



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

The following comments were made in the Zoom chat log by Stakeholder Advisory Group Members and the public during the November 10th virtual meeting:

09:57:42 From Cathy Senderling-McDonald to Hosts and panelists:

hi all

09:59:27 From Linnea Koopmans to Hosts and panelists:

That process sounds good

09:59:39 From Kevin McAvey to Everyone:

Good morning Cathy

09:59:45 From Kevin McAvey to Everyone:

Please chat to "Everyone"

10:01:52 From Emma P., Manatt Events to Everyone:

The program will begin shortly.

10:08:17 From Kevin McAvey to Everyone:

Dr. Hernandez is not able to make it today. Special thanks to Hong Truong who is listening in on her behalf.

10:11:44 From Kevin McAvey to Everyone:

Julie Lo sends her regrets, but thanks to her staff listening in

10:12:39 From Kevin McAvey to Everyone:

Diana Toche also sends her regrets, special thanks to Cheryl Larson for listening in

10:13:55 From Leslie Witten-Rood to Hosts and panelists:

Leslie at EMSA is present had a issue with audio good morning.

10:14:32 From Dana Moore to Hosts and panelists:

Dana Moore at DPH is now present.

10:14:46 From Kevin McAvey to Hosts and panelists:

Good morning Dana and Leslie

10:14:59 From Kevin McAvey to Hosts and panelists:

Reminder: please select "Everyone" to ensure chat is public

10:25:32 From Claudia Williams to Everyone:

Do you want us to suggest missing principles now, or after discussing the set you have proposed

10:25:43 From Michelle Gibbons to Everyone:

Stepping away for a moment. Sorry

10:27:04 From Linnea Koopmans to Everyone:

Question - can you share more about the Consumer & Patient Protection Principles? Are these principles that the State formally adopted? Or are they referenced throughout because they resonate with the State and align with the priorities of the DxF?

10:30:40 From Mark Savage to Everyone:

Agree with Kiran about the need for a next level of granularity and metric.

10:31:41 From Andrew Kiefer to Everyone:
and accountability/enforcement.

10:34:37 From Claudia Williams to Everyone:

Agree with Kiran and Mark about the need for more concrete and specific principles. As they are stated they are more like "goals" and wont give us enough direction on making hard choices

10:35:50 From Claudia Williams to Everyone:

Agree with Carmela that the principles need to be more "data exchange" specific as well

10:40:51 From Kevin McAvey to Everyone:

Terrific comments. Please keep them coming - what's missing? what do we need to think about across these principles (e.g., adding details)? Do you have any specific suggested edits to any?

10:41:53 From Michelle Gibbons to Everyone:

agree on the needs for guidance.

10:44:29 From Lori Hack to Everyone:

I agree with Claudia that we need to imbed the operational/tactical principles and goals within each principle.

10:45:51 From Mark Savage to Everyone:

What's missing? I noticed the consumer/patient principles that were not included: (4) on universal design and interoperability, (6) on preventing misuse of health data, (7) on patient partnership and HIT literacy (although this could have been included in part with principle 3 on whole person care), (8) on accountability, and (9) on enforcement. Not sure why. There was a lot of thinking about why those principles or tools are also critical in conjunction with those listed.

10:46:12 From Claudia Williams to Everyone:

Here are the operational principles I recommend adding to ensure the framework actually WORKS and DELIVERS on our goals

- Decrease burden, complexity and cost of exchange
- Leverage the methods and networks that are already being used - don't rip and replace, don't duplicate
- Ensure every plan and provider can create longitudinal records needed for population health and whole person care
- Focus on most important use cases first - don't boil the ocean

10:46:12 From Andrew Kiefer to Everyone:

Another wys to put is that we should prioritize the 'types' of data collection. Ultimately, there should be some hierarchy to the types of data we collect. And these data points support the advancement of equity, quality, etc.

10:46:46 From Andrew Kiefer to Everyone:

agree with Claudia

10:48:04 From Mark Savage to Everyone:

To Andrew's comment about data types, I find that the same data element is used for multiple priority use cases, so suggest thinking in terms of use cases as well as data types.

10:50:36 From Mark Savage to Everyone:

Agree that the articulation in this draft is more about the institutional actors than the individuals, family caregivers, etc. All are important for shared decision-making and shared care planning--which are core!

10:50:53 From Carmela Coyle to Emma P., Manatt Events(Direct Message):

Agree with point on principles for individuals or providers/plans on behalf of individuals?
Would take us in very different directions

10:54:40 From Michelle Doty Cabrera to Everyone:

Agree with Erica's point on #4

10:55:19 From Amanda McAllister-Wallner (she/her) to Everyone:

Agree, patient access should be separate principle from privacy & security.

