Meeting Notes

Health Information Technology Advisory Committee
Health IT for the Care Continuum Task Force
April 19, 2019, 09:00 a.m. – 10:30 a.m. ET
Virtual

The April 19, 2019, meeting of the Health IT for the Care Continuum Task Force (HITCCTF) of the Health IT Advisory Committee (HITAC) was called to order at 9:00 a.m. ET by Lauren Richie, Designated Federal Officer, Office of the National Coordinator for Health IT (ONC).

Lauren Richie called the meeting to order and then conducted the roll call.

Roll Call

MEMBERS IN ATTENDANCE

Carolyn Petersen, Co-chair, Individual
Christoph Lehmann, Co-Chair, Vanderbilt University Medical Center
Chip Hart, Member, PCC
Susan Kressly, Member, Kressly Pediatrics
Aaron Miri, Member, The University of Texas at Austin, Dell Medical School, and UT Health Austin
Steve Waldren, Member, American Academy of Family Physicians

ONC STAFF

Alex Kontur, ONC
Stephanie Lee, Health IT for the Care Continuum Task Force Staff Lead
Samantha Meklir, Health IT for the Care Continuum Task Force SME
Elizabeth Myers, ONC
Carmen Smiley, ONC
Albert Taylor, Health IT for the Care Continuum Task Force SME

GUEST SPEAKERS

Hannah K. Galvin, MD, FAAP, Medical Director of Informatics, Lahey Health
Stephen Patrick, MD, MPH, MS, Director, Vanderbilt Center for Child Health Policy

Lauren Richie turned the meeting over to Carolyn Petersen, co-chair.

Welcome Remarks

Carolyn Petersen welcomed the task force members and reviewed the agenda. She then turned the meeting over to Chris Lehmann, co-chair.

Chris Lehmann thanked the presenters for taking the opportunity to share their expertise. He noted that last week he received an email from his health insurance organization that showed that one of his grown

children had been seen by a certain provider that would detail the type of care his child received. Using this as an example, he noted that there are additional privacy considerations that need to be considered.

Privacy Considerations Presentation/Discussion

HANNAH K. GALVIN, MC, FAAP, MEDICAL DIRECTOR OF INFORMATICS, LAHEY HEALTH

Hannah K. Galvin noted that she was asked to share her feedback on items in the notice of proposed rulemaking (NPRM).

Data Segmentation for Privacy

She applauded ONC's efforts to be able to tag at the document and section level. In her experience, she previously worked for a large national vendor and championed data segmentation for privacy (DS4P) for that vendor. She had a difficult time getting the vendor to prioritize DS4P onto their roadmap because there wasn't a good business case. Without a regulatory mandate, the developer did not identify this as a priority. Voluntary pediatric certification is a good first step to move things forward. In the NPRM there is a broad definition that requires DS4P, but this makes it difficult to identify success. To promote interoperability some version of standardization is needed. The consolidated - clinical document architecture (C-CDA) is not the only exchange standard; therefore, this only partially addresses the use cases. This is only a first step to addressing this issue. She noted that the task force should encourage ONC to consider sponsoring a workgroup to consider a broader framework.

Consent2Share (C2S)

She applauded ONC's efforts toward proposing consent management standard.

- C2S is compatible with DS4P; allows for consent initiation, management, and redaction.
- Vendor/organization must evaluate value sets to define "sensitive data" which requires alignment with granular data tagging by DS4P.

Pediatric Use Cases

These criteria could help enable providers to:

- Limit the sharing of reproductive and sexual health data from an EHR in order to protect the minor's privacy
- Prevent disclosure of an emancipated minor's sensitive health information, while also permitting a parent or legal guardian to provide consent for treatment
- Segment child abuse information based on jurisdictional laws, which may have varying information sharing requirements for parents, guardians, and/or other possible legal representatives.

She identified all examples of places that information can go and the minimal places that use C-CDA.

- Inter-organizational typically uses C-CDA, but most of the following do not.
    - Clinical systems (e.g., ultrasound, radiology, pharmacy) typically using other standards.
    - Patient portal information
    - Printed materials
    - School notes

Opioid Use Cases

- DS4P is mostly used for external sharing
- Common practices include:
  - Limiting data sharing for patients with "sensitive conditions"
  - Segregated behavioral health information

Review of Recommendations

- Task force should consider suggesting including DS4P as a broader requirement for 2015 Edition criteria to encourage vendor prioritization.
- Recommend requiring discrete metric(s) to focus vendor direction.
- Recognize that data exchange is complex and DS4P and C2S alone will not fully address proposed pediatric and opioid use disorder (OUD) use cases.
- Consider ONC sponsorship of multidisciplinary workgroup forming to develop broader implementation framework, including consensus recommendations around:
  - Industry-wide adoption of these and potentially additional standards to protect privacy while promoting interoperability.
  - Data visualization at the point of care and availability for clinical decision support

Discussion

Chris Lehmann noted the complexities of DS4P.

