WRITTEN TESTIMONY OF

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MEANINGUL USE WORKGROUP

Panel on:
Meaningful Use of HIT in Real Lives of Patients and Families

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Introduction

Good morning Chairman Tang and members of the committee. My name is Eric Dishman, and I am honored to participate in today's important discussion of how healthcare information technologies (HIT) can be deployed in meaningful ways with patients and their families to improve healthcare in America. You are bringing forth an issue that is critical to our national healthcare strategy and economy: namely, how to make sure that our country's investments in healthcare IT don't stop at the hospital door or with the clinician but extend to the home and to citizens who need to be increasingly engaged, empowered, and equipped to collaborate in our own care and good health.

As a social scientist who has run Intel's healthcare research and innovation efforts for more than a decade, I have seen first-hand that HIT, when designed intentionally to fit into the home and community and to connect families with professional providers, can help with prevention, early detection, self care, behavior change, and caregiver support. As co-founder and past-Chair of CAST, the Center for Aging Services Technologies, a non-profit dedicated to the advocacy of personal health technologies to help seniors age-in-place with dignity and choice, I have witnessed hundreds of promising IT solutions in research that now need to move from laboratories to the lives of seniors and families across the country. And as a cancer patient advocate over the past 22 years of my life, I have personally seen how the emergence of internet, social networking, and telehealth technologies can improve the quality of life not only for the patients, but also for their families and their often frustrated, over-worked professional providers.

I look forward to sharing more of the findings—and further questions—below that our research and my experiences have uncovered as you consider policies and programs to insure that health IT includes engaged patients and families as part of our national "careforce." As I do, I should say up front that I am inspired and informed by the 2008 Institute of Medicine report, *Retooling for an Aging America: Building the Health Care Workforce*[i], which calls for an expanded, more inclusive definition of the healthcare workforce that encompasses family, friends, and patients themselves. I believe that the care coordination, workforce, quality, access, and cost challenges inherent in reinventing long term care in America typify and anticipate our broader health reform challenges that health IT, among other things, must address. And given that my particular passion and focus for the past 18 years has been on seniors and their families, much of my testimony will focus there.

Towards Personal Health Technologies with Engaged Patients

For more than a decade now, Intel social scientists, clinicians, and engineers have conducted ethnographic fieldwork in the homes of more than 1000 elderly citizens in 20 countries[ii]. This longitudinal research has entailed observing these patients and their family caregivers (who themselves have often been dealing with multiple chronic conditions, high stress, and other health issues) in their homes, at clinic visits or hospital

stays, at their grocery stores or exercise clubs, and wherever health and wellness intersects with their lives.

Also, we have now conducted more than 14 in-home pilots of HIT—what we call "personal health technologies"—covering a broad range of needs and topics: diabetes, COPD, congestive heart failure, asthma, arthritis, cancer, Alzheimer's, Parkinson's, medication assistance, virtual visits with doctors, vital signs capture, personalized patient education, fall prevention, social support, transportation support, and support for activities of daily living. And we have had the wisdom and support in our research from seniors themselves, from two several-hundred household cohorts—at the TRIL Centre (www.trilcentre.org) in Dublin, Ireland and at the Oregon Center for Aging and Technology (www.oracatech.org) in my home town of Portland, Oregon—where new HIT prototypes are tested in their homes with their families and providers. I'd like you to meet one such participant, "Jean," whose story illustrates some of the key needs and opportunities for personal health technologies to improve access, quality, and costs[iii].

» Jean, a retired elementary school principal now in her mid 80s, lives for email, where students from across the country—many of them now parents themselves—contact her with stories about their lives or memories of their school days. She beams with pride for each one, as if they are her own children. Her actual children—ages 50 and 52—live two time zones away, and she sometimes confuses them with each other and with some of her "school children." One of them calls almost daily, but both of them report that it is hard to have a sense of how Jean is really doing because "she always says she is fine."

Her husband having passed away 15 years ago, Jean lives alone in her 3000 square foot home of 52 years—a 4 acre farm property on the outskirts of a town of about 40,000 people. As she puts it, "I spend most of my life now hunting and searching for reliable people to care for the yard." And more than once, we observed her still trying to do household chores—even mowing the yard with an old hand-push machine—that were dangerous.

She is 45 minutes from her main doctor, though as she puts it, "I have so many that I never know which one I am talking to." She may as well be thousands of miles away from everyone given that she can no longer drive due to some persistent dizzy spells, which left her lonely and isolated until she got online. That loneliness is even more pronounced for Jean during the rainy and snowy months when she can't get outside, and as she describes it, "I may as well hibernate like a bear in a dark, cold cave during that time of year." Meals are the loneliest times, so she eats snack foods all the time.

With emphysema (she smoked back in the days when the teacher's lounge was, in her words, a "grey haze of gossiping grey hairs!"), hypertension, diabetes, obesity, and a history of "heart problems" that she can barely remember the details of anymore, Jean has been to the urban hospital (she calls it "the fancy, loud place") a couple of hours from her home—and a nursing home for recovery—at least a dozen times over the past few years. She struggles to take 11 medications daily and her insulin, though sometimes the neighbor (a retired science teacher from Jean's school) checks in to remind her. Her life savings are almost gone; she dreads the idea of a nursing home.

We have interviewed and lived with hundreds, if not thousands of "Jeans" over the past decade. And we see in her narrative many common needs that personal health technologies can address in helping Jean, her providers, and her family to coordinate her complex, holistic care—often from great distances.