10:55:21 From Kayte Fisher to Hosts and panelists:

I would like to emphasize transparency about data collection and transfer to consumers/patients, and clearly establish a process for informed consent by consumers. Similarly, privacy and confidentiality are critical to consumers, and detailed informed consent should be very clear. We have been talking generally about data sharing, and I think the general idea is that all data be shared with all partners. However, the reality is that some consumers will

10:56:15 From Lori Hack to Everyone:

Agree with Kayte Fisher, informed consent and data use and audit is critical to trust for data sharing

10:56:28 From Kayte Fisher to Hosts and panelists:

*some consumers will want some data not to be shared with some entities, and this demand should be respected.

10:59:53 From Lori Hack to Everyone:

Forgot to mention that the health plan/insurers/intermediaries are not listed in these principles and they are part of the network

11:00:44 From Andrew Kiefer to Everyone:

I think the goal of 'usability' of the data is eluded to in 2, but it's not abundantly clear and should be elevated.

11:05:23 From Claudia Williams to Everyone:

Love Michelle's vision of the data exchange framework contributing to community, not just individual, health

11:08:30 From Mark Savage to Everyone:

The consumer/patient principles can help because they do exactly that: benefits for individual health, benefits for community/population health.

11:10:17 From Mark Savage to Everyone:

Re principle 5 on standards, also USCDI v2 on SDOH data, SOGI, all care team members including community/social services, etc.

11:12:39 From Claudia Williams to Everyone:

Agree that TEFCA is one thing to align with, but I don't think we should assume that TEFCA will be broadly adopted. There is far too much uncertainty today since it is a voluntary framework with no real federal policy hooks (incentives/requirements). So we need an approach

that is resilient to whether or not TEFCA takes hold. Also TEFCA primarily applies to network to network exchange. Whereas AB 133 applies to each individual healthcare organization

11:14:51 From Andrew Kiefer to Everyone:

in the context of accountability/enforcement, the broader point is ubiquitous participation of data sharing across the care continuum. The value of the data from both an individual and public health perspective is directly connected to compliance with the statute and the agreement that is adopted.

11:30:26 From Kevin McAvey to Everyone:

Bonus points for holding to a minute, so we can get to as many Members as possible

11:30:42 From Claudia Williams to Everyone:

challenge noted!

11:31:49 From Claudia Williams to Everyone:

Great point about health departments not having needed data infrastructure

11:33:36 From Matt Lege to Hosts and panelists:

Agree with Michelle's comments. We need to support public health departments their staff, infrastructure and training to ensure that they have the resources needed to fully participate. If the goal is for exchange of information across sectors to meet the individual and communities needs, this investment is vital.

11:34:50 From Kiran Savage-Sangwan to Everyone:

Agree w/ Mark - would like to see the "consumer data access" barrier strengthened to ensure language access and consumer friendly interface + acknowledge that "access" does not only mean ability to view the record but to correct it or otherwise interact

11:38:17 From David Ford to Everyone:

@Kevin - That was 48 seconds. I want my bonus point.

11:39:19 From Andrew Kiefer to Everyone:

Number 6 is perhaps the most important. if the data isn't standardized and consistent, it's difficult to make it usable in solving for our challenges. garbage in, equals garbage out.

11:41:34 From Kayte Fisher to Hosts and panelists:

I would argue that number 5 is the origin of all other items - without the consumer's original and informed consent, no data can or should be transferred anywhere.

11:44:51 From Claudia Williams to Everyone:

Excited to hear from @Linette that there may be opportunities to address the challenges through state initiatives

11:46:14 From Cathy Senderling-McDonald to Everyone:

I think it would be helpful to perhaps define "human services" or "social services" somewhere and distinguish between government entities like county HS departments vs community organizations that provide such services. Some of the barriers listed here for HS and SS organizations do not apply to government.

11:46:33 From Claudia Williams to Everyone:

What does cost sharing look like - yes! Happy to hear from my federal and HIE peers that CMS MES funding can use "provider" cost allocation. That's pretty in the weeds but important.

11:46:43 From Andrew Kiefer to Everyone:

great points Linette!

11:47:08 From Cathy Senderling-McDonald to Everyone:

I'd also suggest we utilize one of those two names for it. Either human services or social services, unless there are different definitions (usually I see them used interchangeably though, we prefer human services).

11:49:26 From David Ford to Everyone:

Rather than raise my hand again, I'll just note here that Education & Technical Assistance is probably the most important component of this whole effort, from CMA's perspective.

11:49:41 From Michelle Gibbons to Everyone:

Under item 1. I would recommend implementation and ongoing T/A and training, keeping in mind staff change over time.

11:51:56 From Lori Hack to Everyone:

Michelle, exactly right! My note as well. Training the staff as well as going back to the vendors when the product doesn't work is essential!

11:53:22 From Lori Hack to Everyone:

The cost of building an interface so that the data in a clinic can be shared needs to be addressed. There is no business need to pay for connectivity when you can fax for almost free.

11:54:55 From Mark Savage to Everyone:

Creating a culture of use!

