California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Meeting 8 Q&A Log (10:00AM – 1:00PM PT, May 18, 2022)

The following table shows comments that were entered into the Zoom Q&A by public attendees during the May 18th meeting:

Count	Name	Comment	Response
1	Lane# Steven MD MPH	It is good to see so many folks staying safe and attending this meeting remotely.	live answered
2	Lucy Johns	+1 to Dr. Lane Prefer chat for this but not available.	
3	Lane# Steven MD MPH	California IS amongst the national leaders in heath data interoperability, having nearly all providers connected to and heavily utilizing the existing networks and frameworks to improve care coordination and quality/efficiency of care.	
4	Lucy Johns	Is it possible for remote participants to know who is speaking? I.e.: can this be signified by Zoom? Thanks	
5	Lane# Steven MD MPH	We should acknowledge, celebrate and build on our success as we strive together to close the remaining gaps and engage a broader group of stakeholders, use cases and data classes in our ongoing exchange.	
6	Lucy Johns	Great, thank you!	
7	Lane# Steven MD MPH	Very exciting to see California pushing the envelope of interoperability to include social service information and stakeholders. Yet another opportunity for us to help lead the country and the	

Count	Name	Comment	Response
		world in our use of technology to support our community.	
8	Lane# Steven MD MPH	There is great policy work moving forward in Europe (https://ec.europa.eu/health/ehealth-digital-health-and-care/european-health-data-space_en) to empower individuals through increased access to and CONTROL of their electronic personal health data, nationally and cross-borders, thus avoiding some of the privacy challenges we face in the US with our reliance on large centralized respositories of data, some beyond the reach of HIPAA, over which individuals have no control.	
9	tien@eff.org	Q: I’m concerned about the restrictions on participant dissemination — my context is the release of the leaked SCt op in Dobbs — there is concern that data about abortion seekers or providers will be exposed to law enforcement or others in states that do not respect reproductive rights — can anyone say whether the drafts being developed have been evaluated against that threat? I realize that the loss of Roe has been feared for a while, but the leak has heightened people’s concerns about data sharing.	CDI has the same concerns, and has communicated them to the leaders of this group but had no response so far. We understand that data sharing can proceed pursuant to current federal rules, but would strongly support the ability for consumers to opt out of the sharing of information that they consider to be confidential.
10	Erik Sternad	Thanks Tien@eff.org, I'd also include risks to domestic violence and human trafficking victims/survivors to these kinds of provider disclosures (risk of exposure of locations of confidential shelters, etc).	
11	Lane# Steven MD MPH	There are already CMS requirements on hospitals to send ADT notifications when patients transition care, sending these to members of the patients identified	Agree! (DeeAnne from CPCA)

Count	Name	Comment	Response
		care team and others who have requested this based on established care relationships. To require ADT notifications to be sent to a broader set of constituents places additional burden on providers and presents additional privacy and data security challenges.	
12	John Helvey	it is difficult to clearly hear speakers	
13	Timi Leslie	It is difficult to hear Jonah	
14	Erik Sternad	Can't hear in-room speakers	
15	Timi Leslie	Can Jonah please repeat the response?	
16	Jennifer Martinez	Much better sound, thank you!	
17	John Helvey	Excellent point DeeAnne	
18	Lane# Steven MD MPH	Despite the well articulated desire on the part of some stakeholders to require the broadcasting of patient information whenever care is provided, this is a very different model than one that relies on established care relationships and patient preference to trigger the exchange of protected health information via query and/or push methodologies.	
19	Sanjay Jain	Audio from the room is not clear. Very difficult to understand.	
20	Lane# Steven MD MPH	Regarding P&Ps, there was a recent release of another round of SOPs supporting the nationwide Trusted Exchange Framework and Common Agreement (TEFCA). We should track this work closely in California so that we can take full advantage of evolving national standards. A TEFCA Update presentation was made this morning at our Federal Health IT Advisory Committee (HITAC)	thank you for that slide deck!

