



Meeting Notes

Health Information Technology Advisory Committee

Information Blocking Task Force

April 05, 2019, 11:30 a.m. – 12:30 a.m. ET

Virtual

The April 05, 2019 meeting of the Information Blocking Task Force (IB) of the Health IT Advisory Committee (HITAC) was called to order at 11:30 a.m. ET by Lauren Richie, Designated Federal Officer, Office of the National Coordinator for Health IT (ONC).

Lauren Richie conducted roll call.

Roll Call

MEMBERS IN ATTENDANCE

Michael Adcock, Co-Chair, Individual

Andrew Truscott, Co-Chair, Accenture

Cynthia Fisher, Member, WaterRev, LL

John Kansky, Member, Indiana Health Information Exchange

Steven Lane, Member, Sutter Health

Arien Malec, Member, Change Healthcare

Anil Jain, Member, IBM Watson Health

Aaron Miri, Member, The University of Texas at Austin, Dell Medical School, and UT Health Austin

Sasha TerMaat, Member, Epic

Lauren Thompson, Member, DoD/VA Interagency Program Office

Denise Webb, Member, Individual

MEMBERS NOT IN ATTENDANCE

Denni McColm, Member, Citizens Memorial Healthcare

Sheryl Turney, Member, Anthem

Valerie Grey, Member, New York eHealth Collaborative

ONC STAFF

Cassandra Hadley, ONC

Mark Knee, ONC Staff Lead

Morris Landau, ONC Staff Lead

Lauren Richie, Branch Chief, Coordination, Designated Federal Officer

Lauren Wu, ONC SME

Lauren Richie turned the meeting over to Andy Truscott, co-chair.



Electronic Health Information

Andy Truscott suggested adding consent and access log information into the electronic health information (EHI) definition.

- **Steven Lane** noted that audit trails should not be included.
- **Arien Malec** commented that if consent is required there needs to be reasonable methods for offering the consent (i.e., meaningful consent). The basic requirement is people need to know how, within the appropriate flow of care and care delivery, to express the wishes of the patient.
- **Andy Truscott** asked if it would be reasonable to suggest that individuals shouldn't have to express consent again.
- **Cynthia Fisher** questioned why opt-out versus opt-in.
 - **Arien Malec** noted this is a state issue, not a federal issue.
- **Andy Truscott** suggested that if consent counts as EHI, it cannot be blocked. It may be that in a particular state, affirmative consent will have to be gathered again.
- **John Kansky** stated that if consent is in the definition of EHI, then the entire country will need to figure out how to fix consent.
- **Steven Lane** noted including consent may or may not be useful, no harm in including.
- **Anil Jain** commented that the important thing is there can be clinical implications related to consent and should be included in EHI. This can have a downstream impact on payment and care. It is compelling that it is part of EHI.
- **Valerie Grey** agreed that it should be part of EHI.
- **Denise Webb** also agreed that consent should be included in EHI.
- **John Kansky** commented that if a state that is opt-out and a patient opts-out, are they required not to respond or are they required to respond that the patient has prohibited the sharing of their data (which might be what the patient doesn't want to be exposed)?
 - **Andy Truscott** said that this is a local decision.
- **Arien Malec** commented that there is a need to be careful to not design additional privacy law. Extra HIPAA obligations in states should not be an excuse not to share.
- **Steven Lane** noted that consent is not just a data field; it is complex.
- **Andy Truscott** noted that there are standards that exist for expressing consent.
 - **Valerie Grey** suggested including consent in the U.S. Core Data for Interoperability (USCDI) in version one.
- **Cynthia Fisher** questioned how to best approach this in light of information blocking.
- **Sasha TerMaat** expressed that she liked the idea of putting a level of definition around consent to include in USCDI. She questioned "consent for what," more is needed here as this varies significantly. It could be valuable to share the information, but more definitional and standards work is needed. Including in USCDI could help in sharing effectively.
 - **Andy Truscott** commented that it should be consent for sharing.
 - **Sasha TerMaat** noted that clarity is needed to define appropriately.
- **Aaron Miri** noted that the Family Educational Rights and Privacy Act (FERPA) rules for sharing are another consideration.
- **Sheryl Turney** noted there needs to be a place where communicating that consent was declined, yet it currently isn't a defined data element. Something is needed to communicate consent when consent is denied.



