Testimony of Marc Donner, Director of Engineering, Google Health
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Good afternoon and thank you for the opportunity to testify before the subcommittee on the important issue of Personal Health Records (PHRs).

My name is Marc Donner and I am the Engineering Director for Google Health™. I have over thirty years of experience in engineering of hardware, software, and complex systems, and I hold a Ph.D. in Computer Science from Carnegie-Mellon University. My role on the Google Health team is to supervise the infrastructure and product design of Google Health. The focus of my attention is on ensuring our ability to scale, receive standards-compliant data from as many sources as possible, protect the integrity and privacy of PHR information, and increase the usefulness of Google Health data for our users.

In my testimony today, I would like to focus on three main points:

First, I'd like to discuss PHRs and their role in the healthcare industry.

Second, I'll describe Google's health-related initiatives including Google Health, our own PHR product.

Finally, I will make a handful of policy recommendations based on the experience that Google™ has had to date with health information technology generally and PHRs specifically.

PHRs and how they fit into the bigger picture

Google Health launched its PHR in the spring of 2008. In 2006, it was estimated that were roughly 200 PHRs. 1 In the past three years, many more products have emerged, along with Google's offering. While more PHR offerings have generated considerably more industry interest, widespread consumer adoption has still not reached a tipping point. From 2006 to 2007, the number of consumers using online PHRs in the U.S. increased from 2.5 million to 4.5 million. And today, approximately 7.3 million U.S. adults use online PHRs. While this is nearly triple the number of PHR users in 2006, the 72.5 million Americans who have said in

1 Markle Foundation, Josh Lemiux, Personal Communication, December 13, 2006

surveys they are interested in using PHRs shows that tremendous unmet demand that exists. 2

There are two primary PHR models. First, there are PHRs that are hosted by providers or payors and are connected to their information systems or Electronic Health Records (EHRs). These are referred to as "hosted," "linked," or "tethered" PHRs. Second, some PHRs are hosted by independent third party vendors, and are maintained by the consumer exclusively. These are referred to as "untethered," or "free standing" PHRs.

This remains a quickly-evolving space, however. For example, a third model -- called the "platform aggregator PHR" -- has emerged recently. Like Google Health, these PHRs focus on allowing the consumer to aggregate her data, but they also offer a platform model by which third parties can build applications that integrate with the PHR at the consumer's direction and with the consumer's consent. These third parties can offer personalized and customized health services -- known as "add-on" services or tools -- to consumers who elect to use them. The platform aggregator model enables a new ecosystem for healthcare services to be offered to consumers directly, and these services can empower consumers to better manage their health conditions, organize their medications, and so forth.

We believe that these new and innovative PHR models help to empower consumers by putting them in control of their health information and can be an important part of the solution as we grapple with increasing healthcare costs and providing better healthcare to more Americans. However, there remain challenges to reaching the promise that PHRs and other innovative tools offer. For example, the lack of interoperability in the industry continues to be a major barrier to widespread adoption of PHRs. In addition, we see a lack of portability in the PHR space that also poses a hurdle. The passage of the American Recovery and Reinvestment Act of 2009 (ARRA) and the corresponding Health Information Technology for Economic and Clinical Health Act (HITECH) incentives for EHR adoption could help overcome these challenges, and I will address this more specifically in our policy recommendations.

Google's efforts to continue empowering consumers in the healthcare space

Every day, people come to Google to search for health information. Discovery of health information is a critical component of health consumer empowerment. In fact, two out of three physicians believe that patients coming to appointments with online health information is a positive trend, and over half recommend health web sites to their patients. 3 But health information is also very fragmented, and that is where we think we can help. We believe that if consumers have more access to and control over their medical records and health information they can make more informed health decisions.

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2 Manhattan Research, "Cybercitizen Health v. 8.0", 2008

3 CHI, Pew Internet & American Life Project, Manhattan Research, & National Center on Caregiving

As a technology company, we're interested in finding ways to make the Internet and cloud computing part of the solution to this problem. Our corporate mission is to organize the world's information and make it universally accessible and useful. There are few areas in which this goal is more important than in health and health care -- and where we take as much pride in being able to provide services to our users.

