CLINICAL DOCUMENTATION HEARING

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REMARKS BY JAN WALKER

Hello, my name is Jan Walker. I am a nurse and health services researcher and a principal investigator of the OpenNotes project, which I co-lead with Dr. Tom Delbanco at Beth Israel Deaconess Medical Center (BIDMC) in Boston. Let me begin by thanking Dr. Mostashari and members of the HIT Policy Committee for inviting me to appear today.

I have worked for 20 years to better understand patients' experiences with health, including their views of what high quality care is and what they need from the health care system to support their own health. I'm very pleased to be here today to share some of what we've learned through our research with OpenNotes, a project we hope will become a movement and eventually a standard of care.

As we all know, one of the big challenges in health care is getting patients to understand what they need to do and then actually do what they need to take care of their health. Here, medical records may hold an opportunity. They have long served the needs of doctors, nurses and all clinicians. But for decades, medical records were guarded like gold in Fort Knox. Although in recent years, patients have been able to read parts of their medical record online through secure portals, they have not had access to the full record. The missing part has been their clinician's notes.

So in 2010, we began a research project testing out the idea of inviting patients to review their doctors' visit notes through secure patient portals. Working with two partners with varying patient populations - Geisinger Health System in rural PA and Harborview Medical Center in Seattle WA - and with primary funding support from the Robert Wood Johnson Foundation - we involved more than 100 primary care physicians and 20,000 patients to help us study the merits of letting patients view those notes. Copies of the results of our efforts, published in the October *Annals of Internal Medicine*, are with my full testimony,

We first examined and reported on what patients and doctors expected before the project started – asking questions of participating and nonparticipating primary care doctors so that we could compare; and one year later, we reported on what they actually experienced.

Our research sought answers to three key questions:

1) Did OpenNotes help patients become more engaged in their care?
2) Was sharing medical notes going to unduly burden physicians?

3) After one year, did patients and doctors want to continue?

So, after 12 months of study, here is what we learned:

- Very few doctors reported having their workload impacted by OpenNotes. And, few reported that patients seemed worried by the notes. Patient visits were not significantly longer; the doctors did not have to spend more time addressing patient questions outside of visits; and the doctors did not spend a lot more time writing/editing/or dictating notes.

- Patients were wildly enthusiastic: Whether young or old, well or sick, well educated or less educated -- everyone liked the idea. And patients read their notes; more than 8 of 10 who had notes reviewed at least one. And they reported that they felt more in control of their care, more knowledgeable about their care, and better understood the plan of their care. Very few patients said the notes were confusing; very few said it made them worry more; and a large number of patients shared their notes with family members or caregivers.

For us, another important test was how doctors felt about continuing with OpenNotes. After a year, not one doctor - when offered the chance of opting out - asked to do so.

The enthusiasm of patients was off the charts. Virtually all patients wanted to continue to be able to see their visit notes on line. And, many patients said access to open visit notes would impact their future choice of doctor or health plan.

OpenNotes is a simple way to give patients information they can actually use to make good decisions about their care. And, it is a good example of a health care innovation that makes use of something that already exists – a doctor's note about a patient visit.

Since releasing our results, OpenNotes has hit a nerve. The project has generated tremendous media attention and gained a lot of new partners who want to embrace this idea or help us carry it forward.

BIDMC will be expanding OpenNotes systemwide by the summer. This spring, Geisinger too will be using OpenNotes with its primary care doctors. The VA has recently embraced OpenNotes for its system of hospitals. MD Anderson in TX has been giving patients access to their visit notes since 2009. We're getting requests from big and small providers around the country asking how to do this.

Tom Delbanco and I are very excited to see that a simple idea like sharing medical notes is beginning to catch fire in so many places, and patients, clinicians and hospitals are seeing the tremendous opportunity that transparency and access to personal health information offer for better health and health care. We look forward to working with you to see that this kind of transparency becomes a routine part of care.

Now let me turn to some of the questions the committee has asked me to address:

How do you define clinical documentation?

The core of clinical documentation is, of course, the medical record, which contains the patient's medical history, social history, allergies, vaccinations, vital signs, test results, and procedure reports. But it is the clinicians' notes that identify interactions between these data and pull them into a narrative. How has the patient changed since the last time they met? Are prescribed medications working, has the patient experienced side effects, do they need to be changed? Do new signs or symptoms suggest a change to the plan of care? What does the clinician think is the underlying cause, what are the possible diagnoses? Is the fact that the patient has been unable to stop smoking making the heart failure harder to manage? This story is part of what is in the notes. It is a window into the clinician's thinking. And patients say reading these notes helps them understand what is going on and why things like taking a particular medication, or quitting smoking, are important.

How is clinical documentation used to support care coordination?