- **Andy Truscott** noted that consent changes over time. There is consensus on the call that consent should be routinely shared and should not be blocked, subject to local policies and procedures.
- **Arien Malec** noted that in order for information to flow there is an affirmative obligation to share, based on the patient's wishes.
- **Steven Lane** questioned if the content of the consent is that the patient doesn't want to share their information. There is some information that the patient didn't want to be shared, but don't express where that took place.
 - **Andy Truscott** commented that the EHI would not be shared.
- **Andy Truscott** asked should consent information be considered EHI and therefore not routinely blocked?
 - **John Kansky** noted that whether the information is shared or not, consent is still implied.

Andy Truscott asked for a vote on whether to include consent in the definition of EHI.

Arien Malec suggested a perspective that in states where the laws are stronger than HIPAA, the consent information should be shared as broadly as necessary to express the wishes of a patient. It would be desirable to share via USCDI. This is a high priority standards activity to be able to do so. His concern is that the group could be asking for something that they don't know how to do yet.

Anil Jain commented that everyone agrees this should be shared, but the standards are not there and a requirement will cause unintended consequences. He suggested encouraging the inclusion but looked forward to having clearly defined standards before it is required.

- **Steven Lane** agreed with Anil Jain's recommendation.

Andy Truscott encouraged the members of the public to share their insights on this topic.

Cynthia Fisher commented that there is a need to make sure that things aren't delayed for years because there is work being done to define a standard.

Andy Truscott noted that wording will be drafted for the inclusion of consent, as long as standards are in place. With that, he asked Lauren Richie to conduct a vote. The results of the vote are below:

- Lauren Thompson - Concur
- John Kansky – Abstain
- Cynthia Fisher – Abstain
- Anil Jain - Concur
- Valerie Grey – Abstain
- Arien Malec – Concur (with some reservations)
- Aaron Miri – Concur
- Sasha TerMaat – Abstain
- Denise Webb – Concur (with clarity regarding the definition of consent)
- Sheryl Turney – Concur (with clarity regarding the definition of consent)
- Steven Lane – Concur (with clarity regarding the definition of consent)
- Michael Adcock – Concur
- Andy Truscott - Abstain



Andy Truscott committed to drafting language for review with the group at the next meeting.

Lauren Richie opened the lines for public comment.

Public Comment

There was no public comment.

Comments in the Public Chat

Steven Lane: Steven Lane here

Arien Malec: Arien here as well

Andy Truscott: can I have the presenter view please?

Andy Truscott: Otherwise I can't see when Steven has his hand up

Lauren Richie: thanks Steven and Arien

Aaron Miri: I am here

Aaron Miri: this is Aaron Miri

Andy Truscott: Sorry Members... My screen had blanked

Sasha TerMaat: Lauren, I missed roll call but I joined about 10:05, just wanted to let you know.

Lauren Richie: thanks Sasha

Sasha TerMaat: Typo, 10:35. Sorry!

Arien Malec: Sasha -- you only get partial credit for attendance.

Arien Malec: Sad!

Aaron Miri: disclosure rules for FERPA: <https://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

Aaron Miri: If we define the term of consent too granularly, that may make it difficult to comply with FERPA which academic (teaching) health systems have to comply with

John Kansky: Steven is raising the same question I attempted to ask earlier. Needs to be clear to those figuring out how to comply

Sasha TerMaat: I agree with Arien, are we trying to indicate the priority of this information, or the readiness for inclusion in this context?

Arien Malec: 🙄



Andy Truscott: Emoticons? ;)

Arien Malec: Sense of the group: 🙏

Arien Malec: ~_(\ツ)_/~

Next Steps and Adjourn

The next meeting is on Thursday, April 11 at 9:00 a.m. ET. **Lauren Richie** adjourned the meeting at 12:30 p.m. ET.