- understanding the array of doctors and experts who provide care
- tracking and managing multiple chronic conditions
- caring for a large home and property with reliable services
- maintaining a sense of purpose/productivity/usefulness
- managing multiple medications throughout the day
- dealing with extreme social isolation and loneliness
- finding ways to get around town or to get to the doctor/hospital
- struggling with falls and the fear of falling from dizziness
- coping with periodic confusion and memory loss
- knowing, as a neighbor, if, when, and how to help out
- determining, as a distant daughter or son, if someone needs help

To address some of these challenges above, here are some of the research prototypes and technologies we have tested with Jean over the years:

A wireless sensor network in Jean's home—from simple motion sensors to "shake sensors" placed on key objects like kitchen cabinets, coffee pots, and hairbrushes—helps Jean herself (via a digital photo frame that shows her progress) and her two children (via their PCs) know if she is engaged in her normal daily routines. Has she gotten out of bed? Has she fixed coffee and breakfast for herself as usual? Is she getting the typical amount of exercise around the home throughout the day? Has she been near her pill caddy and presumably taken her medications around the right times?

Jean has also learned to use a simple telehealth station that she placed back in her bedroom, where she starts each morning. The system flashes and beeps as her "wakeup call" and also when it is time to take her morning meds or to answer a daily survey about how she is feeling, sent to her from her main care nurse who oversees all of her many medical encounters. Jean often plays a few "brain games" and video card games on the system when she feels like it. She takes her blood sugar, blood pressure, and weight—with the data going to her son, the nurse, and to her own records. She has regularly scheduled video chats with her nurse, who occasionally also checks in when some of the vital signs seem out of normal range.

Using their "dashboard" that looks at trends and deviations from those norms—in everything from vital signs to motion patterns around the home to how frequently Jean is playing or losing online games—her family, nurse champion, and neighbor are connected with Jean and each other via social networking technologies to collectively see how she is doing, delegate assistance, and remind or coach her to manage many aspects of her care for herself. They act as a team with each person knowing their roles.

Below are more participants from our pilots and some of their experiences with personal health technologies in their homes (with links in end notes to more detailed papers):

» **“Ben,”** a 72-year old CHF patient, now facing the challenge of taking his 12 medications daily, without support from his wife who recently passed away. Wireless sensors in his home help Ben, his adult son, and a nurse practitioner manage his meds routine, with intelligent prompts that can appear on his watch, TV, phone, or small screens placed around the house but that don’t bug him if he has already taken the meds, is asleep, or on the phone.[iv]

» **“Phillip,”** who is in his 10th year of dealing with diabetes, and gets customized patient education sent to him based on his weekly vital signs, his answers to questions from his physician, and his exercise/nutrition logs that he keeps online with a social support group.[v]

» **“Gladys,”** an 89-year old retired nurse now living in an assisted living facility, was team lead for her hallway to each get 10,000 steps a day. Wearable internet connected pedometers fed their data into a television monitor that showed their progress towards 1,200,000 collective steps for their team that week!

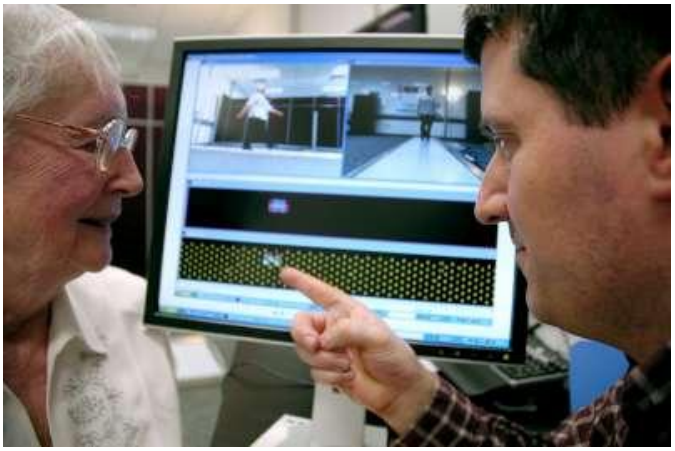
» **“Carl,”** an 86-year old Parkinson’s patient who wears a watch that measures his tremor all the time and uses a laptop-sized prototype to test his speech and motor skills daily to help his physician and daughter monitor the progression of—and some day medications for—this disease that can vary greatly day by day.

» **“Anne,”** is a nurse of 21 years, who is exhausted by all of the paperwork to track the safety and activities of daily living data for the elderly residents she cares for. A sensor network system helps track those activities—getting dressed, toileting, exercise, preparing a meal—and reports back the progress to her and to the families of the residents so she can do more bedside care, less paperwork.[vi]

» **"Betty,"** is only 49 but has early stage Alzheimer's and is using software that helps her practice the names and faces of people who visit her, as well as see a photo and the relationship of the person who is calling her on the phone. Her neurologists and family caregivers can review reports that show Betty being more or less socially engaged than usual, as well as how she is doing on a series of cognitive games that she plays daily on her computer.[vii]

» **"Phyllis,"** is 71 years old and still drives a car in her rural village. She uses a GPS system and a ride sharing social network site to offer rides to other seniors in nearby villages who can no longer drive themselves, thus helping solve a transportation problem and supporting more social connection for everyone.

» **"Jennie,"** who has had some trouble walking after rehab from hip surgery, has a small wearable device and an area of carpet in her home that has sensors in it to look at subtle changes occurring in her movement patterns around the house to alert her and her doctor if she may becoming more at risk for a fall.[viii]



» **"Hal,"** who lives on a farm more than 150 miles from the largest city and hospital, does virtual video visits with his geriatrician to check on his heart disease, weight, and pacemaker without having to make long trips as often.

Across these studies, there are some fundamental capabilities that HIT to the home enables: 1) empowering patients with tools that help them makes sense of—and to do—their own care; 2) collecting real-world biological and behavioral data and trends in the home with alerts for out-of-norm situations; 3) facilitating virtual visits with providers, when appropriate, via a range of media; 4) enabling social networking, awareness, and care support from family and friends who are nearby or distant; 5) personalizing care plans and educational content for each patient based on their needs, preferences, data, and capabilities; and 6) triaging precious medical resources to enable the right amount of care to occur in the right place and time.

