Testimony of

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Health, Education, Labor and Pensions

**Achieving the Promise of Health Information Technology:
Improving Care through Patient Access to Their Records**

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Chairman Alexander, Ranking Member Murray, Senator Collins, Senator Warren and members of the Senate Health, Education, Labor and Pension (HELP) Committee, I appreciate the opportunity to testify today on behalf of Intel Corporation. I thank you for your leadership and appreciate the opportunity to speak today about the enormous — mostly untapped — potential of individuals to own their health and contribute positively toward national health transformation. This is a vital topic you have chosen for today. If we are to achieve the "triple aim" in America, then two foundational principles must be delivered upon: full data interoperability and deep patient engagement.

I am a 23-year cancer survivor, a cancer patient advocate, an executive at one of the world's most innovative technology companies, a member of the President's Precision Medicine Initiative Working Group, and a lucky early prototype myself for the lifesaving potential of accessing your own health data and genome-based precision medicine. Wearing each of these hats, I have thought a lot about what must be done to make health care more customized, more connected and more coordinated. Because of demographic trends toward an aging population, it's not optional to take up this challenge of personal, precision healthcare. It is an imperative of our times, global in scale, complex in scope, and — at its very roots — it should be viewed as an opportunity for every individual.

Across all of my different roles, and backed up by fifteen years of Intel's social science research worldwide, I have concluded that each of us must have better tools to participate in our own health and contribute to the well-being of others. Each of us needs access to our own health information that's convenient, timely, affordable, electronic, and secure. Each of us needs to work with our care teams to build care plans, with goals and accurate tracking. Each of us needs to *own our health* — but the healthcare systems needs to do a much better job of giving us the tools, data, and responsibility to do so.

Let's think of the constellation of our health data over the course of a lifetime. Most familiar are the **clinical and claims data** captured at clinics, hospitals, pharmacies, insurers, etc., including such

information as diagnosis codes, prescriptions, program notes, claims, vital signs, and test results. Secondly, there is **diagnostic data** captured by medical devices and imaging equipment. Adding to this now are two new data streams that are rapidly increasing in importance and opportunity: **consumer-generated health data**, captured outside the traditional health system and including such information as patient diaries, observations of daily living, vital sign monitors, fitness wearables, online and smartphone apps, social media and gaming. And finally, there is **'omics** — vast amounts of information contained in each person's genome (and proteome, metabolome) that will increasingly be used to attack disease at its molecular roots. By their very nature, these diverse data (coming from what we at Intel call the "Four Circle Model" depicted below) are collected at multiple sites, across long spans of time, and in a vast array of structured and unstructured formats.
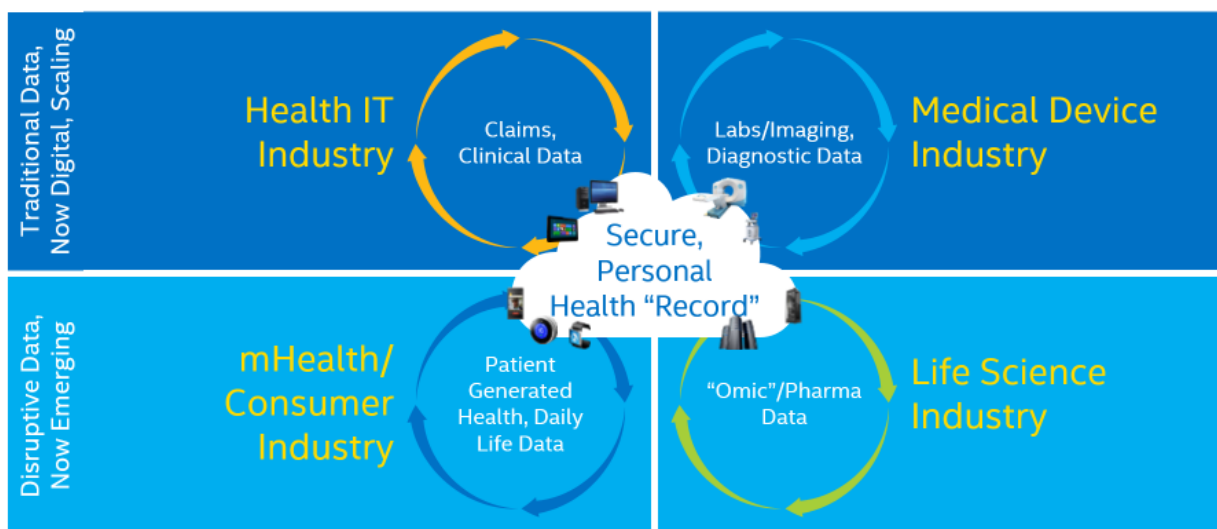
The reality is that personal, precision health in the 21st century will need to make sense of all of this information for deeper insights into population health and individual treatment. These data tell us critical things about one of the most important aspects of anyone's life — our very health and well-being. To me, it's just unthinkable that we would architect a health system — a whole health economy — without facilitating each person's access to one's own data, as well as the ability to contribute meaningful data about oneself back to researchers and data scientists to gain insights into population health and wellness. Sharing of interoperable data must be the foundation of targeted, individual care.

