

**HIT Policy Committee & HIT Standards Committee
President's Council of Advisors on Science & Technology (PCAST) Workshop
Tuesday, February 15, 2011
Washington, DC**

Testimony by Donna Cryer, JD

on

***Realizing the Full Potential of Health information Technology to Improve Healthcare for
Americans:
The Path Forward***

Good morning and thank you for inviting me to testify before this committee today. My name is Donna Cryer. I am an attorney and liver transplant recipient. I am privileged to serve as a patient representative to the U.S. Food and Drug Administration, member the board of the American Liver Foundation, and am CEO of CryerHealth, a healthcare consulting firm committed to developing patient-centric solutions to healthcare challenges of which our nation's HIT policy is surely one of the largest.

I want to applaud the committee for its excellent report and overall support the recommendations therein.

My comments verbal and written will reflect the PCAST report's ability to address the seven principles that generally define what patients seek in an HIT solution.

- 1. Comprehensiveness**
- 2. Accuracy**
- 3. Priority**
- 4. Safety**
- 5. Efficiency**
- 6. Privacy**
- 7. Quality**

Comprehensiveness: An electronic health record should aggregate all my information across time, specialties, and institutions/practices. While metadata tagging and searching through a DEAS across settings may be a workable solution, patients are much more pragmatic, and from our perspective would like to see some version of one patient, one record rather than the myriad siloed

records existing currently. I was very heartened to read the insight on page 15 of the PCAST report, “Every health provider has a somewhat different view of a patient, depending on the expertise the particular specialist brings to the medical team, and no one provider knows everything. In effect, the patient has fragmented into disconnected facts and clusters of symptoms.” This state of events is not merely frustrating, but dehumanizing, and results in cognitive and clinical errors. One concern of creating finely granularized data searchable with great specificity is that specialists would **not** in fact put the patient back together again, but be further facilitated in viewing only that data they deemed relevant to a certain condition or organ system.

The primary barrier to comprehensiveness as noted in the report the lack of full interoperability, even within the same institution and limited exchange of data. Creation of HIEs and RHIO have done little to remedy this. These entities are driven by a practice or facility-centric view that the health data is proprietary to the provider instead of patient, fear of losing the patient to another physician, and the perceived competitive disadvantage of spreading effective treatment protocols when that should be the aim of practice. Acknowledgment of patient ownership, free access to, and ultimate control of our data would provide the foundation for sharing across facility and provider boundaries. Thank you for recognizing as on page 24, “The most significant change is that all healthcare should be organized around the needs and specific characteristics of the patient, not around those of the hospital, doctor’s office, insurance company, or HER vendor.”

As a final point on the concept of comprehensiveness, I would like to point out the false dichotomy between PHRs and EHRs. Patients want a portal into their medical records, not a disconnected, piece meal offshoot. A patient interface, method of entering and validating patient-generated data, and well as tools such as email, appointment scheduling, and review of lab results should be fully integrated into the EHR.

Accuracy: The information must be correct to be useful. Accuracy of information is almost never mentioned in these discussions but deserves a place next to privacy and security.

Priority: My ideal EHR would highlight the important information in my record for my physician, organizing and alerting her to key issues, new results, missing information. Simply distinguishing

between conditions successfully treated in the past from ongoing conditions would be a step up from some current offerings.

Safety: I was thrilled to see the new barcode scanners at my local hospital reducing potential medical errors by checking patient identification bracelets against each medication before administration. Checking for drug interactions, allergies, avoiding overdosing are all important abilities for HIT solutions. The PCAST report does a good job of describing the potential of HIT to alert for adverse events.

Efficiency: Discussions of workflow focus exclusively on savings to physician time. Improved efficiencies through technology also emerge for patients and should be calculated in the overall cost savings. Increased patient productivity through functionality such as viewing lab results, request prescription refills, schedule appointments, receive reminders, instructions for procedures, and orders for bloodwork, in the aggregate would beneficially affect the economy.. Patients can also play a greater role in updating providers and improving information flow through email and other tools. Standardized formats for preparing for visits or completing follow up are also lost opportunities from the current dearth in functional EHRs.

Privacy: There is a spectrum of comfort level with sharing and release of even seemingly innocuous personal health information. In general I believe that most patients would like to have systems that facilitate appropriate sharing of information for purposes of treatment, more individual or consented release of information (even deidentified) for research purposes, and are concerned about discrimination in employment and other settings if information is made public.

Quality: HIT contributions to quality are predicated on everything listed above. One additional significant way that EHRs can improve quality of healthcare delivered is to accelerate the translation of new science, guidelines, or regulatory information to healthcare practitioners.

Additional Commentary

- **Patient Engagement:** Education is not engagement, must avoid a field of dreams mentality, that “if we build it they will come”

- Patients must be involved in every aspect of policy development including task forces and committee leadership
- Patient decision support and shared decision making should be an output of the HER along with physician clinical decision support
- **Models of care:** I have greater confidence in patient-centered medical home, which is nominally accountable to me as a patient, rather than a so-called accountable care organization responsible for a geography but accountable to no one. In a telling aspect of ACOs patients may or may not even know how or to whom they are assigned. Due to asymmetrical capitalization hospitals have accelerated in acquiring physician practices. I don't understand how hospital driven care can ever be cost-effective care.
 - Align motivations; internal/publically available newsletter of a local hospital details their key metrics – inpatient admissions, ER visits, patient collections – not one of these metrics aligns with my interests as a patient to stay or get well
- **Incentives:** Rather than speak of incentives we need to discuss compensation – care coordination fee, support for transition to EHRs—input, training, lost income from initially slower visits particularly for smaller practices
- **Health Disparities:** Review of aggregate data for surveillance holds the promise not only of alerting to adverse events, but provide an expanded evidence base for identify to above average effectiveness in subpopulations underrepresented in clinical trials
 - There is a passing reference to the quality chasm no mention of the promise for reducing health disparities

Patients/Consumers/Privacy Advocates Panel Question/Answer

1. What are the privacy and security concerns, if any, to metadata tagging and the DEAS? What are the privacy and security benefits?
2. Is the PCAST approach to managing privacy and security comprehensiveness enough? Too comprehensive/complex? Will the approach lead to challenges for patients in managing their privacy controls?
3. What are the best ways we can leverage PCAST's technical recommendations – namely metadata tagging and a data element across service – to support principles of transparency and oversight? Patient choice?

The PCAST approach to security and privacy as I understand it is based on the following factors:

- Patient choice of privacy settings
- Differentiated user authentication (different access/permissions for different roles)
- Metadata level privacy settings allowing for different patient preferences for disclosure of different types of data
- DEAS system of locating and assembly of data without possession or access to the specific data

I find this system fundamentally sound, however as the report admits this system is only as good as the people implementing it. As with HIPAA currently, without extensive standardized training of healthcare professionals, office staff, and patients no approach is truly effective. For example, leaving the development of patient privacy forms to each facility or practice would incur the same abuse and confusion as abounds today.

- I recently experienced a new doctor's office which presented me with a privacy notice form that said
 - They could change the privacy policy at any time
 - They may or may not agree to any restrictions on disclosure I requested
 - They owned my data
 - They would not treat me if I did not sign

How can that engender trust?

Plain language explanation of new privacy schema and a checklist of choices should be centrally developed validated and disseminated. Education and training on the new privacy schema should be available in multiple formats and platforms and include information the process for deidentification of data and the benefits, personal and population, of sharing this data. Rigorous enforcement of laws such as GINA and PPACA to protect patients from repercussions of misuse of health data by employers or insurers is also necessary to ensure the reality rather than the semblance of privacy.