These personal health technologies create new, real-world data types and early warnings that aren't available in a clinical encounter or captured in a traditional EHR. They facilitate new modes of care coordination between the "holy trinity" of healthcare: the patient, the providers, and the family caregivers. And they distribute care delivery based on need and appropriateness, whether it's in the home, the clinic, virtually…delivered by an expert professional, an informed family member or friend, or the patient him or

herself. While no "magic pill" for every healthcare challenge our nation faces, they will be a fundamental part of reforming our healthcare system for the 21st century. They will help us move beyond the clinic and hospital into the community—beyond a quantity oriented system to a quality one—by enabling new relationships and delivery models that we need to explore, evaluate, and embrace as quickly as possible.

Preparing for the Y2K+20 Challenge

We live in demographically challenging times. According to the U.S. Census Bureau, back in the year 2000 there were about 600 million people worldwide who were 60 years old and above. By 2025, those numbers will double to 1.2 billion people. And by 2050, a date not so far from now, we will have more than 2 billion people over the age of 60 on our planet[ix]. Our government needs to catalyze a public-private response to this Age Wave that rivals or exceeds what we did for the Y2K challenge. Ten years ago, I referred to this demographic imperative as the "Y2K + 10" challenge because 2010 is when the first Baby Boomers reach official retirement age. But alas, 2010 is here, and we are still largely unprepared as a nation—technologically, educationally, financially, personally.

Perhaps a more updated call-to-action would be to recognize "Global Aging" as equal to Global Warming for the threats and opportunities it presents our nation—to solve a huge social problem while also inventing whole new American-based technologies and industries. Whatever we call it, investing in HIT needs to be one part of a national plan that prepares our country for this Age Wave—not only to meet the healthcare and social needs of an increasing number of seniors but also to be able to offer quality care to people of all ages with increasingly scarce resources and to compete in a global marketplace where healthcare expenditures deplete other sectors of the economy.

It is clear that health care as usual—that is, crisis-driven and clinic-centric care—will not meet the needs of this Age Wave that will yield more people in need of major healthcare interventions, fewer professionals in the medical workforce, and greater competition and crowding for clinical access. In fact, we see this situation already occurring just with the passage of the recent healthcare reform bill which, importantly, provides coverage to 30 million or more Americans who were previously uninsured. With the stroke of the President's pen, there was no sudden increase in the number of doctors, nurses, clinics, appointments, hospital beds, or family members to care for this population. We will need to deploy resources—we will have to *do* care—differently to meet the needs of this uninsured cohort first, followed by the large cohort of retirees coming soon thereafter. Thus, health IT delivered that "last mile" into the homes and lives of citizens—as patients, as caregivers, as parents, as retirees, as employees—is crucial in building a 21st century healthcare system that can be available and affordable to everyone.

The significant investments in health IT infrastructure and the incentives for clinician adoption in the recent ARRA stimulus legislation as well as the health reform bill are an important starting place. Without a national infrastructure—an "electronic highway" for health information—it will be impossible for the United States to deliver quality care to

more people at lower costs. We must move towards a world in which accurate, secure, real-world, and eventually real-time data can be used on a "micro" level (e.g., a physician reviewing lab data at the patient bedside) as well as a "macro" level (e.g., a group practice reviewing its quality data to improve the effectiveness and efficiency of its best practices).

The current policies and laws are designed to get the U.S. to the first phase of Health IT—what I call the "Get Connected" phase. I often use the following four-phase framework with healthcare customers and collaborators I work with at Intel. It is admittedly over-simplistic, but it helps to show a progression of HIT adoption:

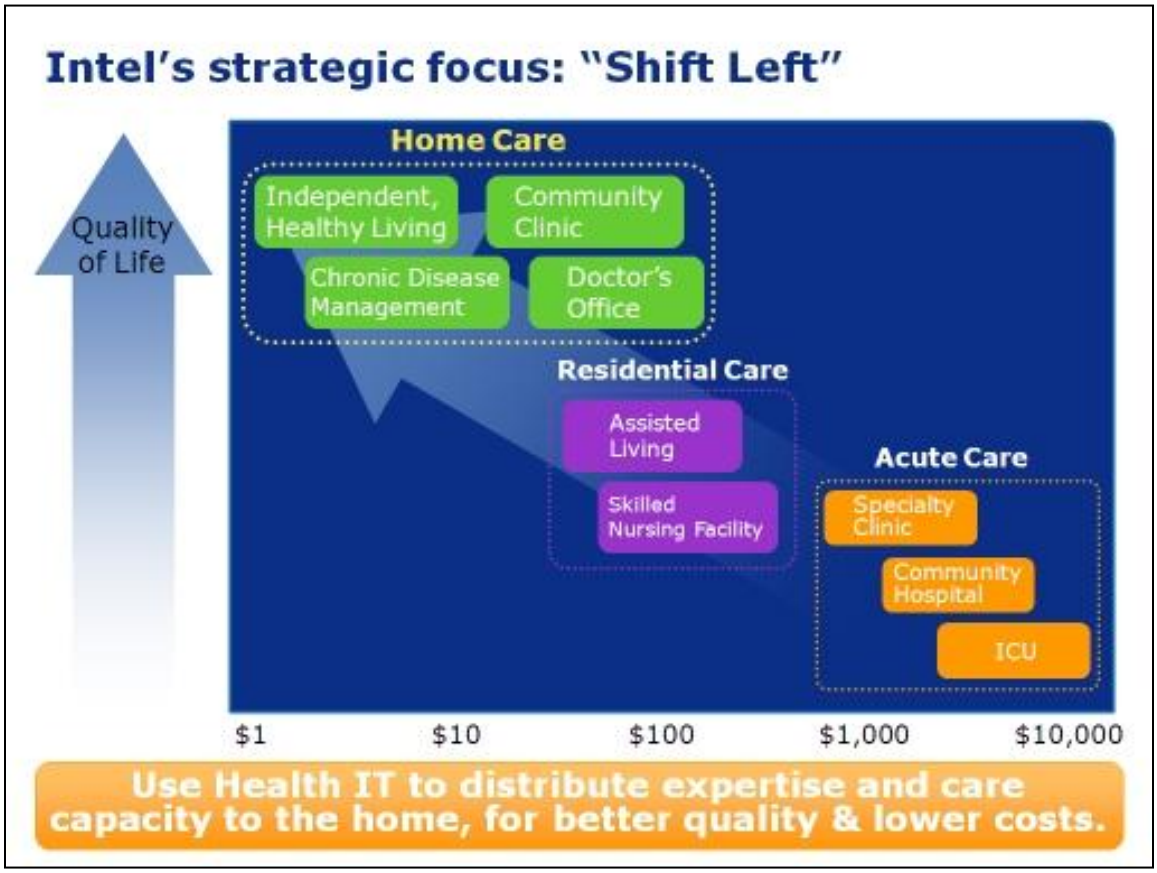
> **Phase I: Get Connected:** All providers have—and regularly use—basic, secure EHR software to collect and share patient data across the medical enterprise, with basic computerized physician order entry (CPOE) as routine for all stakeholders.
>
> **Phase II: Get Decisive:** All providers are using decision-support systems, with best practices implemented, and quality data metrics in place (on top of their EHR) to flag variability, breakdowns, or areas for improvement.
>
> **Phase III: Get Coordinated:** All providers regularly use a wide array of care coordination tools (shared records, shared virtual whiteboards, multimodal messaging, care plan tracking, etc.) with one another and with the patient and family members, with each constituent playing his or her role.
>
> **Phase IV: Get Personal:** We have a proactive, prevention-oriented system of care that personalizes care plans based on multiple diseases, incoming data, patient preferences, available resources, and, increasingly, genetic information, that shifts care and responsibility to the patient and to the home when appropriate.