One recent example of how our technology can help keep people healthy is Google Flu Trends™. Hundreds of millions of people use Google to research health online. Our team discovered that certain search queries tend to be very common during flu season each year. We compared these aggregated queries against data provided by the U.S. Centers for Disease Control and Prevention, and we discovered that there's a very close relationship between the frequency of certain search queries and the number of people who are experiencing flu-like symptoms each week. As a result, if we tally each day's flu-related search queries, we can estimate how many people have a flu-like illness in near real-time. Flu Trends can help inform the public, doctors, and health officials about flu levels one to two weeks before traditional surveillance systems.

These efforts - known as Google Flu Trends - were released last November for the U.S. In response to inquiries from public health officials, the Google Flu Trends team recently published Experimental Flu Trends for Mexico, which provides flu estimates nationally and for 16 states in Mexico. You can see that the system detected increases in Mexico a bit before major news coverage. It is our hope that Flu Trends provides a useful complement to existing public health surveillance data, especially during this time of increased concern about influenza.

We have also been focused on Google Health, an "untethered" PHR with a platform model. Our product is free to consumers and to partners like pharmacies, labs, doctors, and hospitals who integrate with us. Though the product is relatively new, we have spent significant time ensuring that it was built and continues to evolve based on three key principles.

First, Google Health is a consumer empowerment tool. It is a service that we provide for individuals who want to take charge of their health information with easy access and robust controls. In addition, Google Health is not tethered to any one hospital or medical group or payor. The consumer owns her Google Health Account and manages it herself. Users can store as much or as little information in Google Health as they want. They can store current and past medications, allergies, diagnoses and conditions, lab and other test results, and immunization records. They can enter this information on their own, or can download their medical records from integrated providers, such as hospitals, labs, or retail pharmacy chains. Google Health can also serve as a platform for consumers to receive a variety of personalized and customized health services from companies that are subject to Google Health's developer policies, which require, among other things, that third party developers maintain easily accessible privacy policies on their home pages.

Second, Google Health is a product with privacy protection at its core. We do not sell consumers' private health data to any third party. There is no advertising in Google Health. We do not allow personal health data to be shared unless explicitly asked to do so by the consumer. Indeed, as our first principle states, Google Health is about empowering

consumers and this is a critical way to achieve that and protect consumers' privacy at the same time. With very limited exceptions such as when we are required by the government to provide information, consumers alone decide with whom to show their health information, and what to share. In addition, consumers can revoke sharing rights, delete selected data, or delete their entire account at any time.

Third, Google Health best serves consumers if it supports data portability. Google supports well-defined and broadly adopted open standards that enable consumers to move the data that they choose to destinations of their choice. We support the Continuity of Care Record (CCR) and are working to support other data standards such as the Continuity Care Document (CCD) -- and we strive to make Google Health interoperable with other systems. Consistent with our other products, we do not hold health data hostage, which means that we make it easy for consumers to export their data or delete it at their convenience. In fact, we believe that consumers should be able to easily and completely take their data with them wherever they choose and should be able to transfer their data in and out of any system in a non-proprietary format.

What we've learned so far and our recommendations based on that knowledge

While Google Health and PHRs in general are still early in their evolution, there is much we have learned so far. Here are some of our key observations, many of which also inform our policy recommendations:

- ***Raw data should be clearly interpreted for consumers*** -- For data to be truly useful to consumers it must be presented in context, so that they can understand it and ultimately use it for their benefit. Standardized medical concepts, terms, and codes are not used consistently in the healthcare industry and without appropriate context can be confusing to consumers.

- ***PHRs or systems that interact with PHRs should include more features that help users*** -- Consumers want help with daily health tasks like scheduling, reminders for taking or refilling medicines, how to prepare for an appointment, or when to get a tetanus shot booster. They also want easy access to critical data when they need it most, such as when an emergency room calls in urgent need of the medicines a parent or child is taking.

