Collaboration of the Health Information Technology Policy and Standards Committees

Final Summary of the September 13, 2016, Joint Virtual Meeting

KEY TOPICS

Call to Order

Michelle Consolazio, U.S. Department of Health and Human Services (HHS) Office of the National Coordinator for Health Information Technology (ONC), welcomed participants to the Health Information Technology Policy Committee (HITPC) and Health Information Technology Standards Committee (HITSC) joint meeting. She reminded the group that it was a Federal Advisory Committee Act (FACA) meeting being conducted with an opportunity for public comment (limited to 3 minutes per person) and that a transcript will be posted on the ONC website. She called the roll and told members to identify themselves for the transcript before speaking.

Remarks

Vindell Washington, ONC, thanked the members for their work. Interoperability is vital to information sharing for delivery reform. The empowered consumer is an ONC goal.

Review of Agenda

HITSC Co-chairperson Arien Malec noted the importance of each of the agenda items. The agenda was distributed in advance of the meeting. He asked for a motion to approve the summary of the July 27, 2016, meeting as circulated with the meeting materials. A motion was made and seconded. The summary was approved unanimously by voice vote.

> **Action item #1: The summary of the July 27, 2016, joint meeting was approved unanimously by voice vote.**

ONC Data Update

Vaishali Patel, ONC, showed slides with quantified data and reported on select findings on patient engagement from the 2015 American Hospital Association (AHA) Health IT Supplement Survey. Hospital adoption of view, download and transmit (VDT) capabilities increased 700% since 2013. The annual increases in hospital adoption of other electronic patient engagement capabilities were also significant. Hospitals adopted a greater number of patient engagement capabilities between 2014 and 2015 than in earlier periods. Compared to larger hospitals, Critical Access Hospitals (CAHs) and small hospitals lag behind in adoption of VDT capabilities, particularly with regard to transmit. Patel went on to note several policy Implications of the findings:

- Growth in hospitals' adoption of VDT capabilities is likely associated with Medicare and Medicaid EHR Incentive Programs and adoption of certified EHR technology.

- Rural and smaller hospitals' lower rates of VDT capabilities reflect lower rates of certified EHR technology adoption and will require continued monitoring.

- To increase usage of these capabilities, it will be important to make it easy for individuals to access, aggregate, and subsequently use their health information. Examples of relevant ONC

initiatives to support these efforts include: the Patient Engagement Playbook, the Consumer Health Data Aggregator Challenge, and the Blue Button Connector.

For more information, see Health IT Dashboard, data brief #38 at http://dashboard.healthit.gov/.

Q&A

HITPC Co-chairperson Paul Tang noted the dramatic improvements in capability. Paul Egerman suggested that further analysis of the CAHs and other rural hospitals gap be undertaken. He speculated that gaps in IT infrastructure and support may be a factor.

HITPC Co-chairperson Kathleen Blake talked about the need to explore the differential value of specific types of patient-generated health data (PGHD) information. Not all information is valuable to the hospital. Another member agreed, saying that a study of the input and integration of discrete data versus scanned documents would be useful. Content, not just capabilities, is important. This represents a good first step. Tang asked about a possible update on a study of the importance of receiving unstructured data. Patel said that ONC partnered with National Cancer Institute (NCI) on a consumer survey, which inquired about the perceived usefulness of information in on-line medical records. Tang indicated his interest in the usefulness of data exchanged provider-to-provider. Patel said that the American Hospital Association (AHA) survey included a question about the usefulness of the summary of care record. Responses indicated that a significant number of hospital recipients perceived this as a barrier.

Chris Lehmann asked about differences between pediatric and other hospitals. Patel said that data indicate that specialty hospitals, such as pediatric hospitals, have lower rates of adoption of certified technology. She offered to follow up with Lehmann for further analysis.

Larry Wolf asked about the actual use of these capabilities: Are there system-reported data? Patel responded that the government does not have access to system-reported data. Research using such data is being done in the private sector.

Carolyn Peterson referred to slide 5 and asked about the ability to submit PGHD: What kinds of data are being submitted and what is the mode of transmission? Patel said that the survey did not include these questions. Perhaps such items can be included in the next annual survey. Donna Cryer interjected that these issues are being brought forward by the Consumer Task Force. Floyd Eisenberg suggested comparison of quality of data across CAHs and rural hospitals and others.