This first phase is a precursor to everything else we need to do as a nation to transform healthcare delivery to prepare for our Y2K + 10 challenge. This is where medical institutions—even those like rural hospitals, community health centers, and small physician practices that have previously been ignored or under-funded—and clinicians of all types "go online" with an electronic health record. But if all these HIT investments do is manage to automate the "old" way of doing healthcare (reactive, expert-driven, and requiring a clinic visit for every care encounter), that will not be enough to cure our imminent demographic and economic woes.

I had the privilege of working on the National Research Council report, *Computational Technology for Effective Health Care*, which advises: "Organizations should architect health care IT for flexibility to support disruptive change rather than to optimize today's ideas about health care."[x] Meaningful Use of HIT as currently conceived and designed will not take us far enough. We need to anticipate and design for disruptive change, especially as we shift towards a paradigm of payment for results from one optimized and operationalized around payment for visits and tests conducted.

To produce a personal health system that can meet the demands of the Age Wave, we need to broaden the focus of "healthcare" beyond acute care to all its domains: primary care, prenatal care, chronic care, home care, long term care, etc. using HIT to triage resources and shift care to the home, community, and informal care networks as much as possible. And we need to look for ways to drive more disruptive transformation towards Phase 3 and Phase 4 where HIT is not only integrated into the workflow and culture of care but is being used to drive a more proactive, prevention-oriented system. Finally, we need reform policies and HIT investments that focus more attention on the specific needs of seniors, who are most often dealing with multiple chronic conditions, numerous medications and therapies, and the most expensive utilization.

At Intel, a useful phrase that captures our own strategic intent—and rallying cry—for HIT innovation is called "Shift Left." The diagram below shows the basic concept. Our goal is to invest in innovations that ultimately shift care out of expensive acute care settings and into the community (primary care clinics) or even the home, where quality of life is higher and daily costs are lower.



If we can "shift left" much of the chronic and non-emergency care that patients need from the hospital to the home, then we can reserve those most expensive care delivery systems for the most extreme circumstances. As Carol Levine and her co-authors point out in a recent *Health Affairs* article, that shift is already happening: "Almost unnoticed, health care providers have shifted to family caregivers more demanding and complex

kinds of care that last longer periods—sometimes for decades."[xi] We must now *consciously* and *conscientiously* move care, responsibility, training, infrastructure, and resources to the home and community, thus offloading the traditional healthcare institutions that will be besieged by newly insured and/or newly retired citizens. It is not just about technology, but also about "skill shifting" some of the aspects of care done by medical professionals today to patients and family members, who will need training, incentives, and support to take on these new roles and responsibilities.

Whether it is something akin to the HIT phase model or "Shift Left" strategy I described above or something else entirely, we need some clarity about what the "end game" for healthcare reform looks like in order to guide the Meaningful Use of Health IT over time. The President and Congress have repeatedly highlighted key elements of that end state: universal coverage of people and conditions; a health care system as opposed to a sickness care system; a prevention-oriented system; one that focuses on quality of care delivery instead of quantity; a system in which data-driven care coordination and evidence-based best practices are the norm. But these powerful ideas have yet to cohere into a unifying and understandable strategy by which to guide our investments and measure our progress. Ultimately, the President and Congress need to challenge our nation with a going-to-the-moon type goal for healthcare reform that aims high and lets us know, as a country, where we are headed and when we've arrived.