- **Hannah K. Galvin** commented that there isn't going to be a way to fully remove the data. She questioned if medications should be removed from the list (e.g., HIV medications). She suggested starting with limited use cases and trying to get consensus around a path forward.

Chris Lehman asked if the work of the workgroup she is working on would be public.

- **Hannah K. Galvin** noted that the workgroup is in the early stages and will be in the public domain.

Chip Hart noted that almost any element of the chart could be private (e.g. hiding address from an ex-spouse). Almost any diagnosis can be considered private. He noted that this is his biggest concern, how can this be done without causing provider burden with too many clicks?

Sue Kressly noted that without universal adoption nothing is solved.

Steve Waldren commented that this is a deeper issue. A national trusted exchange is needed.

Sue Kressly emphasized that just because this is hard, doesn't mean that it isn't critical to move forward.

Chris Lehmann asked what the next steps are? Is there a need for a minimal privacy data set description?

- **Sue Kressly** noted that users need the ability to tag anything. The only way to solve this is to gather stakeholders and talk through the best steps forward.
- **Hannah K. Galvin** suggested continuing to promote this work and note that this is just the beginning because this is a complex process that needs to be addressed piece by piece.

Chris Lehmann shared that voluntary pediatric certification is just beginning and there will be additional work needed for improvement over time.

Neonatal Abstinence Syndrome (NAS) Presentation/Discussion

STEPHEN PATRICK, MD, MPH MS, DIRECTOR, VANDERBILT CENTER FOR CHILD HEALTH POLICY

Stephen Patrick provided context and background regarding NAS. He noted that substance abuse in pregnancy is not uncommon. Pregnancy is an optimal time to engage in new care patterns. He emphasized that legal substances are also a concern. Approximately 14% smoke cigarettes and a little less than 10% use alcohol.

He walked through treatment options for NAS, highlighting that there is substantial variability in care across hospitals. He expressed concern that there seems to be a sense of 'winging it' when treating drug withdrawal.

What to do?

- Standardize care
- Use information technology to better coordinate care
- Better standardization of discharge
    - Improve care delivered inpatient
    - Appropriately connect with home visitation
    - Interaction with child welfare system
    - Coordinate with maternal follow-up keeping mothers engaged

Closing Remarks

- There is a need to standardize treatment and discharge.
- There are substantial gaps within the current system

Discussion

Chris Lehmann noted that one of the most effective ways to standardize care is through order sets. He questioned whether it would be helpful to have a national group working on this.

- **Stephen Patrick** commented that there isn't one protocol that is superior, but consistency improves outcomes. It would be beneficial for a national group to start this work.

Carolyn Petersen transitioned to a discussion of the feedback from the last task force call.

Recap Discussion - Opioid Use Disorder (OUD) Request for Information (RFI)

Carolyn Petersen reviewed the discussion from the last call on April 12, 2019.

Chris Lehmann commented in regards to prescription drug monitoring programs (PDMPs) that there is a challenge due to varying state laws. He asked the members if they had additional thoughts and concerns.

- **Sue Kressly** noted that technology is not the issue.
- **Chip Hart** asked to review with his subject matter experts to provide additional feedback.

- **Sue Kressly** noted that she would gather more feedback as well.

Sue Kressly commented that clinical decision support can be difficult.

- **Chris Lehmann** agreed and noted that the implementation can also be difficult. He emphasized again that order sets can be effective.

Lauren Richie opened the line for public comment.

Public Comment

There was no public comment.

Comment in the Public Chat

Mike Boucher: Sorry if this was already asked, but will Stephen's slides be shared?

Stephen Patrick: I'm happy to share

Next Steps and Adjourn

Elisabeth Myers shared that ONC and HHS made announcements earlier in the day. These announcements impact the HITAC schedule. The comment period for the CMS and ONC rules has been extended by 30 days, closing on June 3, 2019 (instead of May 4, 2019).

Trusted Exchange Framework and Common Agreement Draft 2 (TEFCA) was released for public comment and the comment period will end on June 17, 2019.

Carolyn Petersen noted that there was a plan to review the feedback from the April 10 HITAC meeting, but due to time, this will get moved to the next meeting.

Chris Lehmann thanked the presenters and the spirited discussion from the members.

Lauren Richie adjourned the meeting at 10:30 a.m. ET.