technological accessibility – that is, no barriers to access via the connection process, and usage that means the human interface works for people with any sort of disability, such as low vision, blindness, cognitive disability, etc.

***AAPD Recommendation:*** We believe there is a need for much further research on what the community of over 50 million Americans with disabilities knows and understands about EHRs and how they would use and benefit from them. AAPD recommends that ONC fund a research project centered on usability and accessibility.

### ***AAPD's Preliminary Research on Personal Health Records May Inform***

AAPD's own preliminary work on Personal Health Records (PHRs) can inform us somewhat about EHRs in general. In a research endeavor, "Uncovering Interests and Concerns About Personal Health Record Use By Individuals with Disabilities: Results of a Preliminary Survey"<sup>1</sup> we looked at some topics within automation of health records. Note that this survey work used a non-random sampling method so the findings should not be generalized beyond the respondents. However, despite this limitation, the survey provides a useful and exploratory window into the perceptions of people with disabilities on our experiences, needs, and concerns.

A key finding of the survey was that people with disabilities would find value in PHR use in medical care coordination, but remain cautious about the utilization of that information by government agencies. While this survey work specifically looked at the perceptions and awareness about Personal Health Records of some people with disabilities, we will say this overall finding could inform what our community thinks about EHRs. That is, there is concern about automation of medical records and who uses them and how they are used.

One conclusion from this preliminary survey work is that there is a need for increasing awareness among those with disabilities as to the range of benefits PHRs can have, especially in longer-term complex situations that might lead to applying for disability determination through SSA. We would say, likewise, that conclusion likely echoes what our community thinks about EHRs. That is, our disability community needs to be made better aware of the benefits of EHRs and how they would work over their life-time and specifically, if and how EHRs might be utilized specifically, such as in disability determination processes and which may greatly impact receipt of other benefits.

***AAPD Recommendation:*** Targeted consumer awareness and education activities via trusted entities to the various disability communities.

### ***Benefits of an Electronic Health Record System***

Typically, people with disabilities require frequent interaction with the healthcare system, potentially with multiple providers, creating a greater need to gather and share longitudinal health information across multiple providers. To the extent that EHRs support and facilitate

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<sup>1</sup> "Uncovering Interests and Concerns About Personal Health Record Use By Individuals with Disabilities: Results of a Preliminary Survey," August 28, 2010, by Lytle, Simpson, Horan & Feldman, on the AAPD website at [http://www.aapd.com/site/c.pv11IkNWJqE/b.6422581/k.6DAC/Uncovering\\_Interests\\_and\\_Concerns\\_About\\_Personal\\_Health\\_Record\\_Use\\_By\\_Individuals\\_with\\_Disabilities\\_Results\\_of\\_a\\_Preliminary\\_Survey.htm](http://www.aapd.com/site/c.pv11IkNWJqE/b.6422581/k.6DAC/Uncovering_Interests_and_Concerns_About_Personal_Health_Record_Use_By_Individuals_with_Disabilities_Results_of_a_Preliminary_Survey.htm), last accessed April 13, 2011.

frequent interactions with the health care system, there is little doubt of the benefits. Our survey provided some windows on this as follows:

In our survey, of those responding, almost half cited experiences where a PHR would be helpful in dealing with multiple providers, such as transporting records from one provider to another, coordinating care and medications among multiple providers, or accessing medical history in emergency situations. Some mentioned the desire to have more information about their own medical history. They believed it would enable them to provide more accurate medical histories to their providers or to become more knowledgeable about their own conditions and empowered to make more informed medical decisions. Based on these responses, we believe that some, if not most, consumers with disabilities would find EHRs very useful to the extent that the EHR facilitates management of their own health care.

Similarly, many of our survey respondents were very interested in various PHR features such as the ability to refill prescription medications, the ability to view laboratory results, the ability to store and retrieve records easily and the ability to schedule appointments and coordinate care. Based on these responses, we believe that some consumers with disabilities would find EHRs very useful to the extent that the EHR facilitates management of these features of an EHR system.

***AAPD Recommendation:*** Survey work about EHRs and related HIT tools should include and address the specific needs of people with disabilities who may have different perspectives than other consumer groups based on the unique conditions and history of people with disabilities.

### ***Privacy and Security, and Accessibility***

AAPD notes that several concerns were raised in the areas of Privacy and Security, and Accessibility, in regard to PHRs in our survey and that would likely impact perceptions, awareness and use of EHRs generally by consumers with disabilities.

For instance, when asked specifically about privacy and security concerns, most indicated that they were concerned about security and roughly the same were concerned about privacy. We note that the open-ended responses indicated no shared common definition and usage of the terms “security” and “privacy.” However, in elaborating on security concerns, respondents focused on illegal access (hackers, identity theft, records getting into the “wrong hands”); some were concerned about unauthorized access; and some wrote about misuse by employers, insurers, and marketers. When asked about concerns with PHRs, one respondent stated: “That it would be hacked into, that an employer or someone who has no need to know would have access to personal information about current or previous medical conditions.” People mentioned similar issues when elaborating on their privacy concerns. “I’m not sure that I’d want just anyone seeing them [my records]. I do want some privacy.”