One of the big, audacious goals we at Intel have been advocating for is: *Move 50% of care to the home by 2020*! Think Y2K + 20, perhaps. This would be a national call to action—a ten year strategy—to drive innovation, infrastructure build out, and industry investment that enlists patients and their families into the care of our swiftly aging nation. Whether 50% is achievable (or even desirable) is up for debate. But the basic concept is well warranted given the demographic and economic realities we face. Patients and families have to be designed into—intentionally, with forethought and planning—our new system of healthcare as proactive, engaged participants. They cannot be an afterthought, or tacked on to an EHR build-out that focuses only on acute care institutions and clinicians. To make the most meaningful use of health information technologies, we must enable and optimize new relationships and responsibilities among patients, professional providers, and family caregivers—and shift from a hospital-and-clinic paradigm to a home-and-community paradigm that is accessible, affordable, and sustainable over the long term.

Designing Patient & Family Engagement Systems

Based on the ethnographic research and home-based pilots Intel has done over the years, what are some of our "lessons learned" about engaging patients and families through health IT? Summarizing 11 years of research done in 20 different countries—with enormously varying cultural contexts, healthcare systems, and infrastructure available—is perhaps a dangerous undertaking. So I've focused only on U.S. households for the sake of this analysis and have tried to summarize below some of the top level findings that cut across many of the studies we have done with American families.

Common Needs for Patients and Families

One of the reasons we spend so much time observing patients and their families "in the wild" is that you can't just ask them how they want to be engaged in their own care in the future and expect much of an answer. Very few people we study have much understanding or imagination of—or even a vocabulary for—ways they could better engage with their providers or with their own health management. Similar to the early days of email when no one knew what it was (and thus told us they would never use email), our survey and focus group data about health engagement technologies would lead you to believe that no one wants them.

But our fieldwork ends up revealing consistent observations and unmet needs for patients and their families that personal health technologies could readily address:

- Access to their healthcare data, vital signs history, lab work, and basic claims history; most have never heard of a "PHR" but express a desire for something just like a PHR

- Holistic records of their total healthcare experiences, across multiple different providers but also including many non-clinical services and systems (like Meals on Wheels, chiropractors, alternative healthcare providers, etc.)

- A coordinated and comprehensive view of their medications & potential drug interactions; intelligent reminders at just the right time without embarrassment

- The ability to share and hide different parts of their health information with widely different stakeholders, and to change those permissions over time

- Multiple ways to view their data; the "visualization literacy" of people we study is so variable that we need to provide them with diverse summaries, charts, and graphs of their data

- Trusted educational content about *their* specific conditions and combination of conditions in terms they can understand

- Some way to motivate and sustain the behavior changes they know are good for them but are hard to carry through on; most think peer pressure and tracking towards goals are the best ways to succeed

- A lightweight way to ask a medical professional for advice about a condition or injury they are worried about without having to go in for an office visit

- Support from a care expert who has all of their conditions & family members in mind to help coordinate confusing and sometimes conflicting specialty opinions

- Some means of "checking in" on the health status and routines of an aging parent or relative who lives anywhere from one mile to thousands of miles away

- Connection to likeminded patients who have had similar conditions or procedures; some want a dedicated patient advocate to walk them through painful or frightening procedures

- An understanding of financial responsibilities associated with their various kinds of care; they are confused by co-payments, deductibles, limits, and who pays for different kinds of care (especially long term care)

- Support and education for family members doing caregiving; especially helping with care transitions such as hospital discharge or transfer to a nursing home

- Financial assistance and/or job flexibility for family caregivers to work part-time while maintaining benefits when faced with the need to provide 20 to 40 hours of care a week

Multiple Roles/Kinds of Engagement

It is clear that HIT systems cannot be "one size fits all" for patients and families. In fact, we find the word "patient" almost useless in our research because there are so many different kinds of patients, and very few people in our studies who access healthcare services identify themselves as "patients." Across their lifespan, we see people moving into and out of specific roles that have very different needs at different times. Thus, HIT systems that are adaptable and personalizable are key. Below are some of the categories we see in our fieldwork; the list is not exhaustive and many people fit into more than one category at a time, but the list itself shows the range of needs and interests people have:

» **Fitness Gurus**: take pride in being fit and/or nutritious; often engage in competitions with themselves or others; sometimes miss signs of a serious health condition because exercise masks symptoms or an "immortality complex"; interested in ability to track detailed data over time to show progress

» **Healthy Employees**: no major health incidents to motivate being mindful about health issues; sometimes are a silent majority; need help with routine problems like seasonal allergies, cold, flu; interested in ability to get quick, on-site or even virtual care without having to travel to a clinic

» **Chronic Patients**: more aware of the need to manage their own condition, at least around the original diagnosis; mindfulness and motivation tend to wane over time unless direct symptoms remind them of the need; most have multiple conditions but don't understand if the conditions are related or connected; interested in someone helping to coordinate and motivate their care consistently and seeing progress towards behavior changes that can make a positive difference

» **Recovery Patients**: tend to be acutely aware of a health need but for a specified period of time with confidence that things will return to normal eventually; often discover other health issues during this experience; need intensive education and social support during the episode; interested in clear steps needed to recover fully

» **Hospice Patients**: have often been long term chronic patients and "frequent flyers" of the healthcare system; tend to know how to work the system but are exhausted by it and "done with it!"; need pain management and help orienting themselves, their families, and their providers to get out of "fix it" mode and into "comfort" mode; interested in engaging with others going through similar experiences and coaching on end-of-life issues

» **Family Caregivers**: often drawn into care for a loved one suddenly (e.g., the classic parent with a hip fracture) with no training and no formal recognition of their role—"it just happens all of a sudden!"; usually women in our studies; most often are trying to juggle a career and/or child care as well so are at risk for stress, burnout, depression, and illness; very few feel supported by professional providers; interested in education on how to deliver best care, respite, and connection to likeminded caregivers for moral and social support

» **Friend & Neighbor Caregivers**: often brought in for temporary or respite care of someone who is a family caregiver; sometimes as a neighbor they have a better sense of what is going on with a patient than a family member far away but don't feel empowered to say or do anything about it; many want to help but worry about liability and risk; interested in lightweight ways to "look in" on someone and share insights with rest of the care team

» **New Parents**: expecting and recent parents enter a special period of time for heightened attention to the health of themselves and their baby; much more mindful about fitness and nutrition and medications than at other times; interested in training and education, social support, safety, and tracking progress of a new baby

Degrees of Engagement

Designing health IT systems for patient and family engagement requires us to identify multiple "segments" of potential end users who have different needs. Their degree of engagement in health issues is complicated by numerous factors we've seen in our fieldwork.