11:55:02 From Claudia Williams to Everyone:

As others say training and technical assistance is super important, but our opportunities to get federal funding for onboarding are limited now that HITECH has expired. Arizona has an interesting incentive model, paid to providers and hospitals through the MCOs, and not paid for by HITECH. That might be a model to adopt or examine

11:55:19 From Amanda McAllister-Wallner (she/her) to Everyone:

Agree with Kiran's point, and I think this goes back to the accountability question as well.

11:55:43 From Kevin McAvey to Everyone:

Great comments all. Any final verbal comments on this set of major barriers?

11:56:02 From Kevin McAvey to Everyone:

Please keep the specific suggestions coming in the chat.

11:58:42 From Michelle Doty Cabrera to Everyone:

I have to jump to another call, but want to leave you all with the reminder to please include a goal of capturing disability related data. Physical disabilities and IDD are essential to ensure proper care delivery. Thank you!

11:59:56 From Kevin McAvey to Everyone:

Thank you, Michelle

12:01:13 From Charles Bacchi to Everyone:

I agree with Linnea- consistency would be great.

12:01:55 From Linnea Koopmans to Everyone:

And we're looking forward to seeing that guidance! Thanks, Jonah.

12:02:26 From Liz Gibboney to Everyone:

I also agree with Linnea and appreciate the work being done outside of the SAG on this.

12:04:35 From Cathy Senderling-McDonald to Everyone:

At times, county counsel has a different interpretation of some laws.

12:04:39 From David Ford to Everyone:

I feel like public health data is more a technological problem than a policy issue. We've seen over the last 20 months that there are some severe limitations to our public health data system in this state. It's one place where there is federal \$ we should be pursuing.

12:04:49 From Liz Gibboney to Everyone:

Can the SAG get a briefing on what the current rules in CA/feds are?

12:06:47 From Claudia Williams to Everyone:

Agree with Linnea, Liz and others that we need to standardize the interpretation (and application) of state and federal data protection laws especially around behavioral health. We need to reduce friction and confusion that is now rampant

12:07:04 From Claudia Williams to Everyone:

that does resonate @jonah

12:07:41 From Jamie Almanza, BACS to Everyone:

yes makes sense

12:07:42 From Ali Modaressi to Hosts and panelists:

I agree with Linnea; consistency is essential. Clarification on the state policies would be great.

12:07:55 From Linnea Koopmans to Everyone:

Agree with what you've outlined, Jonah

12:07:58 From Lori Hack to Everyone:

yes Jonah, thanks!

12:08:15 From Cathy Senderling-McDonald to Everyone:

Agreed. It's not a simple task across so many domains, we should recognize.

12:08:51 From Ali Modaressi to Hosts and panelists:

Agree with your governance comments Jonah.

12:10:29 From Claudia Williams to Everyone:

It would be good to evaluate what impact the last BH SHIG had. In my experience it did not really help. Why is that? I am guessing it was not directive and clear enough. But there may be other reasons <https://www.chhs.ca.gov/wp-content/uploads/2018/10/State-Health-Information-Guidance-January-2018.pdf>

12:13:15 From Lori Hack to Everyone:

I think you should get the sub committee on digital identity established right away.

12:13:47 From Claudia Williams to Everyone:

Dare I say... do we need to meet more frequently than monthly?

12:15:07 From Claudia Williams to Everyone:

Are we going to need to review and provide comments on the recommendations of the common agreement group? Where does that fit into schedule?

12:15:19 From Lori Hack to Everyone:

I agree with Erica that governance is critical. I would again suggest that some of the other recommendations be addressed by separate work groups.

12:16:23 From Claudia Williams to Everyone:

Agree with Erica and Lori that we should have governance discussion sooner

12:17:34 From DeeAnne McCallin (CPCA) to Hosts and panelists:

I was thinking the same, Lori. Committees of the AG to meet in between AG meetings. That would validate the existence of a "subcommittee" that already exists (as Jennifer Schwartz is discussing).

12:17:51 From DeeAnne McCallin (CPCA) to Hosts and panelists:

Committees or Workgroups

12:18:02 From Ali Modaressi to Hosts and panelists:

Ditto @Lori @Claudia

12:22:03 From Lori Hack to Everyone:

On the issue of the data framework, we need to be sure to take into account that hundreds of data participation agreements are already signed and in place with HIEs in CA.

12:22:20 From Charles Bacchi to Everyone:

It would be valuable to see a revised set of principles in far advance of the next meeting so we can work on them and provide more comments. That would allow us to perhaps close this out in December. Thanks.

12:22:40 From Claudia Williams to Everyone:

Agree with that point Charles

12:23:05 From Lori Hack to Everyone:

The MMPA documents were used as the baseline and the CA DURSA is in place as well among HIEs. The design of the framework could be high level, code of conduct/notice of HIE Practice or something of that level.

12:23:53 From DeeAnne McCallin (CPCA) to Hosts and panelists:

I liked the verbal input/feedback time earlier (as opposed to sticking to slides).