

Prepared Statement for Subcommittee on Privacy, Confidentiality, and Security National Committee on Vital and Health Statistics (NCVHS)

Discussion on the Future of Personal Health Records

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There are pockets of people who remain offline, but the advent of mobile internet access may change that.

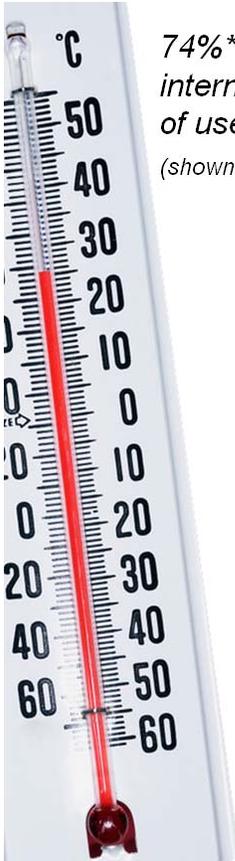
As we talk about the future of personal health records, let's first talk about how much the landscape has shifted in the last decade.

The Pew Internet Project began our work in the year 2000, when 46% of American adults had access to the internet, 5% of U.S. households had broadband connections, and 25% of American adults looked online for health information. Now, 74% of American adults go online, 55% of American households have broadband connections, and 61% of adults look online for health information.

Further, many American adults now have an "always present" connection via wireless devices. Mobile access is changing the behavior of internet users and, in particular, changing the behavior of health care consumers. Our new survey data shows that the mobile internet draws people into conversations about health as much as online tools enable research.

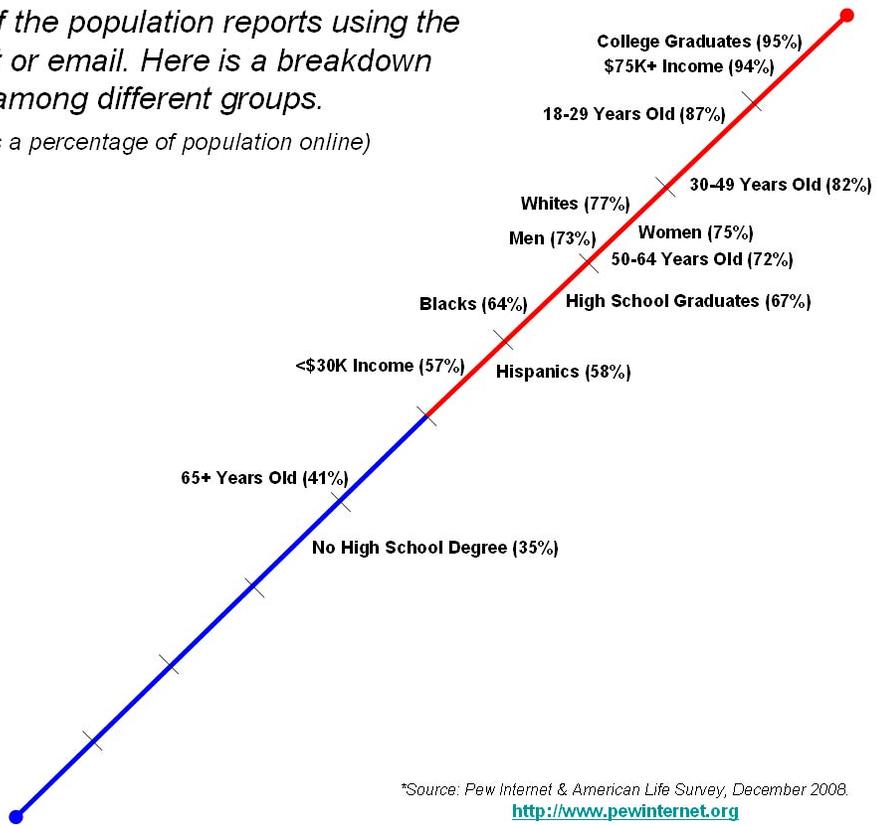
Our understanding of what the "internet" is will change over the next few years as more people access it on small screens, wherever they are, not necessarily on desktop screens at home or at work.

