



## California Health & Human Services Agency Center for Data Insights and Innovation Data Exchange Framework Stakeholder Advisory Group Meeting 1 Public Comment (9:30AM – 12:00PM PT, August 31, 2021)

1. The following table shows public comments that were made verbally during the August 31st virtual meeting:

Count	Name	Comment
1	Marty Omoto	Marty Omoto. Family member for a person with developmental disabilities and extended family member of a person with developmental disabilities and mental health needs who's living with me and also executive director of CDCAN, California Disability Community Action Network, and just want to thank, you know, this stakeholder advisory group for convening, the Secretary for initiating this. I really think it has a tremendous potential depending on the implementation, depending on the framework that you all develop to transform the care and the outcomes of millions of Californians, including those with disabilities, including those with developmental disabilities. So I'm trying to get word out how important your work, that the work that you are doing is so critical to all of us, and I just want to do a shout out to everyone on the stakeholder group. I know I know some of you as friends and I'm looking at Anthony, who I've known for a long, long time and others. And I just want to say we have — Secretary, I want to applaud you for bringing the right people and bringing together the right departments to make this happen and, and all of us as advocates will do all we can to get word out and to help and support the work that you're doing Thank you so much.
2	Hector Ramirez	Good morning, my name is Hector Ramirez. I am a resident here in Los Angeles county and I am a person with a disability and a beneficiary of county programs. And I really want to uplift the comments of the previous member stakeholder. I found out about this





Count	Name	Comment
		meeting through him, word of mouth and the disability community is one of the ways in which stakeholders, like myself, really receive vital information about important stakeholder groups like this one. The census results that came out recently showed that California has one of the most diverse and, you know, really, really fantastic populations in the country, highlighting the fact that Latino Hispanic people are now a significant part of the population, as well as people with disabilities. So I really, as you all start this particular work, I really want to remind folks to work on what has been done before, so we can move past that, so that we can really work to establish equitable health services for all of the people of California, particularly our largest representative communities. I thank you once again, and I look forward to joining you in this journey and spreading the words to my peers, you know, just like myself, so thank you very much. Gracias.
3	Troy Kaji	Hi, hopefully I'm unmuted. I'm a family practice physician who works in Contra Costa county detention health services, and I would like to ask the stakeholder group to remember to provide access for those in the correctional facilities, CDCR and others, especially during the pandemic and the high rates of COVID in those facilities. It's critical that the immunization and other information flow back and forth.
4	Jon Goldfinger	Hi there. Good morning, Jon Goldfinger here, CEO of Didi Hirsch Mental Health Services and, first, I just want to say hi to all the wonderful faces as well, I've known and worked with over the years and applaud the Secretary and the conveners of this incredible group for coming together on something so important. I'd just like to add, what I don't see are perhaps sufficient direct service providers, represented by this group, other than maybe Kaiser. I think including the specialty mental health and crisis care side of California healthcare, in this is going to be critical. We





Count	Name	Comment
		tend, you know, thinking about this from an equity perspective, we tend to neglect those with severe mental illness or substance use or with an emotional, suicidal, or overdose crisis when it comes to investments in data and technology, as if they're incapable or unable to access services. And we found during the pandemic that that couldn't be farther from the truth. There's other ways to get them access to information, to get their information, and to share that for overall public health and safety, so I'd ask that you think about those populations in the work and how they're represented. Thank you.
5	Jennifer Inden	Hi, good morning. I'm sorry, I logged in underneath the wrong Zoom. My name is Jennifer Inden and I am the health IT program manager for Redwood Community Health Coalition and northern California's HCCN. And I would also like to first start off with saying thank you for convening this group, this is really important work that a lot of people have been doing on the ground floor for a really long time. And so we're excited to see where this leads, and truly help our patients. I do agree with a previous speaker that direct to service providers are also lacking in this group, as are other HIE representatives. Currently, the only HIE that has representation directly in this stakeholders group is Manifest MedEx. This group also includes two of their board members, and so we are feeling that we need some additional HIE representation in this group to really make sure that we have a full picture of what's currently happening in this state. And I think that's it. Thank you.
6	Jonathan Feit	Outstanding. Just wanted to append to the previous conversation it's Jonathan Feit by the way. With respect to direct service providers, I'm here today representing the California Fire Chiefs Association EMS section. And certainly when it comes to direct providers, particularly to patients in crisis, whether they have disability or otherwise, both fire and