How proactive they are about managing their health often correlates with how proactive they are about managing *any* domain in their lives (their work schedule, their grades, their house cleaning, their finances, their yardwork, etc.). On one end of the continuum, we see "hyper engaged" individuals where, honestly, a health IT system that makes them more obsessed and mindful of their own signs and symptoms can actually be harmful. On the other end of the continuum, we see "non-engaged" individuals that are in such denial

of a health problem that any engagement is progress. The vast majority of people fall between these two extremes.

What we at Intel call the "horizon of hope" about an illness or injury really matters: if people believe they can be cured or improved, then they are more likely to engage. But if given a prognosis of a rare incurable cancer or something like Alzheimer's where they perceive that nothing can be done, then awareness and engagement can be much more challenging to increase (perhaps even harmful in terms of causing depression). Their orientation towards death (fearful, resigned, embracing, etc.) and how "out" they are about their illness or injury to others also come into play.

Different Cohorts, Different Expectations and Abilities

One of the other big challenges in designing programs and technologies to engage patients and family members is that different cohorts bring very different expectations about healthcare and very different experiences with technology with them. In our studies, we find as a general rule that today's seniors—those from the "greatest generation" as they have been called—are often reticent to challenge a doctor's authority or to press a call button for help. Even if they are PC-savvy, they are often hesitant to go online for health information because of concerns about the reliability of information they will get. We often even see the oldest of the old suffering silently out of fear of not wanting to bother anyone or to spend resources on feeling better.

Baby Boomers, on the other hand, are likely to be very different kinds of patients (and seniors for that matter!). I often say with some humor but also some truth: "Boomers as seniors won't hesitate to push that call button for assistance." We see them more demanding of personal service and information about their health, more prone to ask for second (and third and fourth) opinions, and more ready to adopt technologies in their homes to help them live independently.

Similarly, today's generation of Twittering and texting and Facebooking teenagers and young adults already expect care to occur on and through the technologies they carry with them. They will likely grow into more engaged, proactive patients as they move into middle age and beyond. Thus, designing health IT systems for engagement requires understanding the cultural expectations about life, health, death, authority, spirituality, and wellness and the technological proclivities those different generations have adopted.

Privacy is Personal

Across all of our studies, we explore explicitly the privacy needs, concerns, and understandings that different people have about healthcare and health data. And again, those things vary widely depending on individual preferences, regional differences, cohort expectations, gender and race experiences, and the degree of stigma associated with different medical conditions. It is safe to say that everyone in our studies is concerned about privacy in some ways, but it is also safe to say that almost no two households have the exact same needs or concerns. It is difficult to describe general principles of privacy that work *universally*.

For example, in our pilot that collected social health information (number and length of phone calls, number and length of visits to the home, amount of online interaction) to help those with early stage cognitive decline feel confident in staying socially engaged, the feelings about that data being private ranged widely. On one extreme, one woman was happy to share that social health data with anyone on the internet. On the other extreme, one man in the study wanted assurances that the data was secure and went only to him. Most in the study wanted different levels of privacy and access for different people in their lives: for example, the doctor gets all the data; the youngest daughter gets all of the data; the oldest daughter gets none; the best friend gets most; and the husband gets only a high level summary.

I find today's privacy debates about HIT too generalized and extreme to fit the nuances of what we have observed in our fieldwork. Furthermore, the ways in which HIPAA is misunderstood and operationalized by both providers and patients often leaves people without access to their health data, in contradiction of the very spirit and intent of the law. The bottom line is that patients and families tell us to give them the choice to decide what is private and what is not. They ask that they be allowed to weigh the risks and rewards of collecting different kinds of health information for themselves.

As a 97-year old gentleman in one of our nursing home studies once said to me, "I'm at the point in my life where someone has to help me get dressed and go to the bathroom, so do you really think I am worried about someone discovering whether or not I have taken my medications on time? If your technology could help me get back some independence and privacy, it's a risk I would be willing to take." Perspective is everything, and many who try to speak universally for all patients or all seniors risk misrepresentation. Privacy clearly matters. But privacy is also highly personal. And neither our technologies nor our policies seem adequate at this point to deal with this complex reality.

Myth Perceptions About Seniors and Technologies

Finally, I would be remiss in this summary of high level findings about our HIT research with seniors in particular, if I did not address one of the biggest myths we see from family members, policy makers, and technology designers. Simply put, and contrary to many stereotypes, seniors can and will learn new technologies. In our experience, if the systems are designed well, if the value propositions are made clear to the seniors, and if proper training is done, seniors—even those with early to moderate cognitive decline—can and will learn new systems. Time and time again we are told by a family caregiver or doctor that a particular patient or senior can't learn a new technology; time and time again the patients and seniors prove them wrong when the technology has clear benefits for them.

We have taught 90-year-olds with memory loss who have never used a PC before to use a trackball and laptop to enter records about their phone conversations. We have seen many technology-averse diabetes and heart disease patients easily use a telehealth appliance to take their blood pressure, answer an online questionnaire, or do a virtual video visit with a nurse. We have introduced cell phones to seniors and other patients who had never used one before to do medication prompting, food journals, and multimedia cognitive

behavioral therapy sessions. While it is true that the design challenges are often greater—and the usability testing longer—for systems where seniors have no prior experience with the technology, it can be done. And the payoff is enormous as they rediscover activities they can do again, feel empowered to tackle a health problem, or connect with a long lost friend from their past.