The following illustrations display three "thermometers" of access based on the Pew Internet Project's December 2008 telephone survey. Interviews were conducted in English or Spanish with 2,253 adults, age 18 and older, including 502 cell phone interviews.



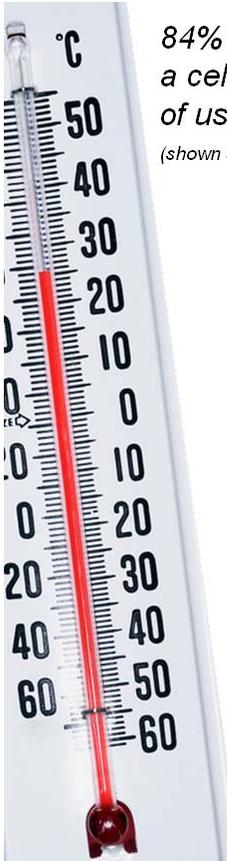
74%* of the population reports using the internet or email. Here is a breakdown of use among different groups.

(shown as a percentage of population online)



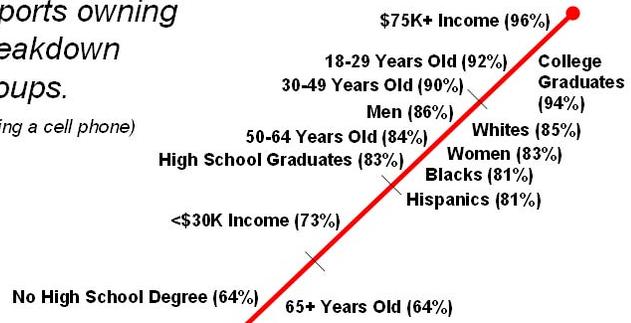
*Source: Pew Internet & American Life Survey, December 2008.

<http://www.pewinternet.org>

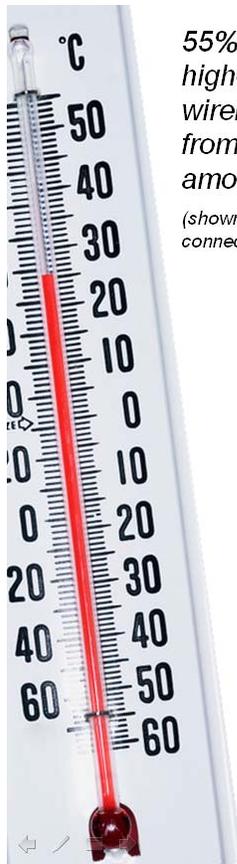


84%* of the population reports owning a cell phone. Here is a breakdown of use among different groups.

(shown as a percentage of population owning a cell phone)