My own life events — from the beginning of my battle with rare and unidentifiable forms of kidney cancer to the happy conclusion 23 years later — have shaped the passion I have for accurate, affordable, comprehensive and timely access to one's own health information. In the summer of 1989 before my junior year at UNC Chapel Hill, I was first diagnosed with a rare form of cancer, hurtling me into more than two decades of chemo, immune, and radiation therapy across 8 states, 6 employers and health plans, and 17 hospitals and clinics. To survive, I had to know my own history, carry my latest data with me, understand the latest clinical trials research, and be on top of promising new treatment options, oftentimes better than many of my oncologists and other specialists. But accessing my own data could be as challenging as surviving the cancer at times.

Five years into this journey, my first near-death experience came because 4 different specialists—none of whom had a complete view of my complex medication regimen—over prescribed off-label treatments that put my heart at risk. Luckily, a nurse and I finally figured out that the drug cocktail—really, a lack of sharing data—was the real culprit, not anything wrong with my heart. Fifteen years into it, the first clinical trial ever for the particular kidney cancer they thought I had at the time came out. After failed attempts for 3 months myself at pulling together my data to be eligible for the trial—and then 3 months more with an attorney doing so on my behalf—I couldn't enter the trial because we couldn't pull my records together in time. In my advocacy on behalf of cancer patients—1220 people so far and counting—I still see this happening every week, even with new laws & technologies that should make it possible.

Much more recently, I was in full kidney failure and running out of options. On what I thought might be my last business trip as head of Intel's healthcare group, I met a genomic startup company that offered to sequence my DNA. After half a year of shipping hard drives of data across the country between oncologists, computer scientists, and data experts, my medical team came back with a plan based on my

molecular makeup. Within months, I was miraculously cancer-free and suddenly on the path to a kidney transplant that saved my life because, for the first time in 23 years, my oncologists had real and detailed data about me as an individual to act upon. I came back to Intel ready to help scale precision medicine to everyone.

In all of these examples, it was simply too hard to collect all of this information on a timely basis so my doctors could determine the best care plan for me. Across my experiences as a cancer patient and advocate—and in the studies of patient experiences Intel has done across more than 20 countries—I see four recurring barriers that often keep data out of the hands of citizens who want it:

1) Medical institutions using **privacy/security policies and laws like HIPAA as excuses** for why they cannot risk sending patients their data;

2) Medical professionals **lacking easy, affordable, interoperable tools to share patient data**, especially because app and device vendors fail to use—or correctly implement—standards;

3) Widespread **beliefs that patients do not have the abilities to use their own medical data safely**, which may be true in many or even most cases, but fail to give them the choice;

4) A growing attitude among almost everyone in the patient data chain—hospitals, labs, payers, software companies, device developers—that **patient data sets are *theirs* to be monetized.**

Revisiting the four-circle model described earlier (which is over-simplified but useful for illustration), we can see that, despite a great deal of progress, each type of data is still not readily available to individuals—or even their clinicians—in most cases:

