

Marko and John, thanks again for the time earlier this week. We very much appreciated the conversation and we appreciate your willingness to restate at the next meeting the Agency's intent to remain consistent with TEFCA and a federated model approach. At your suggestion, we've included a few specific examples in draft products that could lead to a misunderstanding of the Agency's intent.

General

In several places, including the principles, the draft legislative update and the draft data sharing agreement, there are references to health data collection, reporting or analysis. These terms/functions are not in AB 133 and aren't necessary in a federated model, and may suggest the establishment of a more centralized model of data sharing. The use of these terms may cause confusion around goal/intent and overall approach.

The draft data sharing agreement appears to be based on the CalDURSA which was based on the original federal DURSA that is now out of date. For example it does not extend HIPAA privacy and security protections when the data is shared with non-HIPAA entities. The Common Agreement of TEFCA extends HIPAA protections to data collected and held by those entities. To remain consistent with AB 133 and avoid confusion, it would be most logical and efficient for the DSA subcommittee to adopt TEFCA as the model for health information exchange, cooperative agreement privacy and security policies, and privacy and security protections over non-HIPAA covered entities, such as third party apps and others. By leveraging the Common Agreement in conjunction with other existing regulation (e.g., information blocking) as the foundation for California, the focus can be on supporting state specific use cases outside of the broad scope of TEFCA.

Draft Legislative Update

We think this statement should be revisited; it overstates the problem and understates TEFCA's capabilities:

"Gap #1a: National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of Social Determinants of Health (SDOH) and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data."

Risk of suggesting need for a centralized digital identity system

The draft legislative update includes the consideration of a statewide Master Person Indices (MPI) (Slide #37). Rather than considering a centralized statewide master patient index, the state should consider the national federated digital identity approach being developed through initiatives like the CARIN Alliance and HHS ONC, which is being pilot tested to be adopted for TEFCA nationally. KP encourages the emerging federated consumer digital identity model as the future of identity solutions that do not

lead to a proliferation of centralized repositories that have high security and privacy risks.

Governance

AB 133 requires the advisory committee to “assess governance structures to help guide policy decisions and general oversight” and not necessarily create a new state level regulatory entity to enforce data sharing requirements. (Slide 25) We continue to support the role of state government as a convener, to foster adoption, for appropriate enforcement, and to monitor implementation, but this can be done through existing agencies and authorities. Harmonization of state law with federal law should be explicitly called out as a key governance function. (Slide 26)

Timeline

The milestones on slides 40 and 41 are extremely aggressive and compressed and will be difficult to meet given the scope and complexity of the work. Again, to meet these goals, we urge adoption of the final Cures Act Trusted Exchange Framework and Common Agreement, as is.

Please let us know if you have any follow up questions.

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