Count	Name	Comment
		emergency medical services and the range of providers under those umbrellas certainly aim to be
		able to engage with health information exchange and
		the pre hospital environment and in other contexts as
		well, so direct providers from those groups
		represented here. Thank you.
7	John Helvey	Good morning, my name is John Helvey. I'm from SacValley MedShare and we serve the northernmost region of the rural state. And I would just like to advocate we need to, this group and the stakeholder group needs to continue to build upon what we have worked so hard for in the HIE space. We've worked on integrating EMS, we've worked on integrating hospitals, we've used a lot of dollars, federal and state dollars to accomplish this. And I think it's critical that we build upon the existing infrastructure that we have, and support the continued evolution of the health information exchange in California. As well as we leverage data that the state has, and allow it to come back into the exchange to support clinical providers at
8	Amanda McAllister- Wallner	I thank you. Good morning. Amanda McAllister-Wallner. I'm with the California LGBTQ health and human services network. And I just wanted to mention, as folks are mentioning, who aren't represented around the table, the need for LGBTQ representation on this panel. We have seen consistently a need for more sexual orientation and gender identity data collection and reporting throughout the healthcare system. We know that there are best practices and innovations with regard to organ inventories and ways of tracking and treating transgender patients, and a number of, a number of areas within health information, that it's incredibly important to have LGBTQ health experts at the table for these conversations, to make sure that we don't continue to miss vital health information about our communities.





Count	Name	Comment
9	Lisa Chan-Sawin	This is Lisa Chan-Sawin with Transform Health. It's really lovely to see former colleagues, having worked on this issue in the past for the state of California. I just wanted to ask a question and offer a remark here, you know, as somebody who's eyeballs deep trying to operationalize ECM and in lieu of services, there's a county coordination component here that is going to be critical to the success of that program. And I have a question about county involvement, and whether the charge of this group is to look at data exchange solely on the healthcare side, or will it also address covering the social care needs related to bringing social determinants of health to scale. And if so, it may be helpful to have some additional county representatives on. I see Michelle Cabrera's on. It's great to have the behavioral health directors viewpoints. But I think, you know, it might also be beneficial to this group to have others that operate at the county level who also bridge into the social services side, you know, housing data is very different than the type of data that you might collect for domestic violence, Meals on Wheels and things like that. So just wanted to offer a lens from somebody who's working on the ground right now, to not forget about that component. And to see if there might be some opportunities for some additional input as well, since those are the problems that we're dealing with. Thank you.

**Total Count of verbal comments: 9** 

## 2. The following table reflects public comments that were entered into Zoom Chat during the August 31st virtual meeting:

Count	Name	Comment
1	Hector Ramirez	Are there closed captions and or CART for this
		public meeting?
2	Hector Ramirez	Or ASL?





3	John Helvey	Is Ali Modaressi from LANES being added to this
	SacValley MedShare	stakeholder group.
4	Troy Kaji	For health equity during pandemic, needs to
		include CDCR. Troy Kaji MD Contra Costa Health
		Services
5	Marty Omoto - CDCAN	Very happy to see DDS (Dept of Developmental
		Services) and CDA (CA Dept of Aging) included -
		so critical to have every department connected and
		part of this effort to make the framework as
		complete and credible as possible - also shout out
		to a Mark Savage!!!
6	Jonathon Feit	Representing - California Fire Chiefs Association,
		EMS section (direct providers)
7	Marty Omoto - CDCAN	I also totally agree with comments by Hector
8	Michael Marchant (UC	will there be other forums / sub groups created by
	Davis Health)	this advisory committee with additional resources /
		expertise can be included to contribut to this work
9	Marcia Eichelberger	This is Marcia Eichelberger withe the Autism
		Society of California. Thank you to Secretary
		Ghaly and everyone who was involved in creating
		this important committee. We look forward to
		following all of your important work. I concur with
		Marty Omoto. It's amazing to see all of these
		Departments and stakeholders connected. It's
		important and very exciting. Thank you!
10	Lane, Steven MD MPH	California HIEs, providers and other stakeholders
		have been particularly succesful in connecting to
		and leveraging the value and capabilities of
		evolving standards-based national interoperability
		networks and frameworks. These frameworks
		continue to evolve to meet the needs of broder
		stakeholder groups, use cases and data. As the
		national Trusted Exchange Framework and
		Common Agreement (TEFCA) comes online in the
		next year California is well positioned to take full
		advantage of and contribute to the evolution of this
		infrastructure to meet the needs of our state.
11	Michael Marchant (UC	I worked on the CA Imlementation of the EHR
	Davis Health)	Incentive program and with Cal e Connect that