- **Electronic health record data and claims**: Under the Health Insurance Portability and Accountability Act (HIPAA), patients have a right to see and obtain a copy of their medical records. The American Recovery and Reinvestment Act (ARRA) extends those rights through modifications to HIPAA, requiring healthcare providers who utilize EHRs to give patients copies of their medical records in an electronic format, to another person or entity like a doctor,

caregiver, a personal health record or mobile health application. The information is typically provided on paper or through a flash drive or CD, or an online clinic portal. Unfortunately, the regulations have two significant loopholes. First, patients can receive the information in their preferred electronic format *only if* the provider is capable of producing the copy in the requested format; and second, providers *have 30 days* (and an additional 30 if the information is stored off-site) to make the information available to the patient. (Certification for Meaningful Use Stage 2 is a huge improvement by requiring the information to be made available within 4 business days.) Congress must have envisioned a much easier and faster method for patient access to data. This could be much more readily achieved with today's technology, particularly if more of the information was captured as common data sets in standardized formats.

- **Consumer-generated health data:** Today, there is a plethora of apps and services that collect health and wellness data from devices we wear, carry around with us, or use in our homes and workplaces. However, generally speaking, each have different logins, different and confusing user interfaces, different calibration of sensors, different apps and services. Very few integrate with the systems used by clinicians who make up an individual's care team. And consumers have a very difficult time pulling this information into one repository, controlled by them, that will outlast the particular device, app, employer, or insurance company they are currently associated with. As a founding member of Continua (http://www.continuaalliance.org/), Intel supports a developing ecosystem of certified devices that "plug and play" to give consumer-friendly connectivity to individuals who wish to better manage their health and wellness no matter where they are. If industry adopts common standards, the information from the various devices can be curated and exchanged with the goal of helping individuals understand their information, track their progress, stay on track with their care plans, and generally take more ownership of their health. The potential is enormous for remote monitoring of patients with chronic diseases, with

continuous feedback and more efficient, two-way communication between the patient and clinicians, but only if these data are securely shareable and interoperable.

- **Imaging and diagnostic data:** Medical images make up a large percentage — estimated as high as one-third — of all stored data in the world. The storage demands are very high. Fortunately, cloud-computing environments enable much more cost-effective storage of medical imaging, and there have been great strides in transitioning the hosting of medical images to the cloud for electronic retrieval through healthcare provider systems. However, providing *individuals* with convenient, on-the-go access to these often-large data files remains nascent. Think of the advantage to you as a patient if you were able to log on to access all your X-rays, MRIs, ultrasounds, etc., any time you go to a new provider or the ER, instead of filling out request forms and waiting for the files to be shipped, or paying for an expensive test to be unnecessarily repeated. Since these data types are not usually part of the official EHR per se, the progress on patient access to their own data misses important classes of personal information today.

- **Genomics and other 'omic:** The data from whole human genome sequencing are so large they are impractical to send back and forth across institutions, and we are in the early days of having tool for clinicians—let alone consumers—to make use of this data. I learned this myself when my own 5-terabyte files were being shipped across the country from oncologist to oncologist while trying to figure out the optimal way to treat my cancer. As these new data types begin to scale, it is important that we *start* with commitments to—and validation of—interoperability and standards from the outset so we do not recreate the problems that have plagued us with EHR data. Also, new tools for big data analytics are necessary to scale the potential for precision medicine, such as the Collaborative Cancer Cloud that I describe below.

Because each of these data streams are important to understand each person's whole health picture, providing the individual with access to parts of electronic health record (EHR) systems is necessary but

not sufficient. As the National Institutes of Health builds out the extremely exciting Precision Medicine

Initiative, the 1 million person cohort, and our national strategy to compete globally in the economic

opportunity that precision medicine will present, let's make sure we build an architecture for individual

access to personal health information from the beginning. It cannot be an afterthought, or it will never

happen. We need to learn from the hard lessons from the nation's multibillion investments in subsidies

for EHRs and grants for health information exchanges. We must think about interoperability in much

broader terms than merely the doctor-to-doctor exchanges of EHR data. We need to continue to support

the concept of individual's having personal health records available to them and their care team, anytime

and anywhere, and not tied exclusively to a particular institution or company.