Angela Kennedy asked about regional and size and classification differences in adoption. Patel said that those variables have not yet been analyzed. Kennedy suggested looking at the affiliations of rural hospitals, such as whether they are part of larger systems.

John Scott talked about the ability of patients to aggregate data after downloading. Attention should be paid to personal health record (PHR) capability, such as that provided to U.S. Department of Veterans Affairs patients.

Leslie Kelly Hall said that the value is in how the patient uses and appreciates the information. These results are cause for celebration. Patel said that to date the emphasis has been on adoption, but going forward a focus can be placed on use of information. About 30% of hospitals reported that the summary of care records sent were not useful. Tang concluded that data are starting to flow and much has been accomplished in the past few years.

HITPC/HITSC Consumer Task Force Update

Task Force Co-chairpersons Donna Cryer and Patty Sengstack showed slides prepared by staff and reported on the recent output of the task force, which was instructed by staff to review and comment on the Blue Button Connector and the Patient Engagement Playbook. Regarding the former:

- There is still a need for something like the Connector, as all of the members agreed that it is still very challenging for consumers to access their health record online. Members noted that a lack of time, incentives, training, and promotion of tools hindered consumers from accessing their health records.
- Overall members felt the Connector was easy to navigate.
- Members felt the site primarily targeted consumers rather than other audiences like developers.
- Members commented that the site needs to be more clear in explaining the Connector's role in assessing data and set expectations for users of the site.
- Some members felt the Connector could serve as a resource for education and health literacy and could provide more context on why getting your electronic health information is important.
- Members noted that updates on the site are necessary, as some links and videos are outdated, and it is missing newly updated documents and resources.

Moving to the Patient Engagement Playbook:

- Members overall found the Playbook to be aesthetically pleasing and easy to navigate.
- Members enjoyed examples from the field and suggested more be included in future versions.
- Members feel that the content is engaging, the links easy to follow, and the embedded animated graphic presentations are appropriate to the content.
- Overall, members felt the Playbook is appropriate for providers and some suggested that it would require only a little tweaking for patient use.
- Several members expressed that patients are another audience that could benefit from using the Playbook. Members recommend ONC consider a patient audience in future iterations of the Playbook.
- Members suggested having a PDF or printable form of the Playbook could help providers use and share this resource with their care team or patients.
- In regards to the title, members suggested adding a subtitle to provide more clarity and clearly defining patient engagement from the beginning.
- Some members felt there is a need for a more granular step-by-step guide on how to implement tasks to make this more useful for providers. Additionally, the benefits of patient engagement need to be clearly defined to encourage providers to adopt these strategies.

The task force is now working on a review of the Model Privacy Notice.

Q&A

HITSC Co-chairperson Lisa Gallagher and staff thanked the task force. Tang told ONC staff to talk to EHR vendors and ask them to offer the Playbook to their clients. Sengstack reported that her employer recently instituted use of the Playbook.

Regarding the Blue Button Connector, Wanmei Ou asked how many hospitals are connected. Staff will locate and send the information to members. Consolazio asked members to be more concise in their questions and responses, as the discussion had exceeded the time allocated to it.

Gayle Harrell said that the Model Privacy Notice is very important to patients. Privacy is the key component of engagement.

Eric Rose said that in Seattle patient platforms are nearly universal, except in the case of minors. He wondered whether the Playbook dealt with the issue of minors and confidentiality. Sengstack said that examples in Chapter 3 are relevant to adolescents' data. Lucia Savage, ONC, said that the results of the work with the National Governors Association (NGA) on state privacy laws will be presented at the next meeting. Due to the great variation in state laws, it is not possible to be more specific in the Playbook.

Kyle Meadors suggested that the ONC ACBs may be an avenue for distribution of the Playbook. The introduction refers to a meaningful use measure that is no longer in effect and should be corrected.

Kelly Hall said that the Playbook is well done and will be a useful tool.

HITPC/HITSC Interoperability Experience Task Force Findings

At the July 27 meeting, HITPC Co-chairperson Paul Tang announced a change in the agenda. A co-chairpersons' conference call, prior to the joint meeting, had resulted in a decision to postpone the report from the Interoperability Experience Task Force until the September meeting. The co-chairpersons instructed the task force to focus its report and transmittal letter on the role of the federal government.