Count	Name	Comment	Response
		which provides a useful resource: https://www.healthit.gov/sites/default/files/facas/2022-05-18_TEFCA_Update_Presentation.pdf	
21	tien@eff.org	What Steven said here: “this is a very different model than one that relies on established care relationships and patient preference to trigger the exchange of protected health information via query and/or push methodologies.”	
22	Lane# Steven MD MPH	USCDI V2 is final and published (https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi) and V3 will come out later this year based on the establishe annual process. V2 is almost certain to be included in the federal Standards Version Advancement Process (https://www.healthit.gov/topic/standards-version-advancement-process-svap) later this year and a number of health IT vendors are already building the functionality to support the capture and exchange of all of the V2 data elements including SDOH.	
23	John Helvey	Excellent Point about the assignement in the DSA...	
24	John Helvey	To Andrews point - we do not need conflictual language with TEFCA	
25	Zach Gillen	I think all organizations are looking toward USCDI v2 and eventually v3 (once finalized). However, the point is that under existing regulation and even SVAP, this is all currently voluntary. Ideally, language could better align to the common agreement to have flexibility allowing organizations to adopt when vendors can support.	I think all organizations are looking toward USCDI v2 and eventually v3 (once finalized). However, the point is that under existing regulation and even SVAP, this is all currently voluntary. Ideally, language could better align to the common agreement to have flexibility

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			allowing organizations to adopt when vendors can support.
26	Lane# Steven MD MPH	While the initial iteration of TEFCA, being operationalized this year, will be voluntary, a number of federal agencies are considering incentivizing the use of the new TEFCA framework, e.g., for quality (CMS) and public health (CDC) reporting. Hence it is likely that most if not all CA providers will be onboarding to the national framework over time.	
27	John Helvey	Thank you Carmela - Agree on goverance role and clarification...thank you for your comments	
28	Timi Leslie	Enforcement can be accomplished through contracting…Covered CA, CalPERS, DHCS…	
29	Sonal Ambegaokar	On an earlier comment re: consumers. The lack of full representation of the consumer in current data exchange policies is one of the gaps we thought CHHS was trying to address in the DSA. Consumer representation should be more fully addressed, not just in policy and procedures, if CA is really going to improve the ultimate outcomes the DSA is trying to acheive - a more holistic view of those the Participants are trying to serve. Otherwise we are perpetuating existing flaws and power imbalances in today's data exchange structure. Suggest the advisory board creates a specific sub-committee to address the consumer concerns in the current draft.	
30	Lane# Steven MD MPH	Recall that the Common Agreement, under TEFCA, is an agreement to be signed by Qualified Heatlh Information networks (QHINs), not by the end users of the data exchange framework.	

Count	Name	Comment	Response
		https://www.healthit.gov/sites/default/files/page/2022-01/Common_Agreement_for_Nationwide_Health_Information_Interoperability_Version_1.pdf	
31	John Helvey	Excellent Comment @David Ford	
32	Lane# Steven MD MPH	This structure creates a tremendous opportunity for the Governance Entity to change the direction and requirements of the statewide framework, making it all the more important that the Governance Entity be broadly representative and required to adhere to principles of consensus decision making. Otherwise we run the risk of vested interests pushing framework requirements in directions not contemplateed by lawmakers/legislation.	
33	John Helvey	Excellent comment Claudia - Thank you	
34	John Helvey	Can't hear the person speaking very well at all...	
35	Lane# Steven MD MPH	It will be important to clarify which Public Health Activities will be covered.	
36	Heather Readhead - PHMO	It's important to clarify what funding would allow public health to participate in this health information exchange. This has been a challenge for public health since the advent of the Meningful Use programs in the US. Many of the current public health data systems are outdated in terms of the capacity to perform modern health information exchange. Capacity challenges include both tech and staff/skills infrastructure. As highlighted by Dr. Kaiser/CCLHO, many programs still rely on the faxing of charts to help with clinical co-management, case management, quality improvement/registry management (ex. tuberculosis registry) and even	

Count	Name	Comment	Response
		outbreak management. These are are public health "use cases" that represent very clinical functions that mirror the same kind of work that primary care panel management, health care delivery systems, ACOs or health plans do. Public health does this work across health systems, regardless of health insurance status, for diseases/hazards of public health importance.	
37	Lane# Steven MD MPH	These provisions appear to be very close to those required under existing federal law. It will be important to assure that there are no conflicts and that any differences are clearly communicated so that participants are not forced to spend additional resources comparing state and federal regs to guide their compliance. Insofar as possible, our state requirements should be limited to those areas where we feel we need to contrast with or extend federal regulations.	
38	Lane# Steven MD MPH	Thanks you Dr. Readhead! I was looking for your recent email listing the many Public Health use cases to share with this group.	
39	Lane# Steven MD MPH	There has been a rich discussion within the Carequality data exchange framework regarding the challenges related to participants who want to access data without a reciprocal requirement to provide data to others. There would seem to be limited situations in which this exception shuld be applicable.	
40	Heather Readhead - PHMO	Public Health Use Cases for Health Information Exchange:	