To help show what's possible, I'd like to share what Intel is doing in its own journey to make health care

more effective and affordable and to accelerate the possibilities for precision medicine for all.

Intel's Connected Care Program – an employer initiative for value-based purchasing:

The Connected Care vision is to improve Intel employees and families' healthcare experiences, outcomes,

and reduce costs over time. EHR interoperability plays an important role to help Intel achieve this vision.

In 2013, Intel launched the Connected Care program in Albuquerque, New Mexico. It is essentially an

employer-sponsored and -facilitated accountable care organization (ACO). In focus groups, we heard

from our employees and families that they wanted streamlined access to primary care and specialists. In

response, Intel significantly changed its relationship with the healthcare system in the Connected Care

Program. We contracted directly with the healthcare supply chain, removing middle men. We built a

network of 11 primary care medical homes, including an onsite clinic, and medical neighborhood of

specialists and facilities. To ensure timely access to care, Intel and Presbyterian Health Services agreed on

protocols for call responsiveness and established acceptable levels of appointment availability. We

contracted directly with Presbyterian Health System in an arrangement that aligned incentives and shared

risk, with outcomes measured according to the following accountability metrics:

- **Right care:** Use of evidence-based medicine to improve population health, focusing on diabetes, hypertension and depression.

- **Right time:** Timely access to care in the optimal setting, including a nurse hot line.

- **Best outcome:** Patient satisfaction 100 percent of the time.

- **Right price:** Material decrease in the cost of care, per patient per month.

- **Best life:** Rapid return to productivity.

Employee response has been excellent: More than 3 in 4 eligible employees opted to join the Connected Care Program. So far, major successes have included greater member engagement with the healthcare system, very high satisfaction ratings, and statistically significant improvements in diabetes control. We have yet to demonstrate an improvement in costs. In the long term, we believe that promoting proactive primary care with deep patient engagement and accountability should improve health outcomes *and* costs as we iterate this program.

Successful preliminary results in New Mexico drove the decision to scale Connected Care to Oregon this year. The Oregon implementation had a deeper need for sharing of our employees' electronic health records because it included two large health systems — Kaiser Permanente and Providence Health and Services — in addition to ambulatory providers The Portland Clinic and Premise Health. With our partners, we addressed the data liquidity problem head-on first through contracts that focused on seamless care that required data sharing across institutional boundaries.

The Connected Care interoperability team at Intel selected the Direct messaging standard and the Healtheway eHealth Exchange (recently renamed The Sequoia Project) to support the business and clinical requirements for coordinated care. The Connected Care data exchange model utilizes the HL7 Consolidated Clinical Documentation Architecture (C-CDA), which is a key part of the data

interoperability specifications in Meaningful Use Stage 2. The EHR interoperability model in Oregon is nationally recognized for having an innovative approach for point-of-care access to electronic health records. New care coordination workflows are using data exchange with healthcare information coming to them in real time, resulting in quicker access to care with less work for everyone involved. Having the most up-to-date healthcare data means a more efficient model where physicians and patients can now make the best possible choices about their care planning, leading to lower costs over time. And, critically, this data exchange model is enabling consumer health pilots that will improve Intel employee experience and improve health engagement.

We relied upon the security, authorization and privacy measures governed by national standards (eHealth Exchange/NHIN and Direct messaging), and HIPAA for exchange of clinical records. This includes end-to-end encryption of data, authorization, PKI/digital signatures and appropriate access controls. The underlying technology standard is called SAML, which is used to assert authentication of the user. Members of the eHealth Exchange secure their communications using x.509 certificates whose chain-of-trust begins with the same Root Certificate Authority (CA), thus facilitating trust between organizations without the need to exchange certificates.

For more specific information on the interoperability challenges and the value provided from joining Healtheway/Sequoia for a query-based system, Intel, Kaiser Permanente, and Providence Health and Services, The Portland Clinic and Premise Health have produced a white paper accessible at the following URL: https://www-ssl.intel.com/content/www/us/en/healthcare-it/advancing-interoperability-healthcare-paper.html.