Task Force Co-chairpersons Jitin Asnaani and Anjum Khurshid showed slides and reviewed the charge and process used by the task force, repeating material that had been presented in interim reports at previous meetings. They referred to the presentation slides and transmittal letter, both of which were circulated with the other meeting materials. The task force identified and prioritized needs and use cases and eventually agreed to recommend three priorities:

- Work is needed around clinical information reconciliation and curation to reduce the burden of clinical data import. Because of a broadly published set of guidance and best practices, these issues are being encountered and encumbering data exchange in a multitude of silos across the country. A convening body could establish some degree of consistency and reasonable expectation, balanced with private sector innovation.
- Incorporation of non-clinical data is needed so that it is useful to clinicians. Stakeholders across the industry need better methods, and potentially new standards, to effectively capture and use non-clinical data (including unstructured data), such as the behavioral and social determinants of health. Most focus has been on EHR-to-EHR data, but to better care for a person, non-clinical information is needed.
- Work is needed to better understand how to deal with PGHD, as interoperability includes PGHD (broader than non-clinical data above). Methods and standards for inclusion are needed, as well as a better understanding of how to best summarize data.

Discussion

Blake thanked the task force for reconvening and refocusing as requested by the co-chairs of the committees. She referred to recent studies that support the priorities. A time and motion study funded by the American Medical Association and published in the Annals of Internal Medicine found that for every 1 hour of patient face time, physicians spend 2 hours in EHR record keeping and other desk work. *Evolutionary Pressures on the Electronic Health Record: Caring for Complexity* by Zulman, Shah and Verghese, JAMA, September 6, 2016, is also relevant.

Eisenberg noted that there is a cost to the provider in terms of work flow. He reported that his work on reconciling with immunization registry data reveals that reconciliation is not the same for all types of data. The reconciliation of immunization data is very different compared to medication data reconciliation. Therefore, usability must be taken into account to make reconciliation work. One finding pertained to the extent to which providers send their reconciliation results back to the immunization registry for correction. Eisenberg asked that ONC act on a Transitional Vocabulary Task Force recommendation made some time ago and set a target date for standardization of terminology.

Andrew Wiesenthal said that although the National Library of Medicine (NLM) is recognized worldwide as the national release center for vocabularies, the United States has yet to so designate it. Recognition should be granted immediately. Reconciliation requires standardized vocabularies. The costs and harms of not being interoperable must be considered.

Rajesh Dash talked about the need to establish a central registry and index for medical documents in the United States, saying that the root issue of interoperability goes beyond technical and terminology factors.

Kelly Hall commented on the need for a consumer vocabulary. Regarding usability, patients must also be taken into account. PGHD should be considered holistically. Patients can contribute to efficiency.

Richard Elmore requested an explanation for the narrowing of eight priorities to the three listed. Asnaani replied that the original eight overlapped somewhat. The task force focused on demand and root causes to select three. The task force members eventually voted, and the votes clustered around the three.

Jamie Ferguson recommended a change in the third priority to add "relevant to a health condition." He explained that there are at least three distinct types of PGHD that are typically considered: (1) one-time electronic questionnaires, (2) data from consumer wellness devices, and (3) professional grade health monitors for serious conditions. The recommendation is not specific to the professional monitors of conditions such as diabetes or congestive heart failure. The recommendation should differentiate which data are useful and which are not. A more reasonable recommendation would center on providing means for the collection and use of PGHD when there is an agreement between the patient and the provider. Another rationale is that there is a real problem with excessive alerts and noise, which can detract from a more focused approach to medicine. Additionally, the liability for holding unsolicited data should be considered. The sentence would then read "Work is needed to better understand how to deal with the patient generated health data that is relevant to a health condition …"

Blake said that Ferguson was making a motion to amend the recommendation. She asked for a second to the motion. Eisenberg seconded the motion to amend, but he also asked to delete the words "(broader than non-clinical data above)." Blake pointed out that only one amendment can be considered at a time. However, Ferguson agreed to restate his motion to include Eisenberg's deletion. Blake ruled that comments on the amendment would be entertained prior to any additional comments on the recommendations themselves. Kelly Hall emphasized her opposition to anything that stated that the physician alone determines what data are relevant.