- ***Acceptance by physicians is important for PHR adoption*** -- If doctors use PHR data at all, we expect them to rely primarily on information from professional sources like pharmacies, labs, and other doctors. Data from medical devices like glucometers and blood pressure meters will probably gain acceptance before other patient-sourced data. Doctors will also need to interact with PHRs in ways that do not interrupt their already busy workflow.

- ***Identity verification is critical*** -- In our model, providers must verify the identity of the patient before any medical data is released and sent to Google Health per the consumer's request. Patient identity verification has been a barrier to working with some providers who have no electronic way to do this.

- ***Incentives must be aligned to fulfill the promise of health IT --*** Partners who have integrated their systems with Google Health are generally early adopters of Health IT and believe in a patient-centered framework of care. Beyond these early adopters, there appear to be no aligned industry incentives for providers and payors to make patient data available to free standing PHRs.

Google believes that over time the broad adoption of PHRs will help empower patients, reduce medical errors, keep costs down by helping to eliminate redundant tests and procedures, and improve the overall quality of patient care. To that end, we support the following policy and industry recommendations:

Make patient data accessible to patients

Google believes that PHRs are a critical component to achieving the "patient-focused health care" goal contemplated in the June 3, 2008 *Federal Health IT Strategic Plan*. As such, Google believes that the Secretary of Health and Human Services should explicitly support the broad exchange of health information between EHRs and PHRs. With regard to the industry-wide certification of EHRs, given the value that we see in PHRs, we believe that having the ability to exchange data with PHRs should be a phased in requirement in the very near term. And with regard to the open definition of "Meaningful Use," requiring recipients of federal funds who purchase EHRs to make patient medical records available online in a semantically interoperable format, using non-proprietary vocabularies where possible, would further encourage both interoperability and portability, both of which are key components to increased consumer adoption and empowerment.

Focus on uniform standards and interoperability

We believe that in order for widespread interoperability to be achieved, the government needs to provide incentives to the industry to work towards a national infrastructure for data exchange using an Internet-based architecture. Consumers and industry will benefit most from a single functional and widely-adopted standard for health information exchange.

One particular effort that the Secretary could focus on in the interest of standards and interoperability is ensuring that all medical concepts can be unambiguously identified through a freely available set of authoritative codes such as SNOMED-CT. True semantic interoperability requires the unambiguous identification of medical concepts. For example, "hypertension" and "high blood pressure" should resolve to the same standard code. In addition, effort should be made to accelerate the readiness of RxNorm, the freely available federal registry of codes to identify medications.

Ensure identity verification on the Web

The Secretary should encourage the industry to create an open network and authentication protocol to specify the exchange of clinical documents. This is similar to the specification of the HTTP protocol which is critical to the browsing of the Internet.

Continue protecting consumer privacy

Google takes the privacy and security of our users' data seriously, and we believe that we have strong privacy and security protections in our PHR. Because protecting consumers' privacy is critical to achieving the goal of empowering individuals with tools like PHRs, privacy should continue to be an area of focus for policymakers in the health IT space.

So far, we have seen several positive steps taken on the privacy front. For example, we are strongly supportive of the ARRA's health information breach notification requirements, which we believe will improve privacy and security practices by PHRs and others and build greater accountability into the healthcare system.

In addition, we applaud Congress's strong desire to spend time determining the best way to ensure strong privacy protections for PHR users, and we look forward to working with this Subcommittee, Health and Human Services (HHS), and the Federal Trade Commission (FTC) to find the best privacy protections that encourage the creation and enhancement of tools for health consumers while at the same time protecting their privacy and security.

Conclusion

In closing, let me reiterate the key points of my presentation today.

The Google Health PHR is a tool first and foremost to allow the consumer to securely and privately accumulate health information about himself and people for whom he provides care.

For this and other PHRs to succeed, consumers' rights must be clearly articulated and effectively defended, open standards must govern the interchange of data, and incentives must be established to align the needs of the consumer with those of the various providers who serve him.

Thank you for the opportunity to share my thoughts with you this afternoon.