Intel's work with consumer-generated health data:

The Michael J. Fox Foundation for Parkinson's Research (MJFF) and Intel Corporation are collaborating on improving research and treatment for Parkinson's disease — a neurodegenerative brain disease second only to Alzheimer's in worldwide prevalence. The collaboration includes a multiphase research study using a new big data analytics platform that detects patterns in participant data collected from wearable technologies used to monitor symptoms. This effort is an important step in enabling researchers and physicians to measure progression of the disease, improve medication adherence and speed progress toward breakthroughs in drug development.

With wearable technology, the potential to collect and analyze data from thousands of individuals on measurable features of Parkinson's, such as slowness of movement, tremors and sleep quality, could enable researchers to assemble a better picture of the clinical progression of Parkinson's and track its relationship to molecular changes. Wearables can unobtrusively gather and transmit objective, experiential data in real time, 24 hours a day, seven days a week. With this approach, researchers could go from looking at a very small number of data points and burdensome pencil-and-paper patient diaries collected sporadically to analyzing hundreds of readings per second from thousands of patients and attaining a critical mass of data to detect patterns and make new discoveries. It is a dramatic shift from data-poverty to data-wealth — and in my view it signals the future of research and discovery.

MJFF and Intel share a commitment to increasing the rate of progress made possible by open access to data. The organizations' aim to share data with the greater Parkinson's community of physicians and researchers as well as invite them to submit their own de-identified patient and subject data for analysis. Teams may also choose to contribute de-identified patient data for inclusion in broader, population-scale studies.

We have also launched the YOU.24x7 Study, a 6-month observational pilot study of nearly 500 participants that uses an end-to-end prototype platform consuming patient-generated data for research into health trends and behaviors to analyze cardiovascular risk factors and potentially improve outcomes. Patient data are collected through a number of devices: a Basis watch to track sleep and activity, plus blood pressure and weight scales in the home. These data are combined with electronic medical record information, labs and other key metrics to give more holistic view of the population. Data scientists and cardiologists are using an advanced analytics platform created by Intel, looking at the de-identified data to gain trending and correlation insights into cardiovascular wellness. Meanwhile, the individual participant has 24x7 access to all of his or her own information through the secure personal health collaboration hub provided online by a company we helped to form called Dossia.

Intel's work in precision medicine

Intel and Oregon Health & Science University (OHSU) recently announced the Collaborative Cancer Cloud, a precision medicine analytics platform that allows medical institutions to securely share insights from their private patient genomic data for potentially lifesaving discoveries. Intel announced that key technology components of the Collaborative Cancer Cloud (CCC) will be opened sourced. Hospitals and research institutions of all sizes could use the technology to advance personalized cancer research. They can also apply it to advance personalized research in other diseases that are known to have a genetic component, including Alzheimer's, diabetes, and more. Intel and OHSU also announced that they will partner with two other large cancer institutions to extend this capability in 2016.

The project combines next-generation Intel technologies and bioscience to enable solutions that can be used to make it easier, faster, and more affordable for developers, researchers, and clinicians to understand any disease that has a genetic component, starting with cancer. It will enable large amounts of data from sites all around the world to be analyzed in a distributed way, without having to move the data itself, preserving the privacy and security of that patient data at each site. The end goal is to empower

researchers and doctors to help patients receive a diagnosis based on their genome and potentially arm clinicians with the data needed for a targeted treatment plan. By 2020, we envision this happening in 24 hours — a challenge to the computing and life science industries that we call *All in One Day*. The focus is to help cancer centers worldwide — and eventually centers for other diseases — share with one another the insights that reside in their private clinical and research data without having to share the data itself. This approach is designed to protect data privacy and the business models of the research centers while at the same time unlock the insights from far larger datasets to benefit research and inform the specific treatment of individual patients.

As an employer faced for years with unsustainable healthcare cost inflation for the 53,000 employees we are proud to employ in the United States and their 88,000 Intel Health Plan dependents, Intel has initiated these projects for business reasons — both to support a healthy, productive workforce and to grow the global market for the powerful computing needed to scale precision medicine. We hope these programs can become examples for the rest of the country to build upon. And we believe Congressional support of four key themes can help examples like these proliferate across the country.