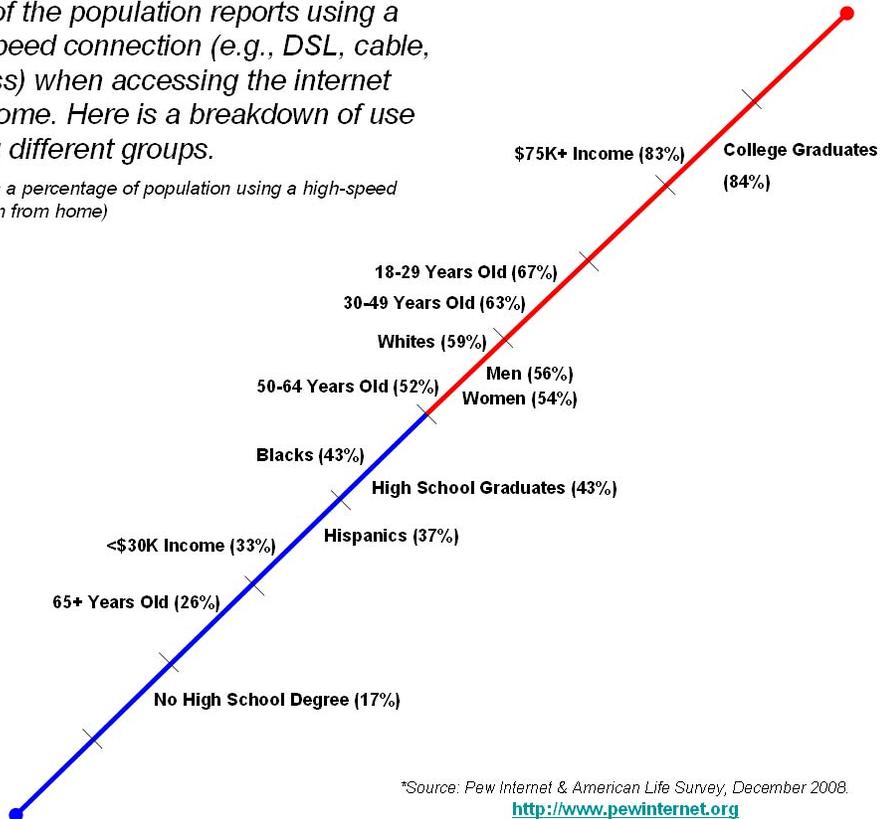


*Source: Pew Internet & American Life Survey, December 2008.
<http://www.pewinternet.org>



55%* of the population reports using a high-speed connection (e.g., DSL, cable, wireless) when accessing the internet from home. Here is a breakdown of use among different groups.

(shown as a percentage of population using a high-speed connection from home)



*Source: Pew Internet & American Life Survey, December 2008.
<http://www.pewinternet.org>

Health care, including health information gathering, is a social activity.

Americans' pursuit of health takes place within a widening network of both online and offline sources. The internet supplements, but does not replace, traditional sources of health information. The vast majority of people with a health question or concern say they consult a health professional. The second most popular choice is to ask friends and family. The internet and books, or other printed reference materials, are essentially tied at third place among U.S. adults who need information or assistance dealing with health or medical issues.

Looking closer at how people use the internet for health care, it is clear that some are going online to connect, in fact, with what we think of as traditional sources: health professionals, friends, and families. People tap into their social networks, both online and offline. Whereas someone may have in the past called a health professional, their Mom, or a good friend, they now are also reading blogs, listening to podcasts, updating their social network profile, and posting comments. And many people, once they find health information online, talk with someone about it offline.

Americans increasingly want access to industrial-strength information, not consumer-strength.

These are signs that people want to access and share “industrial strength” information instead of being satisfied with the “consumer strength” information previously offered to them. In the political arena, more adults than ever before used the internet to read or watch “unfiltered” campaign material last year, such as candidate debates, announcements, position papers, and speech transcripts.¹ In the health arena, e-patients are reading medical journal articles, viewing photos or video of other people with similar conditions, and uploading details of their symptoms and treatments.

Trends to watch: mobile access; generational shifts

Change is coming. First, mobile access is on the rise. More people have a cell phone than have an internet connection. Wireless internet connections are associated with deeper engagement in social media and an accelerated pace of information exchange.

Second, adults between the ages of 18 to 49 are more likely than older adults to participate in social technologies related to health. As younger adults face more health care questions and challenges, they may turn to the tools they have sharpened in other contexts of their lives to gather and share health advice.

What if personal health records could be designed to be part of the naturally-occurring network we see in the Pew Internet Project’s survey data? What if personal health records could take account of the primary relationship between a patient and a health professional, but not make it an exclusive relationship? What if, instead of a health information exchange being one-to-one, a personal health record allowed it to be many-to-many? What if a personal health record gave people access to what the doctors and nurses and insurance companies see, that is, the industrial-strength information? Finally, is it **meaningful** if a patient can’t **use** it?²

Americans’ longstanding practices of asking a health professional, a trusted friend, or a wise family member persist as patients pursue good health – online or offline. These are practices which, in the words of John Seely Brown and Paul Duguid “will not budge” and therefore require designers of any new health care application “to look not ahead, but to look around” in order to see the way forward.³

¹ Aaron Smith, “The Internet’s Role in Campaign 2008” (Pew Internet Project: April 15, 2009). See: <http://www.pewinternet.org/Reports/2009/6--The-Internets-Role-in-Campaign-2008.aspx>

² Ted Eytan, MD, “Is it meaningful if a patient can’t use it?” See: <http://www.tedeytan.com/2009/05/28/3086>

³ John Seely Brown and Paul Duguid, *The Social Life of Information*. (Harvard Business School Press: 2000).