In an ideal world, there should be a fully transparent record that is designed and organized in a way that everyone who needs it can see it. Providing all the actors in a patient's care with the same information would improve the coordination among those actors. But until we can attain that integrated information state, we can improve coordination now by giving full and easy access to clinical documentation to the one individual who deals with all the others – the patient. And the patient may grant access to others as his or her proxy. As sick patients and their caregivers interact with multiple specialists, order medical equipment, coordinate multiple medications – it's vitally important that they have the best understanding possible of everything that is happening. Ultimately, this idea of a secure "fully shared record" should be what we are aiming for.

And we know when patients are engaged it can influence how well they do. Our study showed that when doctors shared notes with patients, 77-85 percent reported better understanding of their health and medical conditions; as many as 87 percent felt more in control of their care; 69-80 percent felt better prepared for visits; and 60-78 percent of those taking medications reported doing better with taking them as prescribed. And, nearly three quarters of patients across all the sites reported taking better care of themselves.

What challenges have you faced integrating data across care teams and settings? What solutions have you identified to address those challenges?

One of the biggest challenge is overcoming resistance from clinicians. Some doctors still don't think patients should have access to their notes and that these are not a vehicle for patient communications. But it is not an insurmountable challenge. We found that while doctors are initially resistant, once they have experience with the process of sharing their notes with patients,

that resistance evaporates. As an example, one of the doctors who participated in the OpenNotes trial said that he initially feared it would lead to longer notes, more questions and messages from patients. After participating in the project, he found "it was not a big deal."

Another challenge is that while so much of what we do today is through digital technology, not all electronic medical records have the capacity to enable clinicians to easily open their medical notes to patients. We aren't yet sure what the solution is – but it is a challenge we need to overcome, working with providers, vendors, and patients.

Despite these challenges, BIDMC is embracing OpenNotes wholeheartedly – not only with doctors but with all clinicians affiliated with our institution. As this intervention starts to roll out, we have been talking to nurses, social workers, physical therapists, and many others, and by and large they are open to the idea and see benefits for patients. We have encountered remarkably little resistance at BIDMC, including among mental health professionals. And the process for enabling patient access to notes through patient portals is no longer an arduous task. Reprogramming is clearly necessary, but in our experience in 3 institutions, this process has taken weeks, not months, to accomplish.

Our experience to date suggests that institutions that decide to fully open records to patients will need to make a decision about how to best to roll it out. There are a number of ways to provide opt-out strategies to provide initial comfort to skeptical clinicians. Should clinicians be able to exclude patients from OpenNotes? Should clinicians be able to hide particular notes? Should individual clinicians be able to opt out altogether? But we also think it can be promoted as an important and inevitable tool, one that is integral to the patient-centered medical home, could help patients and families contribute to safety, and could provide caregivers with vital information they need to provide the best care.

We have been looking at where OpenNotes will take us. The findings from our research offer some clues: 30-40 percent of patients wanted to be able to approve what is written in the note; 59-62 percent of patients wanted the ability to add comments to their notes; and 49-56 percent of patients wanted patient proxies to have access to their notes. And 86-88 percent of patients wanted access to their hospital notes.

The logical evolution may be that in the future we could see patients and doctors sharing in negotiating, generating and signing the note; virtual visits, with notes initiated by patients; and/or co-generated notes as individual quality contracts, along with metrics for assessing both patient and clinician performance.

What were the benefits to patients having access to clinical documentation notes? Challenges?

Our research collected the evidence to show this has real benefits for patients in primary care: 69-80 percent felt better prepared for visits; 77-87 percent felt more in control of their care; and

60-78 percent reported doing better with taking their medications as prescribed. Some anecdotes: When a patient saw in her notes that her doctor called her "mildly obese," it prompted her to immediately enroll in Weight Watchers and get daily exercise. She was surprised by the notation and she said it forced her to commit to reverse that comment by her next check-up. One patient said he it made it much easier to inform her caregiver since the notes are more accurate than her recollection. She said it allowed her family to understand what was actually going on with her health, not just what her memory decides to store.

In terms of challenges, many questions still need to be resolved. What will be the intersection with patient safety and quality improvement? What will it mean for the use of medical resources and associated costs? How exactly can caregivers participate in the benefits of increased transparency? Who should write what in the note, and how might notes be amended? How will the use of notes vary in different settings -- the primary care office, inpatient settings, specialty care? And finally, how should we educate clinicians to write notes more carefully, to consider tone and phrasing and overuse of medical terminology that patients don't understand?

In conclusion, we have initial evidence that OpenNotes works – patients love it and clinicians don't seem unduly burdened by it. We still have a lot to learn, but it is taking hold. We are glad that the conversation is expanding, and we are happy to collaborate in further efforts that prompt patient engagement and support patients and clinicians working effectively together.

Thank you for the opportunity to testify before you today. I am happy to answer any further questions.