California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Meeting 7 Chat Log (10:00AM – 12:30PM PT, April 7, 2022)

The following comments were made in the Zoom chat log by Stakeholder Advisory Group Members during the April 7th virtual meeting:

12:54:45 From Amanda McAllister-Wallner (she/her) to Hosts and panelists:
      Can we get the captions turned on?
12:55:05 From Amanda McAllister-Wallner (she/her) to Hosts and panelists:
      Thank you!
12:55:16 From Carmela Lopez to Hosts and panelists:
      Yes. Thanks, Amanda.
13:49:06 From Charles Bacchi to Hosts and panelists:
      Just to clarify my comments without speaking again- there needs to be
governance so my point was different from Davids- that has to include some way to
ensure compliance- I was commenting on the interplay of the board and agency.
13:55:33 From Jonah Frohlich (he/him) to Hosts and panelists:
      Thank you Charles, understood
13:55:49 From Andrew Kiefer to Everyone:
      from my vantage point the question is really about who is ultimately making the
policy decisions. Do we want an independent board with input from vested
stakeholders or a department director with input from the same stakeholders. Agree
with Charles on the need to coordinate across the government AND we should have
enforcement held with the existing regulators with jurisdiction of the covered entities.
13:56:01 From David Ford to Hosts and panelists:
      @Charles - Sorry if I mischaracterized your comments.
13:56:13 From Lori Hack to Everyone:
      Agree that the policy board would need to understand the initial points that there
is a dichotomy between current robust exchange and areas that are not as developed
and selecting those policy board members would be a challenge.
13:57:07 From claudia williams to Everyone:
      Thanks for the clarification. I am confused about why a policy board is preferable
as a regulatory body to the government itself.
14:02:13 From DeeAnne McCallin (CPCA) to Everyone:
      I lowered my hand so as to comment here. Agree with David Ford's verbal
comments about regulations already overseeing health care providers (both federal and
state). A detail I heard stated (by Jonah) was "every entity in CA needs to sign" As I
read AB133, many entities are encouraged to sign but not required. The entities

required to sign are provider organizations, the ones already under regulations.   Agree with Carmela Coyle about verbal comments on Meeting 6 general agreement. The point I had raised my hand for is this - Probably over simplified but seems that governance is appropriate for ensuring that the terms of the DSA and P&Ps are met, as in "general oversight" (as is a bullet item on slide 16.

14:02:22 From Erica Murray to Hosts and panelists:
Agree with Carmela - if there was agreement on the relationship between TEFCA and governance at the last meeting, that was unclear - seems like an analysis needed in order to discern the best governance model.

14:05:16 From Carmela Coyle to Hosts and panelists:
Who is speaking pls?

14:05:43 From CalHHS CDII to Everyone:
Mark Savage

14:07:26 From claudia williams to Everyone:
I agree with Mark's suggestion of not having a policy board. I am more comfortable with the government retaining the regulatory role

14:09:34 From David Ford to Hosts and panelists:
In the interest of time, I'll leave this comment here - If we go with an Advisory Group approach, there will need to be multiple advisory boards. Providers, Plans, HIOs, Consumers (off the top of my head).

14:10:05 From DeeAnne McCallin (CPCA) to Everyone:
and where are the humans (aka patients, residents, etc) in all of this?

14:10:24 From Amanda McAllister-Wallner (she/her) to Everyone:
Agree with Kiran's comments. I think the continued engagement through a policy board will help to provide opportunities for continuous oversight and improvement. And also agree on the need to spell out consumer involvement.

14:10:50 From claudia williams to Everyone:
I will double check it, but I believe all other state examples of HIE governance bodies include providers, plans, HIEs etc.

14:13:57 From claudia williams to Everyone:
Requiring TEFCA at some point may be a good idea. But TEFCA is still only partially defined right now. The initial use cases are only treatment and patient access. Nothing has been defined yet about operations or payment use cases - and they don't have a timeline for rolling those pieces out. So I think we have no choice but to forge ahead separate from TEFCA since AB 133 covers all of TPO

14:16:18 From Lori Hack to Everyone:
Texas Health Authority for HIE is another example

14:16:22 From Mark Savage to Everyone:
Along with considering TEFCA, then, should also consider FHIR API access for individual and population services, going live soon.

14:18:40 From David Ford to Hosts and panelists:

Michigan and New York, two common examples, both have a State Health Information Network. NOT a state HIE, but an entity that helps move data between networks and - importantly - between the state government and he HIOs. We don't have that in California. I've long believed that is something we should consider.

14:22:04 From Cathy Senderling-McDonald to Everyone:

It seems to me the role of a public board vis a vis the role of the state departments (and/or other existing regulatory agencies, as well as CalHHS) should be carefully considered in making a decision about governance. For example, would any action of such a board be considered a recommendation to the Agency or to CDII and one of those entities is then carrying forward that recommendation to the relevant departments/provider groups/other entities? Or is the board actually making enforceable policy? If the latter, is that not creating a regulatory agency? It seems to me that there are options for creating public spaces for input without such a body being part of that. I'm not espousing that as a position today - CWDA doesn't at this moment have a position on this - but wanted to share this thought, because it creates a confusing point for me when I think about the role of a new body such as this tacked onto an existing government structure vs being created de novo as was the case with Covered Cal. Thanks.