Recommendations for a Personal Health Infrastructure

Since I come from a technology company like Intel, it might be surprising to hear me say that technology should not be the only, or perhaps even the primary, focus of a committee focused on Health Information Technologies. Put another way, our biggest barriers to deploying these kinds of personal health technologies to meet the Y2K+20 challenge may well be the breakthroughs in training, financial infrastructure, R&D infrastructure, and policy as much as in technology itself. I realize many of these recommendations may exceed the purview of this committee or the scope of today's discussion, but it is important to lay out a holistic strategy for HIT and patient engagement.

I. Training Infrastructure: Our goals should be to prepare a "careforce" for the 21st century that trains patients themselves and family/friend caregivers on how to use HIT to be part of effective care coordination teams, while also developing curriculums and credentialing for new kinds of care workers—both paid and volunteer—who augment and complement scarce personnel like nurses and physicians.

1) Workforce: Commission a study to identify new kinds of care workers needed to support HIT-enabled home and community based care, some clinically trained, some not (e.g., care coaches, care coordinators, patient advocates, etc.).

2) Workflow: Develop workflow models (staffing models, shift design, care management) for HIT-enabled care coordination across patients, families, and providers that help providers transition from clinic-only to home, clinical, and virtual care.

3) Health IT workforce: Accelerate job training programs and growth of a workforce of people with expertise in health IT design, engineering, usability, and informatics.

4) Family Caregiver Training: Identify the best family caregiving training programs being done in many states and scale those into a national curriculum of best practices to be taught at community health centers, community colleges, churches, and other forums in the community.

5) Credentialing: Build mechanisms for certification and credentialing of these new kinds of care workers, both paid and volunteer, such as the "Grand Aid" program being developed by Tim Garson at the University of Virginia to train and credential grandparent age citizens as chronic care managers in their communities

6) Licensure: For new kinds of care workers and our telehealth workforce, develop national licensure rules that allow them to work across states and virtually. It is important that care and care teams "follow the patient" with some continuity, even if he or she crosses borders. And virtual care support centers will not achieve economies of scale if they cannot deliver assistance across state lines.

II. Financial Infrastructure: Our goals should be to incentivize patients and families to be more engaged and proactive about their own health and wellness challenges and to insure that new payment models for clinicians have the infrastructure and incentives to meaningfully include patients and their families to help offload the medical system.

1) Cash and Counseling: C&C programs are currently in effect in more than a dozen states and would benefit from extension to all fifty. Identify tax credits, stipends and other types of payments to family caregivers, giving more flexibility to elder and chronic care.

2) Family Leave Policies: Creative part-time and other family leave policies are needed for family caregivers in the workforce, to help mitigate caregiver burnout and to help them maintain their own income and independence during the caregiving period.

3) Global Aging Technology Discounts: Explore subsidies or tax credits for families purchasing new technologies to help with family caregiving. Think of these as the moral equivalent of hybrid car or green water heater discounts, but for independent living and disease management services.

4) Care Coordination/Payment Bundling Pilots: As ARRA and the health reform bill fund new payment reform pilots for coordinated care such as Accountable Care Organizations, require that patients and families be included in the workflows, infrastructure, and incentives for those pilots…and that successful pilots have the ability to scale up to nationwide benefit.

5) HCBS Pilots: Incorporate HIT strategies and designs into plans that create financial incentives for states to shift Medicaid beneficiaries out of nursing homes into home and community based services (HCBS).

6) "Care Corps": Experiment with "Americorps" type training and volunteer organizations that incentivize neighbors and families with training to help care for frail or chronic members of their community. For example, a CNA might receive scholarships for college in exchange for a period of time to do caregiver support or training in the community.

III. R&D Infrastructure: Our goals should be to accelerate the invention, evaluation, and deployment of new technologies and services that help move care to the home and

community and help promote prevention, early detection, behavior change, caregiver support, and independent living.

1) National Research Priority: Put in a place a mechanism that can work across the National Institutes to prioritize cross-disciplinary research in personal health technologies, home-and-community-based care delivery, and engaging patients and families in their own care. Without an agency owning this agenda, it will likely be lost in the focus on acute care settings and EHR adoption in hospitals.

2) 10,000 Households Study: Commission a national cohort study of 10,000 elderly, broadband-connected households—think of this as the "Framingham Heart Study for Personal Health Technologies"—who can test promising inventions and interventions on a larger scale and help accelerate commercialization of new technologies for engaging patients/families.

3) User-Centered Design: Embed social science and pilot research functions in RECs (regional education centers) and the CMS Innovation Center as well as other government funded Centers of Excellence to insure that there is a foundation of understanding the real needs of patients, families, and providers through grounded fieldwork, as we invent and deploy HIT solutions.

4) Retirees Registry: There is a large untapped reservoir of clinical and technical expertise in homes, assisted living facilities, and retirement homes across the country where retired nurses, physicians, and engineers reside. Create a national registry and campaign to sign them up as volunteers to co-create and test out independent living and personal health solutions of the future.

5) Incentivize Personal Health Technology Startups: Look for ways to accelerate and encourage the development of a new industry of personal health technologies, perhaps by catalyzing the Venture Capital community in this domain. Also, revisit the medical device tax in the healthcare reform bill to insure it does not curtail or limit emerging technologies and small startups from bringing new solutions to market.

IV. Technology Infrastructure: Our goal should be to make sure that government and private investments in fundamental technologies such as health IT and broadband prepare us for a distributed, community-and-home-based health delivery system that is ready for the 21st century and the Age Wave, especially as retiring Boomers require (and demand) a more personalized, home-based healthcare experience.

1) Meaningful Use: The next phases of Meaningful Use requirements should prioritize use cases and care delivery models that shift care into the home and community. It is important that HIT, such as interoperable RPM devices, personal health technologies, and independent living technologies, be certified as EHR modules and can meet the requirements of MU certification criterion.