		provided incentive funding for healthcare providers to adopt EHR technology that created a
		foundational level of technology to support data
		exchange - if that same investment is not made for
		those other segements (Public Health, Social
		Services, Behavioral Health, EMS, Long Term
		Care, etc) it will be difficult to engage in meaningful
		exchange across the state
12	Jonathon Feit	FYI Fire & EMS aren't shown on this list **at all.**
		Do they fit into Behavioral Health? Hospitals?
		Public Health?
13	Jonathon Feit	in reality, Fire & EMS are **the inter-role care provider**
14	Daula Kluga Suprica	•
14	Paula Kluge - Sunrise Fiduciary	Will this new system include Social Security  Administration benefit information? Will the current
	i iducial y	Meds system used by H&HS for social service
		public assistance benefits still be utilized, or will it
		be replaced by this new system?
15	Lane, Steven MD MPH	While not an official member of the Advisory
13	Lane, oteven will in	Group, I am a California primary care family
		physician and clinical informaticist, and serve on
		the federal Health IT Advisory Committee (HITAC)
		adn the governance teams of a number of national
		non-profits working to expand nationwide and
		international interoperability. I and am happy to
		serve the Advisory Group as an SME, providing
		and supporting additional linkages between our
		statewide efforts and the tremendous progress that
		is being made across the health and social care
		ecosystems.
16	Michelle Rousey	How will this interconnections with all my providers
		and services reflect in real life in a way that I'm not
		having to be juggling my services as I do now?
17	Janelle Lewis	A very general question: Under this data sharing
		agreement, how will individuals maintain their
		privacy rights and maintain control of the sharing of
		their personal health information? Thank you.
18	drchr	When you have time, will you please discuss if an
		Organizational Change Managment (OCM) will be





	T	
		used to ensure implementation effectivness of nthe
		Data Exchange Framewowrk.
19	Lane, Steven MD MPH	One of the many opportunities that this stakeholder
		group has is to engage in and contribute to the
		work being done to advance the US Core Data for
		Interoperability (USCDI) -
		https://www.healthit.gov/isa/united-states-core-
		data-interoperability-uscdi. I help to lead and
		members of this Advisory Group serve on the
		federal taskforce working to advance USCDI. We
		are currently in an open public comment period
		collecting submissions and input that will contribute
		to Version 3 of the USCDI to be published next
		year. This will define the data that stakeholders
		are able to and eventually must exchange.
20	drchr	drchr is Kevin Christo[he, PhD
21	Dr Rahul Dhawan	I hope this finds you and your family safe and
		healthy. I am a primary care physician and
		abdominal transplant specialist, in a medically
		underserved area and happy to serve with the goal
		to further integrate social determinants of health
		and improve overall integration of care from
		academic tertiary centers to FQHCs and all the
		facilities including hospital , radiology and
		ancillaries in between to help patients get the best
		care. Thanks a lot Dr Rahul Dhawan MedPOINT
22	Lane, Steven MD MPH	Another key opportunity we have is to provide input
		on the evoling national Trusted Exchange
		Framework and Common Agreement (TEFCA). We
		are currently in an open public comment period for
		the technical framework that will inform the first
		iteration of the TEFCA when it goes live next year.
		Input can be provided at
		https://rce.sequoiaproject.org/ As the chair of the
		board at The Sequoia Project and Chair of the
		Steering Committee at Carequality I would be
		happy to facilitate linkages and informational
		presentations to the Stakeholder Advisory Group to
		assure that our California solution set is consistent





