

Jeff Donnell/NoMoreClipboard Testimony

Thank you for the opportunity to address the policy and standards committees regarding consumer mediated exchange.

I recall securing meetings with HIE professionals five or six years ago to discuss connecting with consumers, and the concept received a lukewarm reception at best. HIE leaders expressed valid concerns about technical and policy challenges, including a lack of proven mechanisms for patient matching. There were also underlying concerns that the value of an HIE might be reduced if each patient serves, in essence, as their own HIE.

To be fair, five or six years ago electronic patient engagement rarely made the priority lists of physicians, hospitals and health systems, and other entities involved in healthcare. Promoting patient engagement has been an uphill battle, and in the eight or so years I have been involved in this space, hundreds of PHR and patient portal vendors have come and gone – with most lacking the staying power required for those who came to the party early.

Fast forward to January 2013, and the landscape has changed dramatically, thanks in large part to the leadership of the ONC and your committees. Meaningful use stage one placed patient engagement squarely on the map, and stage 2 requirements including view/download/transmit and the modest five percent patient participation threshold have moved patient engagement from a check box item to a health IT strategy imperative.

ONC consumer access and engagement efforts ranging from the pledge program to the model PHR privacy statement to education initiatives have contributed to changing attitudes. Add in other factors including shifts in the healthcare cost burden toward consumers and the simple fact that well over 75% of Americans access and use the internet and often do so with health and wellness in mind, and we are finally reaching a tipping point.

That tipping point extends to HIEs. A few years back, the ONC initiated the Challenge Grant program, designating modest funding to fuel innovation – including funds for consumer mediated exchange. In Indiana, we have used Challenge grant funding to work with five HIEs, each with a different business model, and nearly a dozen pilot sites including practices, hospitals, labs, employer clinics and safety net clinics. We are making HIE data available to patients with a PHR, and we are using HIEs as secure messaging conduits. We are working through thorny issues including patient identification/authentication/matching; determining what data is shared (or not) and with what kind of delay; modification of data use agreements that never contemplated consumer access; navigating state laws regarding sharing data for minor patients; and a host of other obstacles that put the “challenge” in the Challenge Grant label.

As we share learning from this project with other HIEs in other states, the response has been encouraging. Many HIEs are interested in and actively working on statewide or

community wide patient portals or PHRs. Rather than view engaged patients as a threat, these progressive HIEs recognize patient participation is a way to add value and contribute to HIE sustainability.

The ability to populate a PHR or portal account with HIE aggregated data overcomes a major obstacle for consumers – accessing data from their various healthcare providers. While a tethered portal has value, the patient who receives care from five different unaffiliated providers is unlikely to create and manage five separate portal accounts. HIEs can offer a community portal solution that complements rather than competes with these tethered solutions and puts more, and more accurate, information in the hands of the patient.

More encouraging still, several HIEs are working on solutions that use Direct for secure messaging. While these solutions are initially deployed for provider to provider communication, they are now being expanded to connect consumers and clinicians. A consumer in an HIE sponsored PHR or portal will be able to pre-register, request an appointment or refill, or ask a question of a nurse or doctor. These messages can be sent to an HIE provided, Direct compliant mailbox, and clinicians and administrative personnel can respond using this same system – no need to log into a separate application.

Your work in the HIE space is critically important, as HIEs are uniquely positioned to overcome the interoperability challenges faced by individual HIT vendors. While few EHR vendors are eager to share electronic data with untethered patient-facing applications, most are willing to interface with an HIE that can serve as an impartial intermediary.

ONC policies and standards are inspiring, goading, prodding and in some cases dragging those in the HIT community kicking and screaming to the electronic patient engagement table. Individual and organizations, including HIEs, are embracing standards, policies and initiatives that emanate from this group and those you collaborate with. In the last 60 days, I have been in countless meetings with HIEs where the agenda is dominated by discussions of Direct, CCDs, seamless interoperability, Meaningful Use stage two compliance and Blue Button.

We have seen more patient engagement progress in the last twelve months than in all the previous years combined since we formed NoMoreClipboard in 2003. However, there is still more work to do and the ONC and your committees cannot ease up on the gas pedal. Within the last few months, I met with a health system CEO who stated rather emphatically, “I have no interest in making it easy for my patients to access and manage their data, as that makes it easy for them to seek care outside our system.” Evidently, this individual did not get the data liberation memo and has not seen some of the correspondence from Mr. Rodriguez. While many in the provider community recognize that long-term success is predicated on turning patients into happy captives whose loyalty is based on superior service, treatment and outcomes, too many still believe in holding patients, and their data, hostage.

While we have made great strides in fostering easy consumer access to health data, we are still slithering in the primordial ooze when it comes to patient generated data. In research we conducted last year with our consumer users, the greatest source of frustration came from providers who responded to a carefully constructed and curated PHR with a clipboard, a shrug or a “we don’t recognize electronic data provided by a patient.” Many of these providers then ask patients to fill out, by hand, in the waiting room, a paper form that they then rely on, often after re-keying the data into an EHR. The ONC and these committees can help to foster collaboration and communication between consumers and clinicians, highlighting and codifying the benefits of an engaged patient working closely with their doctors, nurses and other caregivers.

As we look ahead to Meaningful Use Stage Three, please keep the patient front and center, and know that patient engagement requirements are making a difference. Recognize that even proposed rules, PIN documents and pronouncements at meetings, conferences and other public forums help to raise awareness, move the needle and alter behavior. We are often amazed that as ideas or potential paths forward filter out of the ONC and its committees, they quickly end up as functional requirements in an RFP or topics of discussion with clients, prospects and business partners.

The concept of each individual as HIE, once a nebulous, way out in the future and somewhat intimidating concept, is rapidly coming to fruition. One can now envision a robust “universal” health record with the patient at the center and connected appropriately to HIEs, EHRs, apps and not yet invented innovations designed to improve health and wellness. One could argue that HIEs are in the best position to make this a reality, and several progressive HIEs are actively making progress in this exciting arena. With continued prodding, cajoling, telegraphed intent, policy and standards from the ONC and your committees, the pace will continue to accelerate and we will foster a population of engaged, informed, connected and enthused consumers who will take a more active role in collaborating with consumers to improve outcomes, reduce costs and improve efficiency.

In consumer research, our users were asked what they would request if a care coordination genie could grant them a wish. One user wished for a centralized medical database that could be accessed by hospitals, doctors, patient advocates and the patient him or herself. Based on the work we are doing with several HIEs, that wish is actually coming true. With continued support from the ONC, that wish can become widespread reality.

Thank you.