



California Health & Human Services Agency Center for Data Insights and Innovation Data Exchange Framework Stakeholder Advisory Group Meeting 3 Q&A Log (10:00AM – 12:30PM PT, November 10, 2021)

The following table shows comments that were entered into the Zoom Q&A by public attendees during the November 10th virtual meeting:

Count	Name	Comment	Response
1	Lane, Steven MD MPH	The chat function appears to be disabled for public participants. Should we assume that public written comments will be submitted here in the Q&A?	That is correct. Public comment and suggestions are very much welcome via the "Q&A" feature. Thanks, Dr. Lane.
2	Michael Marchant (UC Davis Health)	How would this scenario be handled if the patient had no 'assigned PCP'	We should find a pcp local to the patient who is accepting patients and has appointments access and availability
3	Michael Marchant (UC Davis Health)	Part of this question is whether a person with Mental Health issues would know or have an assigned PCP - the framework would need to accommodate that aspect of this scenario	
4	Lane, Steven MD MPH	This first step of data access for the patient in the scenario could be accomplished today using queries via the existing Carequality framework. Care coordination messaging can be accomplished today via existing Direct secure messaging functionality available to all applicable stakeholders at nominal cost and with the only technical requirement being Internet access.	One problem with that is the behavioral health information is not being shared outside the practice. Many clinics will keep dual records and only send to





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			Careequality and other HIEs
			the standard medical record
			to protect behav health and
			Substance use data
5	Le Ondra Clark Harvey	Good question, Michael. It appears the PCP is a critical link.	
6	tien@eff.org	where else is the data going, though?	
7	Michael Marchant (UC Davis Health)	My assertion is that we can not design a system assuming all have an assigned and identified PCP	
8	Lane, Steven MD MPH	Our work is to enable, support and eventually require that stakeholders in exchange utilize and optimize the interoperability tools already available and continuing to evolve as Californians and others across the country push forward with information exchange.	
9	Le Ondra Clark Harvey	Agree with Michael	
10	Lane, Steven MD MPH	While we should not assume that all individuals have a functional relationship with a PCP, we should design systems that take advantage of such relationships where they do exist, whether with an individual provider or a provider system such as an FQHC.	
11	Richard Perez	I agree, standardizing an assessment that can be shared across all providers is the way to go	
12	tien@eff.org	how will the state measure equity/bias?	
13	Lane, Steven MD MPH	Shared treatment plans should be a goal of our system. Much work has been done on this, including by Mark Savage. Existing vendors, such as Collective Medical Technology support this functionality specifically. Also Assessment and Plan of Treatment is specifically identified in the U.S. Core Data for Interoperability (USCDI) with associated requirement	





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		for all providers and HIEs to be able to exchange this	
		data electronically. https://www.healthit.gov/isa/uscdi-	
		data-class/assessment-and-plan-treatment#uscdi-v1	
14	Le Ondra Clark	Thanks Steven. I agree that systems should be	
	Harvey	designed that are accessible by multiple provider	
		types.	
15	Lane, Steven MD	Health equity has been identified as a national priority	
	MPH	for health information technology and exchange. This	
		has been incorporated into multiple regional data	
		sharing initiatives as documented here:	
		https://www.healthit.gov/buzz-blog/health-it/onc-	
		annual-meeting-2021-perspectives-on-the-impact-of-	
	_	sdoh-on-health-equity-and-care	
16	Lane, Steven MD	Today the federal Information Sharing rules REQUIRE	
	MPH	all providers, health information exchanges/networks	
		and vendors of certified health information technology	
		to share the patient data that they maintain, including	
		with the individual and their proxies. In California we	
		have the opportunity to consider extending these	
		requirements to other stakeholders such as social	
4.7	All All and Al	service providers, public health, etc.	
17	Allen Noriega	How are the equity or other principles going to apply	
		towards standardizing what SDOH variables will be	
4.0	Lana Ctavan MD	implemented or counted in the finished product?	
18	Lane, Steven MD	Suggest that the Principles reference data "access,	
	MPH	exchange and use". It is not a technical or functional	
		requirement that the data be copied and stored in	
		duplicate by every actor needing to use that data.	
		Modern technology standards support real time	
		access to the most current relevant data without the	





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		need to copy, compile, normalize, deduplicate, store and protect historical data.	
19	Kevin	When do we know equity has been achieve? What are the goals/acceptable metric?	
20	Michael Marchant (UC Davis Health)	I'd like to make sure to include State Agencies and departments accountable to these exchange requirements as well	
21	Lane, Steven MD MPH	Metrics That Matter for Population Health Action: Workshop Summary - https://www.ncbi.nlm.nih.gov/books/NBK424503/	
22	Lane, Steven MD MPH	6 Tips for Measuring Health Equity at Your Organization - http://www.ihi.org/communities/blogs/6-tips-for-measuring-health-equity-at-your-organization	
23	Allen Noriega	On the subject of operational principles, one of the subjects that stood out was a discussion on minimizing or clearing up duplicate records, systems, and efforts that are already capturing data that DxF is mapping out today. Will there be a discussion later avoiding duplicate work/data that's currently being done?	
24	Lane, Steven MD MPH	Developing Health Equity Measures - https://aspe.hhs.gov/reports/developing-health-equity-measures	
25	tien@eff.org	I'd like to echo Mark's Q in the chat about the omitted consumer/patient principles, e.g. preventing misuse of health data, and accountability so that patients can trust that their data is well cared for.	
26	Jim Sullivan	To Ali's point - what is the consumerism functionality, access, and adoption expectations? Also, where doe a state-wide approach for eMPI/MDM and (informed)	To Ali's point - what is the consumerism functionality, access, and adoption expectations? Also, where