Cryer spoke in favor of the amendment as well as Kelly Hall's opposition. Tang said that he was lost in the discussion and proposed another change in wording, which Ferguson then declined to accept. They debated the interpretation of "relevant." Meadors said that what is important is what is eventually included in the record—physicians are always responsible for listening to the patient. Blake proposed amending the recommendation by deleting this part of the sentence: "as interoperability includes PGHD (broader than non-clinical data above)." Ferguson, Kelly Hall and Cryer said that they had no objections.

Elaine Hunolt, VA, said that the first recommended priority should also apply to PGHD. Kelly Hall and Eisenberg agreed. Blake added PGHD.

Asnaani and Khurshid approved of the proposed modifications. An electronic vote was conducted. Consolazio announced that the priorities recommended by the Interoperability Experience Task Force were accepted as amended by the PGHD changes. The count was not announced.

> **Action item #2: The priorities recommended by the Interoperability Experience Task Force were amended pertaining to PGHD and accepted by electronic vote.**

ONC Updates

Steve Posnack reported that the 2017 Interoperability Standards Advisory has been published for public comment. It contains links to the proving ground. Select papers received in response to a recent challenge will be presented at the upcoming conference co-sponsored by NIST. Responses to another challenge are currently being reviewed for Phase 2.

Public Comment

A number of comments were received via the chat function of the web meeting site.

John Scott wrote, "I would echo the importance of being able to aggregate information just mentioned. I believe that capability requires use of a Personal Health Record (PHR). I think highly functional PHRs are an essential component for the development of patient centered HIE, and that PHRs need specific attention and incentives."

David Tao wrote, "Regarding what patients regard to be 'of value', I wish to call the committees attention to an article published in JAMIA on August 7, 2016, entitled 'Patient and Clinician perspectives on the outpatient after-visit summary: a qualitative study to inform improvements in visit summary design'. This deals with the exact question that the committee is asking about, and is based on interviews with patients using clinical summaries given them by providers."

Elaine Hunolt wrote, "Can we please have a comparison between these great findings and the ONC Interoperability Roadmap? Would these findings change any of those priorities? Because the usability of the data and reconciliation is so important to address the burden on the clinician. Finally, we have found in VA that lack of standards surrounding human services or non-clinical data has been an issue. We know that there has started to be modeling on this non-clinical data for standards, as presented to the Federal Health IT Advisory Board."

Thompson H. Boyd, III, MD, Hahnemann University Hospital in Philadelphia, PA, wrote, "Comments regarding slide #10. PGHD also includes the Patient's Narrative: the patient's story, the patient's preferences, the patient's wishes - all part of Shared Decision Making."

Scott again wrote, "In reference to including PGHD in the medical record: Good health care providers have always emphasized listening to the patient (see Osler). But clinicians and other CE staff have always managed what becomes part of the medical record for which the CE takes responsibility. I think we need systems that make it easy to ensure validity of PGHD and to include it in the health record, but that we must draw a distinction between data in patient controlled spaces and data in the CE's health record on a patient. The rationale for this is that a CE needs to be able to hold clinicians responsible for what is in the health record. If the CE does not maintain control over what enters the health record, the burden on the clinician becomes unbearable."

Donna Doneski, Director of Policy & Membership National Association for the Support of Long Term Care (NASL), wrote, "NASL is pleased to hear that ONC outreach on the Patient Engagement Playbook will include vendors. As a national association representing the majority of health IT vendors serving the LTPAC community, NASL would be pleased to highlight ONC's outreach and share information with our members about the Patient Engagement Playbook. Please include us in whatever you do in terms of vendor outreach. Thank you."

Next Meeting: The joint committee will meet in person on October 5th.

SUMMARY OF ACTION ITEMS

Action item #1: The summary of the July 27, 2016, joint meeting was approved unanimously by voice vote.

Action item #2: The priorities recommended by the Interoperability Experience Task Force were amended pertaining to PGHD and accepted by electronic vote.

Meeting Materials

- Agenda
- Interoperability Experience Task Force recommendations transmittal letter
- Summary of the July 27, 2016, joint meeting
- Presentations and reports slides