Good morning Chairman Collins, Ranking Member Warren, and distinguished Committee Members. My name is Kathy Giusti. I am the Founder and Chairwoman of the Multiple Myeloma Research Foundation (MMRF). It's an honor to be here today to provide a patient's perspective on the importance of health information technology (IT).

In 1996, at the age of 37, I was diagnosed with the blood cancer multiple myeloma. Hearing the word "cancer" was devastating. Hearing the words "fatal, 100% fatal", took me completely off guard. I realized my cancer was uncommon, had no funding, no awareness, and no pipeline of drugs.

As a patient, I could see the problems. As a business woman, I saw ways to fix them. I founded the MMRF to put those ideas into practice. Working with academia, government, industry, and technology partners, the MMRF created an end-to-end system in precision medicine.

We built our own data bank to capture the genetic changes in myeloma patients and their responses to treatment. We made this data publically available to all scientists. We built a clinical network that has conducted 60 trials of 30 compounds. We educate our patients so they enroll in the right trial for them. Our community has seen 7 new drugs win FDA approval, with 3 more expected in the next year. Our patients have benefited, nearly tripling survival from the 3 years when I was diagnosed to 9 years today.

Myeloma, however, remains fatal. In today's world, health IT can and should accelerate new treatments and cures. So today, I would like to discuss the importance of health IT from the patient's perspective.

Number 1: Engaging Patients

Access to digital health information allows us to collaborate with our doctors and health-care providers and make better decisions. We review our test results and lab reports on line, and identify and act on important trends. We can learn at our own pace - when it is quiet and convenient - not when we are stressed in the doctor's office or in the infusion room.

The promise is so clear, but the percentage of patients taking advantage of these technologies is too low. According to a recent survey, only 36 percent of Americans

online were using patient portals. 35 Percent of Americans did not know they had a patient portal.

In contrast, when we looked at MMRF data, we found that 85% of our newly diagnosed patients know they have a portal, and over 95% use their portal. This shows the importance of trusted third parties in raising awareness and education amongst our patients. Physicians, hospitals, advocacy organizations, and the government must ensure that patients are educated on how best to use the technology.

Number 2: Integrating Data

As a patient, I now have 6 electronic health records (EHRs) scattered from Dana Farber in Boston to the Mayo Clinic in Minneapolis. I have no central repository where I can aggregate, store, and access this information. And, I cannot make this information available to my healthcare team or scientific researchers. To prove the point, when I recently developed osteonecrosis, my surgeon needed my treatment history. There was no easy way to find it.

The greatest efficiency will come from our ability to integrate EHRs across the vast number of specialized doctors and centers that patients now see. That data must be integrated into a centralized portal that we as patients feel like we own, share, update, and provide.

Number 3: Accelerating Cures

The MMRF recently launched its own genomic initiative and our CoMMpass trial which sequences 1,000 patients at diagnosis and at every relapse to understand our disease heterogeneity. We have already identified a significant genetic mutation - BRAF- in myeloma patients. And we are pushing drugs that target this cancer causing mutation into clinical trials. But there are many more targets to uncover, more efficient trials to run and new drugs to develop. The ability to understand, integrate, aggregate and analyze EHRs is on the critical path to improving outcomes and accelerating cures. We have shown the impact of data sharing in one uncommon, fatal disease. Let's work together and improve patient outcomes in all diseases. Thank you for the honor of speaking today.