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		consent registry stand, both from a shared commercial and public-sector perspective stand?	doe a state-wide approach for eMPI/MDM and (informed) consent registry stand, both from a shared commercial and public- sector perspective stand?
	A.I. A.I.		good point Jim!
27	Allen Noriega	Building on the possibility of expanding Patient Access as an additional principle. There may be an opportunity to explore Andrew Bindman's earlier point in rethinking these efforts to be used by patient's first than provider's using the platform for the patient. Is that a practical initiative that can be discussed later?	
28	Lane, Steven MD MPH	A lot of work is being done nationally and regionally to lop technology standards that would allow individuals to control access to and use of their data at a granular level. https://healthcaresecprivacy.blogspot.com/2019/02/what-is-ds4p.html https://www.drummondgroup.com/pp2pi/	
29	Lane, Steven MD MPH	It will be critical to have processes that allow patient preferences regarding access to and use of their data to follow that data as it is exchanged between stakeholders, and certainly if it is compiled in a centralized data store where that data may be repurposed/reused.	





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30	Lane, Steven MD MPH	'@ Allen Noriega - There is an entire model of Patient- Centric Health Information Exchange which looks to	
		the patient to collect and curate their data as opposed	
		to placing this burden/expectation on providers,	
		payers, HIEs or others -	
		https://pubmed.ncbi.nlm.nih.gov/32396110/	
31	L. Johns	Not sure I see who is responsible for ensuring that	
		patient data are accurate. We've all experienced that	
		data in our own individual records is incorrect and	
		there doesn't seem to be a way to ensure that	
		corrections can be made. Where would that fit here?	
32	Allen Noriega	I'm calling in	
33	Allen Noriega	How do i unmute	
34	Lane, Steven MD	Bravo Jonah for recontextualizing the scenarios in the	
	MPH	landscape of ongoing data exchange.	
35	Kristine Toppe,	In my public comment, I referenced NCQA's work to	
	NCQA (she, her,	stratify measures and may have said "risk	
	hers)	stratification" but I meant stratification of HEDIS	
		measures by race and ethnicity for the purpose of	
		addressing disparities in care. Here is a reference to	
		this work. https://www.ncqa.org/about-ncqa/health-	
	BALL IBA I	equity/data-and-measurement/	
36	Michael Marchant	Jonah - would you want to include the human capital /	
	(UC Davis Health)	technical competence as a barrier for non-connected	
0.7	l labas	entities	
37	L. Johns	Maybe consider another set of barriers: some social	
		service organizations are esp. sensitive about data	
		collection and/or sharing. So a barrier for SDoH	
		sharing can be mission, history, values, high level	
		reasons some organizations will resist data sharing.	





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38	Kevin	The existing HIE networks are not well funded that	
		inhibits their ability to respond to the needs of	
		organizations accessing their networks with specific	
20	La Oradina Olanik	requests	
39	Le Ondra Clark	Excellent points, Michelle, about the need to connect	
	Harvey	across sectors for various populations- especially	
40	4:	those experiencing housing insecurity.	
40	tien@eff.org	I think we should recognize that patients and	
		organizations can have very legitimate reasons for not	
		sharing, and it's troubling to see privacy or adherence	
		to data minimization principles labeled as barriers.	
		Operationally they may be barriers, but they are	
1.4	Lana Chavan MD	barriers to be respected.	
41	Lane, Steven MD MPH	ONC data shows the progressive uptake of certified	
	IVIPH	EHRs and other health information technology across	
		the country. It is interesting to note that California	
		hospitals' uptake and use of available technology	
		seems to lag somewhat behind those in other parts of	
		the country, suggesting that we have opportunities to	
		do more with the tools that are already available. https://www.healthit.gov/data/data-briefs/use-certified-	
		health-it-and-methods-enable-interoperability-us-non-	
		federal-acute	
		https://www.healthit.gov/data/data-briefs/state-interoperability-among-major-us-cities	
42	L. Johns	'+1 to tien@eff.org. Another way to point to what I said	
42	L. JOHNS	about sharing in the social services sector.	
43	Lane, Steven MD	Someone mentioned that EHRs are not able to	While they are supposed to
43	MPH	receive data submitted by others. All certified EHRs	While they are supposed to, and likely can, the practices
	IVIFIT	•	have no idea how to support
		have the ability to send and receive Direct messages,	
		which allows the submission of data from any sender	it. From my work with