2) Standards: As diagnostic, self-care, and care delivery technologies extend into the home and community, it is important that they be interoperable and "plug and play" to enable patients and families to install them. The Continua standards should be adopted and promoted, for example, to drive such interoperability.

3) Broadband: Ubiquitous, affordable broadband is essential for extending healthcare to the home across the United States, particularly for rural and underserved communities. As the National Broadband Plan is enacted, we need to make sure that the infrastructure meets the requirements for a community to ensure adequate connectivity among all of the constituents in a coordinated care model: hospitals, clinics, doctors' offices, labs, and pharmacies, and homes. The specifications should press for a reliable, higher bandwidth connection that supports personal health delivery, and we should identify ways to expedite connection service for patients with health related issues.

4) Personal Health Records: While we focus on the rollout of EHRs to clinicians, we should insure that they connect via PHRs to provide data and/or data summaries to all patients and their designees. Patients should have the right to specify that they want electronically transmitted information sent to their PHR at costs that should be presumptively zero and never more than the cost of sending the same information to other EPs, hospitals, and insurers.

V. Policy Infrastructure: Our goal should be to remove other barriers to—and create new policies for—the advancement of HIT that engages patients and families in their own care and helps us achieve quality care for more people with fewer resources going forward.

1) Evaluate American Competitiveness for New Health Industries: Authorize the Commerce Department or some other appropriate government agency to study the emerging industry of personal health technologies and to evaluate America's strengths, weaknesses, barriers, and competitiveness in catalyzing new products, services, and jobs in this marketplace.

2) Y2K+20 Commission To Drive Personal Health: We need to insure that patient/family empowerment and engagement is part of our national healthcare strategy, not an afterthought or unfunded mandate. We need a Y2K-equivalent Commission to promote cross-government and private initiatives that ready our nation for a 21st century healthcare system that can personalize care and distribute delivery across time, place, and personnel to meet the needs of the Age Wave.

Conclusion

In closing, I realize that this testimony is both lengthy and incomplete. Similarly, these recommendations are both too many and too few to achieve the kinds of health care reforms that our nation deserves and needs. What we're really talking about is behavior

change—culture change—for one of our most personal issues—healthcare—on a very large and long scale. To make "meaningful use" of health IT, we need to remember that there is a place for technology, but we also need to keep technology in its place—thus, as just one part of a comprehensive national strategy for healthcare. We shouldn't glorify technology; nor should we ignore it. We should simply try it, evaluate it, improve it, and try again.

At the end of the day, these HIT solutions are merely modern tools—both flawed and amazing as are most human creations—to enable and enhance how we live together on this Earth. We're in the process of redesigning our social covenant and financial arrangements with institutions and individuals who help care for us when we're sick, injured, recovering, well, or somewhere in-between. That redesign of health care takes on some added urgency in the midst of Global Aging and the economic/cultural shocks those demographic fault lines produce. My hope is that, at a minimum, this committee finds new ways to tap into the reservoir of knowledge, compassion, and commitment that engaged, educated, and empowered patients and family members can bring to healthcare. I believe HIT, especially when extended to the home and community, can help us do that, and in so doing, will distribute care across time, place, and personnel in ways befitting our 21st century democracy.

In sum: Prepare for Y2K+20! We can go home again (and must). 50% of care to the home by 2020! And we all need to be part of the solution—enlisted in the 21st century careforce. Thanks for the opportunity to share these ideas and recommendations today.

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[i] See http://www.iom.edu/Reports/2008/Retooling-for-an-Aging-America-Building-the-Health-Care-Workforce.aspx

[ii] For a brief description of one of the ethnographic studies we have done on aging, see http://www.intel.com/healthcare/hri/pdf/gaexperience.pdf. Also, download a free white paper from the recent Intel Technology Journal with more about the global aging work at http://www.intel.com/technology/itj/2009/v13i3/ITJ9.3.1-Global-Aging.htm.

[iii] Per our human subjects and consent agreements with our research participants, all names and potentially identifying characteristics have been removed or revised to protect their privacy. All photos used in this document are from participants who have signed photo release consent forms with Intel.

[iv] See more about our CAMP (context aware medication prompting) research here. Also see, "A study of medication-taking and unobtrusive, intelligent reminding," *Journal of Telemedicine and e-Health* 15 (8), 770-776, October 2009. Tamara L. Hayes, Kofi Cobbinah, Terry Dishongh, Jeffrey A. Kaye, Janna Kimel, Michael Labhard, Todd Leen, Jay Lundell, Umut Ozertem, Misha Pavel, Matthai Philipose, Kevin Rhodes, Sengul Vurgun.

[v] See http://www.intel.com/healthcare/ps/healthguide/.

[vi] See Sheri Reder, Gwen Ambler, Matthai Philipose, Susan Hedrick. *Technology and Long-term Care (TLC): A pilot evaluation of remote monitoring of elders.* In Gerontechnology 9(1), Winter 2010.

[vii] See "Social Networks as Health Feedback Displays," *IEEE Internet Computing*, Volume 9, Issue 5 (September 2005), Pages: 29 – 37. Or click here.

[viii] See http://www.trilcentre.org/falls_prevention/falls_prevention.474.html.

[ix] See "An Aging World: 2001," November 2001, by Kevin Kinsella and Victoria A. Velkoff. At http://www.census.gov/prod/2001pubs/p95-01-1.pdf.

[x] See *Computational Technology for Effective Health Care: Immediate Steps and Strategic Directions*, edited by William W. Stead and Herbert S. Lin, National Research Council of the National Academies, The National Academies Press, 2009, page 33.

[xi] See "Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care," January 2010, by Carol Levine, Deborah Halper, Ariella Peist, and David A. Gould, *Health Affairs*, page 117.