Creating Access to Real-time Information Now
through Consumer-Directed Exchange

Meeting Recap

CARIN Community Meeting
August 8, 2025

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Make Health Tech Healthy Again Q&A and Open Discussion – Ryan Howells, CARIN Executive Director & Aneesh Chopra, CARIN Co-Founder

- Ryan opened the meeting with a nod to the recent White House meeting for the Make Health Tech Great Again initiative and the webinar that Leavitt Partners hosted today on Kill the Clipboard. This is a movement, not a mandate, and scope can go beyond this initial set of ideas rallying the industry.
    - He emphasized CMS is running the initiative, and those interested in participating need to email CMS at HealthTechRFI@cms.hhs.gov and identify where you will commit.
- The group discussed how liability for the data holder and possible penalties are being addressed. This may need formal FAQs from the Office of Civil Rights (OCR), but OCR gave a statement at the White House event that if the data holder is following the IAL2 process and inadvertently sends the wrong record, they will deem the matter settled if they communicate with both parties.
    - From the 7/30 CMS press release: “The Office of Civil Rights (OCR) supports actions that improve the timeliness in providing individuals with access to their electronic protected health information, without sacrificing health information privacy and security,” said OCR Director Paula M. Stannard. “If an individual receives another individual’s electronic protected health information in error, generally, OCR’s primary HIPAA enforcement interests are ensuring that the affected individual and HHS receive timely HIPAA breach notification.”
    - https://build.fhir.org/ig/HL7/fhir-identity-matching-ig/patient-matching.html has a Consumer Match section, and other sections speak to requirements on the responders and the CSPs.
    - The CARIN wrong record work has also been working to address this and is trying to get OCR to say that because it is a low probability of compromise, that this becomes a non-reportable incident as long as there are methods to take care of it and you do take care of it.

        - The group noticed that documentation coming out of TEFCA was saying there is never a breach if the wrong record is sent to another covered entity, which did not sound right as this would be a misinterpretation of HIPAA. However, this is not being treated as incidental exposure; instead, this is being treated under a low probability of compromise. So, the CARIN group asked OCR to take the guidance already written on low probability of compromise and apply it to the situation where a record goes to an IAS entity that is obligated to comply with HIPAA and was not passed on to the wrong patient.

- The group also discussed consent preferences and stated that we need to determine what functional requirements are, whether organizations will want to share information, and whether nodes will be able to abide by it. Without this buy in, we will have patients simply recording their consent preferences, rather than identifying what they are consenting to.
    - Additionally, members discussed the need to keep audit logs to see where data is going, which will require technical effort/API development on how to expose/ask for permission to see audit logs.

Open Forum with Amy Gleason, Senior Advisor to HHS/Acting Administrator of the US DOGE Service

- Amy offered initial remarks about the initiative's kick off, which had over 60 organizations that have pledged. CMS is hoping to email companies soon with updates on next steps and is awaiting final clearance to launch the technical working groups. Additional organizations interested in committing should be specific on which track(s) they want to participate in when emailing CMS.
- CMS is asking the community to weigh in on which use cases they are focused on, and within those, what are the parts they consider generally agreed upon today and that would not require a lot of discussion, and which areas have the biggest debate and will be the hardest so CMS can determine where to focus in the technical groups.
    - **CARIN Action Item: Consolidate this feedback and send it to the CMS email.**
- TEFCA tie-in: ONC is running the TEFCA process and CMS will partner with them generally. But this initiative is a step outside of TEFCA to include all those who can be networks, whether they are a QHIN or not, and this is focused on how to get all players to align on vision and use cases.
- Wrong record: OCR added a comment in the press release that their main priority is that notifications happen and as long as organizations are using best practices and the proper means of validating identity, OCR is more concerned that organizations are notifying persons that the data was shared with someone else than enforcement.
- Privacy with RLS Queries: RLS is not very mature, so will work with the technical group to better flesh this out.
- Standards: The initiative will work to incorporate the right standards at the right time and update them as we go along.
- CMS App Store: There is an idea to highlight vetted apps for patients when on the Medicare.gov webpage (for example, if you have diabetes, the website may recommend a diabetes app). This will consider the type of data collected and shared before it goes live.

- IAL2 and Patient Identifier Issue: There is no desire for a single patient identifier, but the thought is that ID credentials can pass more information than was traditionally shared to make identity matching better (for example, old addresses).
- Network Roles: This will depend on the type, i.e., QHIN versus HIE, so CMS is leaving it up to the individual business models of the organization. Clearinghouses could become network partners if willing to take queries.
- Federated Patient Consent: The technical way to do this is still open and there is no specific way CMS is thinking about doing this. They are focused primarily on patient consent and clarity.
- Cryptographic Signatures: This may be an opportunity for TEFCA.
- Patient History and Sharing: CMS is mainly focused on patient history and ability to share medical records with providers, so trying to clear as much bulk FHIR data as they can.
- PIQI & Data Quality: The PIQI framework focuses on quantifying the quality of data moving across the networks. This is something CMS can look into more during this work.
    - Ryan shared the link for prior imaging access work for reference.
- Data Set Expansion to Images: This is a problem that is a priority, but CMS made the decision to start with a more limited set like jpegs.
- Data Quality Measures: CMS started simple and included two quality measures.
    - Ryan shared a link for DQIC data quality work and 14 measures that are compatible with USCDI.
- Caregiver Access: Part of the redesign will include caregivers, but CMS is early in the design process on this.
- Enforcement: Networks will self-attest to meet the interoperability criteria in the guidelines and agree to be reviewed. Those that do not meet the criteria will be removed from the list.