

## SUPPLEMENTAL TESTIMONY

### Health Information Exchange Hearing HIT Policy Committee and HIT Standards Committee

**FROM:** Alan Blaustein, Founder, CarePlanners ([alan@careplanners.com](mailto:alan@careplanners.com))  
**TO:** Members of the Health IT Policy Committee and HIT Standards Committee  
**DATE:** January 29, 2013  
**RE:** Consumer-Mediated Exchange Panel

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#### **Further Background & Request –**

My testimony today is that of a patient first and an entrepreneur second. I strongly believe putting us all in the first-person when thinking of the healthcare system will result in the strongest set of solutions as the system continues to evolve. It also most quickly cuts through the clutter and some of the jargon as we determine how best the healthcare consumer (i.e., patients and caregivers) are made part of the decision making process. As you continue to have these discussions and make decisions, I ask that you consider doing so first in your capacity as a current or future consumer of the healthcare system because at some point we have all been, are or will be patients and care givers.

I have also taken the liberty of attaching links to several patient-centric healthcare system pieces I have written for Huffington Post (<http://www.huffingtonpost.com/alan-blaustein/>) and a talk I gave last Fall at Chicago Ideas Week (<http://chicagoideas.com/videos/310>). Both speak to the absolute need to elevate the patient and the caregiver to the center of the ongoing conversation.

#### **Supplemental Written Testimony –**

##### ***1. What products and services is CarePlanners currently offering for patients and caregivers?***

The ONC often speaks of healthcare information in terms of “access, actions and attitudes.” “Access” is ensuring that the healthcare consumer not only the right, but the ability, to procure her healthcare records from all of her providers. Such access is being driven through the Adopt Blue Button Initiative and similar programs being developed by these esteemed committees.

“Attitudes” relates to both consumer and industry attitudes about consumers having the ability to access all of their medical information. These “attitudes” are asked about in further questions, so let’s address them elsewhere.

CarePlanners was created with respect to “action.” Assuming the healthcare consumer gets unfettered access to their information, what exactly are they being asked to do with it? Are they being asked to understand it – because if they are, they clearly need help. Just getting hold of 500+ documents does not in any way, shape or form make one necessarily able to make sense of healthcare-eze. In fact, without appropriate help it creates further perceived distance for the patient or the caregiver from the system. And if we are not looking for the healthcare consumer to understand the volumes of information, then are we only asking them to be the conduit through which the information passes? If that is the case, then aren’t we putting an increasing burden on a party that has no understanding of the information they are passing forth?

For the system to work correctly, particularly as information becomes more widely accessible (which is a great thing), healthcare consumers need assistance in understanding our complex system. Much like your attorney or your accountant assist you with complex legal and accounting systems, respectively, CarePlanners was established to help healthcare consumers better understand, make better decisions and be more confident in their ongoing dealings with the healthcare system by providing them a mix of tailored personal services and interactive online tools.

As an example, CarePlanners offers its clients a “curated” personal health record – the ability to have a Careplanner (a trained healthcare professional, generally a social worker, a nurse, a senior care expert, an insurance billing expert and other healthcare advocates) assist the family in pulling together the patient’s truest personal health record. At this point in time we all have multiple healthcare records, meaning we have multiple “unauthorized biographies” in the marketplace. Having your healthcare “autobiography” right is of the utmost importance in garnering sufficient and efficient care, and ensures the healthcare consumer stays in the middle of the conversation. Beyond the development of these curated records, our Careplanners help families through a myriad of situations involving the healthcare system – acting as their guide or their counsel throughout the process.

From a technological/automated perspective, CarePlanners wants to be much more critical to the healthcare consumer by helping them see a burgeoning crisis before it becomes an actual crisis. For example, if the CarePlanners database knows that Mom is on Coumadin and has a colonoscopy scheduled in three weeks, we want to make sure Mom (and likely Daughter) are alerted to bring that point to the doctor’s attention prior to the colonoscopy. Knowing a patient’s vaccination history, for example, can yield an accurate and timely reminder for future vaccinations. It is the use of information, plus advanced matching algorithms, that allow us to play both an acute role in a crisis and an ongoing role to help avoid some of the avoidable crises. The more complete the information in the curated personal health record, the more CarePlanners can do for its clients.

**2. *Let’s imagine that all your clients could easily download and transmit their health information in a structured form from EHRs -> what new capabilities could you offer? How would this help with care coordination and care planning? What will be the challenges in supporting your clients to request, aggregate and share their health information?***

As per above, CarePlanners’ ability to help our clients is positively correlated with the amount of information that is available to them. The more information, the better we can match that information and provide better guidance in terms of care coordination and care planning.

**3. *What are the opportunities and challenges to enable consumer-mediated exchange in the next two years? (e.g., patients have access to their own data, and have a way to share it with providers)***

The greatest challenge of the consumer-mediated exchange in the next two years is a clear communications strategy that explains the value to the healthcare consumer. The consumer-mediated exchange must be communicated as a first step to the overall engagement of the healthcare consumer in their healthcare experiences. Otherwise these efforts will be simply seen as an additional burden on the healthcare consumer, particularly if the healthcare consumer now thinks that she is primarily responsible for moving a particular file from Point A to Point B with nothing more at stake.

Furthermore, the culture of our healthcare system will need to begin changing and the healthcare consumer must be invited into the conversation. Countless times we get calls at CarePlanners from clients whom the system has largely ignored, where their facts and opinions were not considered. That requires far more change and self-evaluation than can possibly be rectified in the coming two years.

**4. *How should we get the word out to patients about new opportunities to access, aggregate and share their data through meaningful use and ABBI efforts?***

Please see answer 3.

**5. *What policies, technical requirements, funding changes or convening at the national level would be helpful to further consumer-mediated exchange?***

Will be discussed during testimony.