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		with a Direct messaging account (available at a nominal cost with nor infrastructure requirement) - https://www.adldata.org/wp-content/uploads/2015/06/15-things-to-know-about-direct-messaging.pdf	CTAP, we had to convert the CCD to a PDF and secure fax it thousands of times because the specialty practice had no idea what a CCD was let alone how to connect one EHR to another.
44	Michael Marchant (UC Davis Health)	Thanks Claudia for restating my earlier comment	
45	Lane, Steven MD MPH	Sincerely hope that the text of the Chat and the Q&A will be captured and included in the minutes / public record of these meetings so that they are available to committee members and the public. (This is standard practice for federal Health IT committees).	live answered
46	Lane, Steven MD MPH	'@ Lori Hack - Absolutely! We need to provide support to clinicians to fully implement and utilize the tools they already have at their disposal.	Yes, they told us before the meeting that all of it is documented. You and the rest of the folks have incredibly valuable information on this!
47	Jeff Blackmon - Tulare County	Just a thought, how about a centralized State or Private vendor where health organizations without the capacity to share data or enter the data. Can send their paperwork/information for it to be processed for them on their behalf into the exchange. This would allow them to focus on providing care. This could be used while the health organizations bring their technology up to date or allows them to continue to participate without having to take on cost of updating their technology.	





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48	L. Johns	NB re Gravity Project and standardizing terminology for reporting demographic data! USCDI, ICD-10 are already adopting, enabling standard recording where it didn't exist before.	
49	Lane, Steven MD MPH	https://www.hl7.org/gravity/	
50	Nesreen Gusbi	I'm not sure if this was mentioned but it might be interesting to look at counties like Sweden that have a system in place similar to this. It could be used to look for best practices.	
51	Lane, Steven MD MPH	Great recent HIMSS webinar: Standards Paving the Way to Address Social Determinants of Health - https://www.himss.org/resources/standards-paving-way-address-social-determinants-health	
52	tien@eff.org	What Claudia is saying. EFF is trying to protect privacy, but we do not know what the actual public health reality of data governance is. No clear baseline.	
53	tien@eff.org	exacerbated by the gap between state and non-state in CA given the limits of the state Information Practices Act	
54	Lane, Steven MD MPH	'@ David Ford - LOTS of work being done at the federal and state level to support public health data modernization. We should design our statewide framework based on a full understanding of the future state of PH interoperability - https://www.cste.org/page/DM-2021	
55	Lane, Steven MD MPH	https://www.cdc.gov/surveillance/surveillance-data- strategies/data-IT-transformation.html	
56	Karen Ostrowski	Could not agree more! For the communities we work with, this continues to be the biggest barrier/issue and more or better guidance and resolution is desperately	





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		needed. Also worth noting that County agencies are also struggling to align varying state requirements	
		associated with different kinds of data and/or data that comes from different sources, e.g., DHCS Medi-Cal	
		PHI, DSS PII, and ensuring that downstream vendors comply with those requirements as well.	
57	Michael Marchant (UC Davis Health)	'@Karen - agree - we need the state agencies / entities to line up around this exchange strategy and not create their individual entity requirements	
58	Timi Leslie	I know this was discussed, but would strongly recommend the wholesale adoption of the Consumer and Patient Principles for Electronic Health Information Exchange in California (Oct 27,2010) These principles are centered around the patient and consumer. Thank you to those who did this work over a decade ago.	
59	Timi Leslie	Agree Lori, digital identity is will require alternative analysis. I would look to other state success, including Michigan and Arizona to start	
60	Bill Barcellona	Will the unique patient identifier issue be covered in the December 14th meeting on technical and digital identity?	
61	Cary Sanders	It looks like the subcommittee is only looking at the US Core Data for Interoperability v.1, which only includes race, ethnicity, and preferred language (and sex assigned at birth) in patient demographics. We recommend the state use v.2, which also includes sexual orientation and gender identity in patient demographics, plus SDOH Problems/Health Concerns:	





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		https://www.healthit.gov/isa/united-states-core-data-	
		interoperability-uscdi#uscdi-v2	
62	Karen Ostrowski	Recommend also looking at data sharing agreements	
		developed by WPC pilot programs, since those were	
		designed to support cross-sector data sharing and	
		may have good insights for this effort.	
63	Timi Leslie	MiHIN's approach here: https://mihin.org/active-care-	
		<u>relationship-service/</u>	
64	Lane, Steven MD	'@ Cary - Agree that we should leverage the latest	
	MPH	version of USCDI as this becomes possible. The	
		publication of a new USCDI version does not	
		immediately make that data available, as health IT	
		standards and vendors need to develop and	
		implement the tools to share the new data classes	
		and elements and this can take a couple of years.	
65	Allen Noriega	Thank you for the Advisory Group's time!	

Total Count of Zoom Q&A comments: 65