April 29, 2009

To Chairman Reynolds, Dr. Blumenthal and the NCVHS executive subcommittee,

Thank you for this opportunity of offer testimony on meaningful use criteria. I ask for your consideration to not forget the ultimate beneficiary of meaningful use – the patient or consumer, whose voice was silent during these hearings. While the provider absorbs the change, the provider does not bear the consequence of the medical error or physical harm that can come from the lack of sharing of information. I was a home life support nurse, and saw the devastation of those families, and wrote about them during the Clinton administration call for public input. I was the only RN who wrote about her patients in a group of 25 letter writers who were picked out of 1 million letter writers to meet the President and Mrs. Clinton. I went on to Volunteer at the White House in Healthcare reform reading the devastating letters that citizens and family members would write to the President. There was family after family wrote of the devastation emotionally of having to repeat histories and be the "data repository" for their loved ones who were very ill, going to multiple doctors for comprehensive care.

Since that time, I have lived through horror of losing my mother from her healthcare providers not being able to trend her lab results across visits and across providers. Even more sadly, my family has been affected by one of the worst hospital acquired medical infections that I know of – my 30 year old nephew is permanently paralyzed on the right side after getting eColi in his brain when someone did not wash their hands, or his hands during a hospitalization for a brain tumor. The brain tumor was to be a "simple" removal; the hospital acquired infection has paralyzed him. We have lived through the horror of him losing insurance, preexisting condition lack of coverage, then Medicaid coverage, then getting dropped because disability started coming, then no coverage and finally the long wait was over to now have Medicare coverage. My brother and his family frequently have to have tests repeated and have to recount my nephew's entire history if they are out of town.

I have been in the Healthcare Informatics arena for 15 years, and work now tireless hundreds of hours on behalf of HITSP and CCHIT. The story of Interoperability from a patient perspective that is used by HITSP in their webinar series is "Steve's Story", which I wrote, and it is the real life story of my nephew, the loss of my mother, and the struggles of my father to get through the healthcare system without interoperability. It aligns with each of the AHIC use cases, and what the functionality means to the patient and family. I have also attached to this testimony the electronic file of the large chart I showed in public comment period that shows the elements of HITSP in each AHIC use case and also the frequency of use for the HITSP elements for review by NCVHS.

While I still do not know the outcome of my nomination as a consumer representative on the HIT Standards Committee, I make this recommendation on behalf of consumers and I urge the NCVHS in their recommendations to the ONC not forget these consumers in a complex healthcare world. I ask you to consider including in meaningful use a care summary phased in with over time with discrete data elements as is the current track for HITSP and CCHIT. Sharing of the elements of the CCD could absolutely save lives in care coordination and during large scale evacuations we see during hurricanes. I suggest these goals for meaningful use:

- **Goal for 2011** – Share medical summary in CCD format, coded headings, and coded medication list
- **Goal for 2013** – Share CCD with coded values for Problems, Allergies, Histories, lab results and send data to CDC for population reporting
- **Goal for 2015** – Share Level 3 CCD "push and pull" discrete data among vendor products and send CCD summary to Social Security Administration for processing disability claims

Thank you for your consideration of these goals as part of meaningful use.

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**HITSP Education, Communication and Outreach Committee**