14:22:12 From Carmela Coyle to Everyone:

I think the debate is this: TEFCA has broad capabilities, just not yet implemented. It is likely unrealistic to think we in CA can outpace and get ahead of TEFCA implementation. To do so will place those regulated by TECCA in conflict with federal law if CA does jump in front

14:22:58 From claudia williams to Everyone:

To David's point, it is hard to imagine how our goals will be achieved without a backbone like NY and MI have. NY discovered through COVID that it's backbone SHIN-NY needs to be much more robust to create a unified, statewide COVID response, and statewide organizations to go to get the data they need

14:23:40 From Andrew Bindman to Everyone:

@Carmela +1

14:24:37 From David Ford to Hosts and panelists:

From AB 133:

3) The California Health and Human Services Data Exchange Framework shall align with state and federal data requirements, including the federal Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191), the Confidentiality of Medical Information Act of 1996 (Part 2.6 (commencing with Section 56) of Division 1 of the Civil Code), and other applicable state and federal privacy laws related to the sharing of data among and between providers, payers, and the government, while also streamlining and reducing reporting burden.

14:24:39 From Janice O'Malley to Everyone:

Appreciate Sandra's comments, particularly focusing on how consumers need to have the opportunity to share their voice. This is their personal information that is being shared and the engagement piece is a critical part of establishing trust.

14:24:45 From David Lindeman to Everyone:

@Carmela +1

14:24:45 From claudia williams to Everyone:

Those are good points Carmela. But no one is "regulated" by TEFCA since participation is completely voluntary at this point

14:25:52 From Mark Savage to Everyone:

Should have said: if not Option 1, then hybrid model.

14:26:13 From David Ford to Hosts and panelists:

Unrelated note: In case you aren't following the news, Judge Brown has been confirmed by the US Senate.

14:26:25 From Lori Hack to Everyone:

I agree with @Ali that the key provisions that need to be implemented would make me incline to support the hybrid model in which the Board would have a limited list of policies that could over time increase as the Framework and digital identity programs are implemented.

14:26:35 From claudia williams to Everyone:

Woo Hoo! thanks for sharing @David

14:26:49 From Lori Hack to Everyone:

@Andrew exactly

14:35:45 From claudia williams to Everyone:

Given potential conflict, I will not participate in the digital identity part of the discussion

14:51:47 From Jonah Frohlich (he/him) to Everyone:

regarding David's Comment here: Michigan and New York, two common examples, both have a State Health Information Network. NOT a state HIE, but an entity that helps move data between networks and - importantly - between the state government and he HIOs. We don't have that in California. I've long believed that is something we should consider.

14:52:27 From Jonah Frohlich (he/him) to Everyone:

Neither NY nor MI started with a statewide HIE or network. Those evolved over time as the state and stakeholders defined the need for specific purposes.

14:56:03 From claudia williams to Everyone:

In NY I believe the SHIN-NY has existed for as long as the state has accessed and distributed federal funds first through HITECH and now through MES, and made participation required through licensing (licensed entities must share data through

SHIN-NY). So I would argue that the data sharing mandate, and distribution of federal funds were linked/depended on having this info sharing backbone

14:57:42 From claudia williams to Everyone:

Similarly I think CA should consider implementing this backbone as part of a broader package of actions including 1) qualifying info sharing organizations 2) implementing data sharing requirements through AB 133/DxF and 3) accessing and distributing federal funding

15:02:42 From Jonah Frohlich (he/him) to Everyone:

The SHIN-NY's "backbone dial-tone" (shared) services came after the original HEAL grants (almost 20 years ago!) that supported the regional Health Information Exchange Organizations (RHIO) and there was considerable debate - and some consternation -about the creation of those services. The benefit of the public governance process there (and in Michigan) is that the governance and public stakeholder process allowed for input that resulted in the state authorizing and funding the creation of some statewide services. That evolution could transpire here, and would benefit from a transparent, public process. What we're talking about here (a statewide MPI) is an example of what could be instantiated. I would argue that it needs to be vetted thoroughly through a public stakeholder process.

15:08:25 From claudia williams to Everyone:

Helpful Jonah. Sorry, I am not talking about the eMPI but about David's prior comments about the data sharing backbone in NY and MI. I believe the NY data sharing mandate (NY's equivalent of AB 133) and the SHIN-NY backbone were implemented at the same time. We should consider the risks/implications if we do not do the same

15:11:34 From Cathy Senderling-McDonald to Everyone:

So as not to monopolize the conversation, auto-matching without human intervention can be difficult and can result in errors. Counties use a file clearance process for registering applications to ensure we do not create duplicate entries OR connect an application with the wrong person, and that includes a human review, and at times human input in order to ensure they have identified the correct person. All-electronic attempts haven't worked as well thus far. So, consideration of how many matching data items are needed, what items those are, and so forth, in order to feel confident with a fully automated system, is a really critical consideration.

15:17:18 From claudia williams to Everyone:

Here is the NY regulation that established the SHIN-NY (backbone) defined QEs (equivalent to our qualified data sharing entities), and established provider data sharing requirements (equivalent to AB 133). I do think these things are highly linked and inter-dependent. https://regs.health.ny.gov/content/part-300-statewide-health-information-network-new-york-shin-ny

15:17:36 From Charles Bacchi to Hosts and panelists:

It is important to remember that the state is also separately going to be collecting claims data and giving access to researchers to do studies on population health and health disparities. In addition- population health data services will be rolling out in Medi-Cal in a year- all designed to use data to identify, stratify, and increase equity of services. So the subcommittee is rightly focused on one slice of the various initiatives.

15:25:41 From David Ford to Everyone:

For those of us who were part of the eHealth Coordinating Committee years ago, this room is a palace compared to the one where we had those meetings. We have windows!

15:26:04 From claudia williams to Everyone:

thank you!

15:26:12 From Cameron Kaiser to Everyone:

Thank you!