Count	Name	Comment	Response
		1) epidemilogy/analysis (understanding disease/hazards) 2) surveillance (situational awareness/emergency response) 3) population/registryoutbreak management, 4) individual case management, 5) individual clinical care/consultation	
41	Heather Readhead - PHMO	Edit to the above -	
42	Heather Readhead - PHMO	Public Health Use Cases for Health Information Exchange: 1) epidemilogy/analysis (understanding disease/hazards) 2) surveillance (situational awareness/emergency response) 3) population/registry/outbreak management 4) individual case management 5) individual clinical care/consultation 6) birth/death registrar	
43	Jennifer Martinez	Alameda County HCSA will also follow up with information on how it was supported Non-HIPAA-covered entities to access its Social Health Information Exchange.	
44	Bill Beighe	Here is my public comment - just to put on the record.	
45	Bill Beighe	SCHIO Public Comment – May 18 I represent Santa Cruz Health Information Exchange Organization. We are members of the CA Association of HIE’s and member of the EQUITY Coalition.	

Count	Name	Comment	Response
		In order to achieve AB 133, health care organizations and HIO's need additional funding to meet the needs of AB 133 and realize the health benefits of CalAIM. While the Governor's May Revise includes a $50 million allocation to provide technical assistance to small or under-resourced providers, the proposal falls far short of addressing the urgent gaps in health data sharing across the state. Assembly Member Wood brought forward a request for 95 million dollar budget request based on a 90/10 federal state match but that request seems to be missing or dropped and needs to be restored to provide that funding to help implement CalAIM, closing equity gaps, improve health care quality, address gaps in the data, and establishing the new Data Exchange Framework.	
46	Lucy Johns	To record my comment: there will be great interest in how SB 133 plays out. The Gov Entity must specify data to be reported by Participants at least semi-annually and must require that Participants report. Such data should include metrics concerning volume, scope and use of data exchanged by whom for what. I would put this in the DSA, to underline that reporting signifies accountability. Thank you.	
47	Timi Leslie	where are these materials available?	
48	Lucy Johns	As member of the public listening today, I support cautions about reporting of sensitive data, e.g. abortion, interpersonal violence. Also: please consider reporting requirement concening abortion provided to non-CA-residents. Capacity for this is	

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		being funded and anticipated. This data must be protected with every possible precaution.	
49	Lucy Johns	Pl repeat how we can be notified when draft re Digital Id will be released for comment.	It is to be released today Lucy
50	Lucy Johns	And pl put that info into Q&A, sound quality from the room is poor. Thanks.	
51	Lane# Steven MD MPH	It is clear and understandable that our regional HIOs around the state are interested in additional public support. It would be most advantageous if state funding can support connectivity via any/all established and available methods, including with HIOs as well as the established national networks and frameworks that all certified EHRs can utilize today to exchange current data and coordinate and streamline care. Funding to HIOs should ideally be tied to those HIOs providing frictionless access to these established interoperabilty tools, in addition to the siloed data held by the HIOs themselves.	
52	Lucy Johns	Thanks Lori! On the website, I assume.	
53	Heather Readhead - PHMO	Example of PH "research" that would require data that PH may not already have or individuals that PH may not already have a relationship with - why are we seeing young men in their 30s and 40s dying of idiopathic lung disease? Were there occupational exposures or other environmental exposures? Did they work in a stone cutting factory?	
54	Heather Readhead - PHMO	Although we would not want to compete with providers for funcing, please consider if public health can apply for the funding assistance to clinical practices, given that public health performs cinical care, clinical case management, consultation, and	

Count	Name	Comment	Response
		clinical outbreak management (including rx of prophylaxis and treatment of vulnerable populations).	
55	Lane# Steven MD MPH	Regarding the risks related to the increasingly "sensitive" nature of data regarding reproductive care, we should recall that this may extend not only to gender affirming and abortion services but also to contraception, STI prevention/treatment, etc., highlighting the risk associated with creating/incentivizing the use of data silos that may be accessible to those not involved in a patient's care or otherwise authorized by the individual.	live answered
56	Lane# Steven MD MPH	Regarding the risks related to the increasingly "sensitive" nature of data regarding reproductive care, we should recall that this may extend not only to gender affirming and abortion services but also to contraception, STI prevention/treatment, etc., highlighting the risk associated with creating/incentivizing the use of data silos that may be accessible to those not involved in a patient's care or otherwise authorized by the individual.	100% agree Steven, excellent points that require careful consideration.
57	Lucy Johns	'+1 Steven!!	

Total Count of Zoom Q&A comments: 57