Based on these responses, we believe that consumers with disabilities would find EHRs acceptable to the extent that the EHR system has very high levels of Privacy and Security features. Our understanding of this point of view is informed by the reality that people with disabilities have, historically, experienced significant discrimination in the workplace, when trying to find and secure employment and in maintaining employment. Therefore, any EHR system would have to be “as secure and private as my banking records” as one consumer with disabilities recently told us.

***AAPD recommendation:*** EHR systems should have the capability to segment information by the consumer and, for institutions, such systems should have the capability to track who has opened, viewed, copied and otherwise made use of the record and that there should be very strong penalties for misuse.

Accessibility or usability from the technological perspective is another concern of people with disabilities. In our survey work, almost half were concerned about accessibility and this – naturally -- varied by disability type. Respondents with vision impairments were most likely to be concerned while those with “just medical conditions” were the least likely. Interestingly, when asked about desired accessibility for a PHR, one respondent stated, “Because I'm visually impaired, I believe that online formats are the most convenient and accessible both for me as a consumer and for my healthcare professionals.”

Based on these responses, we believe that some consumers with disabilities would find EHRs very useful to the extent that the EHR system addresses technological accessibility and usability in such a way that it requires no expensive additional equipment or add-ons, or clunky work-arounds, for consumers – particularly those with vision disabilities – to benefit from an EHR system.

***AAPD recommendation:*** EHR systems should be developed and designed to be technologically accessible at the outset and to the widest range of users. The medical privacy of health care consumers with disabilities should be understood to include but not limited to people with vision, speech, and hearing disabilities. This notion relies upon user interfaces that are both accessible and usable from the technological perspective. That is, the technology involved must allow the individual with a disability to not be compelled to ask someone else to operate or otherwise utilize the record for them or on their behalf. AAPD finds it very disturbing the notion that usability, including accessibility, stifles innovation. It is clear that innovation is required to make things accessible and usable.<sup>2</sup> The principle here is to ensure that technologies for electronic medical records systems are designed, developed and fabricated so that persons with disabilities enjoy the same functionally equivalent access to and usability of their medical records as people without disabilities.

***AAPD recommendation:*** We believe it possible that ONC can gather some lessons learned from the federal government’s implementation of Section 508 of the Rehabilitation Act and could engage with the offices responsible for its implementation to see how procurement is best addressed and then translate these to guidelines for the field. To further this approach, and as part of its overall planning, ONC could consider how ongoing technical assistance and training on accessibility will be provided to healthcare organizations trying to meet meaningful use.

### ***Some Additional Recommendations***

AAPD also makes the following recommendations to the Adoption/Certification Workgroup for the purpose of formulating recommendations to the HIT Policy Committee and the National Coordinator on usability of Electronic Health Records.

***Terminology:*** AAPD recommends use of the term “health care consumers” rather than “patients. This is a matter of sensitivity to people with disabilities who have long been considered

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<sup>2</sup> Note that accessibility and usability are separate terms for purposes of usage by people with disabilities. For instance, something can be made accessible but it is unusable, and vice versa.

exclusively in terms of their medical diagnoses or physical condition<sup>3</sup> and to the detriment of civil rights.

*Ownership of medical records:* AAPD recommends that the Workgroup start from the perspective that people with disabilities see themselves as owning their medical records, as belonging to them and something that they authorize the sharing of, and to whom. Health care consumers with disabilities may have larger and more complicated medical records than others, may have had very bad experiences in the health care delivery and services system, and may perceive negatively any sharing of their medical records across systems.

Additionally, we know there are caregivers who currently manage the health care and records of adults with disabilities who are unable to manage their own records either due to the disabilities of age or some other medical or temporary condition. We know there are people with mental illness who want to own their records. We know there are concerns about adults with intellectual disabilities, about who has access to and controls access to this health care record when there are multiple providers and payers and where they may be agency jurisdictional and control issues. Likewise, there are concerns about researchers delving into records even if identifying information removed. AAPD recommends further investigation of these ownership issues.

*Incentives for Consumers:* While we believe there are consumers with disabilities eager and already using electronic tools for their medical records,<sup>4</sup> AAPD encourages the Workgroup to find ways to greater incentivize consumers to use electronic health record systems such as through direct incentives to consumers who take up PHRs and who bring their records electronically to providers.

*General recommendation:* AAPD recommends the Workgroup find a way to say that health care service delivery cannot be conditioned on using electronic medical records as there will remain consumers who are distrustful of electronic medical records generally and who will need health care. There is need to proceed slowly, with trials and pilots, and constant evaluation and assessment, and with focus on the needs of consumers with disabilities in order to ensure adoption.

END

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<sup>3</sup> For example -- although these are rapidly disappearing terms -- “the blind”, “the disabled,” “epileptics,” “spastics,” “the deaf,” “Mongoloids,” “wheelchair bound,” “the mentally retarded,” ad nauseam.

<sup>4</sup> We know of one person with disabilities who has all her medical records on a thumb drive that she takes to new or replacement specialists for health care service provision because her records are complex and she can’t remember her own medical history well. Interestingly, she says, they usually print off these records onto paper, for their files.