1) **Sustain momentum toward standards and interoperability:** As Intel's Connected Care Interoperability team demonstrated, a standards-based approach for health information technology enables quicker and more efficient deployments to share data from different sources. This provides scalability, interoperability, and innovation as new services can be built upon a common framework of standards, data models and clinical vocabularies. Intel supports an implementation specification compatible with baseline standards that are specific, well-documented, tested vigorously, and shared publicly, as described in HR 6, the 21st Century Cures Act.

2) **Encourage patient engagement by removing obstacles for patients to access and share their data.** With the adoption of electronic health records comes enormous potential for creating value from data held in millions of patient records. Today, the use of this information is regulated by a series of highly regulated consent requirements constructed by not only the federal government, but by states. Intel invites policymakers to partner with industry to pursue a standardized machine readable consent form to allow patients to donate their data to ongoing research without the need for securing and faxing consent forms each time patient data is requested. The International Rare Disease Research Consortium has recognized this problem. The Consortium has assembled a task team from the Global Alliance for Genetics and Health to explore the machine readability of consent and its impact on data use and accessibility. PCORI has launched research into patient preferences for consent,[1] and The Broad Institute has launched "Count Me In", a patient consent effort to facilitate genomic research. Consistent with the 2013 memo from the HHS Office of Civil Rights[2], individual access to personal health data could advance if personal health record organizations are allowed on the eHealth exchange network run by The Sequoia Project to collect information across provider systems on the patient's behalf. Credible personal health records should be allowed to securely capture and transmit patient consent electronically to the source systems and establish connectivity.

3) **Continue to push toward value-based care:** We support the HHS goal announced this year to move 30 percent of care to alternative payment models by 2016 and to 50 percent by 2018. When incentives are aligned toward value-based care and managing population health, the demand for information-sharing goes up. Fee-for-service models work the opposite way, in which providers are paid based on the volume of service they deliver. Based upon Intel's experience with

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[1] http://www.pcori.org/research-results/2014/demonstrating-respect-and-acceptable-consent-strategies-what-matters-patients
[2] http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/righttoaccessmemo.pdf

Connected Care, we have seen increased patient engagement and better outcomes based upon shared risk, shared goals and consistent metrics for success. As the U.S. healthcare system moves to outcome-based payments through the Medicare Access and Chip Reauthorization Act (MACRA), Congress can assist through providing funding for new care delivery tools for training and discovery until the 2019 implementation date. Specifically, pilots should be funded for remote patient monitoring (RPM), which remains mostly unpaid in today's fee-for-service environment in spite of studies showing as much as a 75 percent reduction in hospital readmissions when provided to chronic care patients.[3]

4) **Erase disparities**: Despite amazing advances in health and healthcare, many dimensions of disparity remain, particularly in health. The recommendations that we've outlined today – standards and interoperability, giving people access to their health data, lowering barriers for people to participate in and access precision medicine, and value-based purchasing must be achieved with a mindful eye on the diversity of our nation, ensuring that solutions are a good fit for people across the array of incomes and ethnicities and in both rural areas and in urban ones. Achieving health equity means making sure that all Americans have a fighting chance to own their health, which is not possible if they can't first own and use their own health data.

Conclusion

I am a lucky, living prototype of the precision medicine future that countries around the world are competing to develop for their own citizens and for their own economic growth through the invention and

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[3] http://healthaffairs.org/blog/2014/04/04/the-role-of-remote-care-management-in-population-health/
http://www.telehealthresourcecenter.org/sites/main/files/file-attachments/snell-smalley_hospital_-physician-summit-feb-2013.pdf

intellectual property of precision medicine. As a cancer survivor and kidney transplant recipient, I collaborate on improving my health (and lowering my costs) together with my care teams, and I am very engaged in owning my own care. At every step of the way in my health journey, access to my own health information has factored heavily in the difference between success and failure. But Congress and the health sector should not be designing our infrastructure, systems, and policies for me, a fortunate, well-educated, well-compensated Intel executive who has connections with health experts all over the world. We should design policies, standards and economic incentives to promote individual access to personal health information for people who have none of my advantages. We need to design for people with big health needs but low health literacy, and then those systems will work well for everyone. On behalf of Intel Corporation, thank you for your leadership and opportunity to speak today.

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