		with and takes full advantage of our evolving national interoperability framework which is being built on the same guiding principles being discussed here.
23	John Helvey   SacValley MedShare	Can someone address how this stakeholder group will support navigation of the county legal deprtments in navigating the sharing of information as outlined in AB133 while maintaining compliance with 42 CFR Part 2 and sensitive data?
24	Jonathon Feit	Per Ms. Coyle's point please remember / be aware (if you're not yet) that there are SEVERAL different data systems involved in this ecosystem. For **very good reasons** not all systems use HL7-based structures, and in the past (and even now, in many places) the fact of "separate but equal" getting forgotten has ground down the interoperability discussions. We need to engage the ecosystems as they could be yes but also as they ARE. E.g., Fire and EMS each has its own but also overlapping datasets (NFIRS and NEMSIS, respectively). Home health nursing has its own as well (OASIS).
25	Jonathon Feit	EMS & Fire not mentioned
26	Sharon Wolff	SB 528 (Jones) Health Information Summary - psychotropic medication (two-year bill) would create a health record exchange accessible to medical providers, schools and behavioral health agencies for foster kids. The concept is good - shared medical records - but there is concern about privacy with psychotropic medication and BH data as well as the workload for Foster Care-Public Health Nurses who would be having to enter information into both CWS-CMS and the newly envisioned database.
27	Daniel Savino	I am getting a lot of cutting out of audio. I have switched from wifi to wired, and then to a landline, but it's still pretty spotty.
28	herb@hksstrategies.co m	My company rep has put in one comments and is trying to enter another and it has him locked out.





		Not sure why since others have had more than one comments. Thanks
29	Connie Arnold	Sounds like Big Brother collection of data and
	(she/her/hers)	tracking everyone!
30	Connie Arnold	How about we move home and community based
	(she/her/hers)	services completely out of healthcare?
31	Connie Arnold	How does this apply to implementation of electronic
	(she/her/hers)	visit verification (EVV) of home and community-
		based services recipient employers of care
		providers?
32	Connie Arnold	Answer the question!
	(she/her/hers)	
33	drchr	Does the Charter call for a recommendation report
		by Jan. 1,2022 (in four months) with an update
		report by April 1, 2022
34	Connie Arnold	Are you specifically talking about tracking managed
	(she/her/hers)	care delivery of home and health care services
		through managed care, home health care
		agencies, group homes, nursing homes, hospitals,
		and other health care services or programs?
35	Connie Arnold	So as partbof equity are you planning to track low-
	(she/her/hers)	income and all recipients of home and community-
		based services as criminals?
36	Connie Arnold	We should be stopping data tracking through
	(she/her/hers)	Electronic Visit Verification (EVV)!
37	Connie Arnold	Are the unions behind this?
	(she/her/hers)	
38	Michelle Rousey	How does this reflect in how we get our services in
		our homes and community and how is GPS
		tracking as in EVV will be Implimented into these
		systems?
39	Connie Arnold	Is this part of tracking all home and community-
	(she/her/hers)	based services recipients and their non-relative
40	· A 11	community care providers?
40	Connie Arnold	First off, people with disabilities and seniors who
	(she/her/hers)	are reliant on home and community based services
		(HCBS) are not patients unless we are in the
		hospital or doctor's office!





41	tien@eff.org	Hi, will the committee address the topic of privacy and security rules for personal health information that has entered the public health system, whether collected by a public health authority from individuals, or from covered entities? Especially curious about rules or governance of non-state entities, including private entities that possess/receive public health data (given public-private partnerships in apps and similar issues.
42	Jonathon Feit	is there opportunity for stakeholder feedback on this topic, picking up on a previous mention?
43	Michael Marchant (UC Davis Health)	A consent model will be vital in any solution implemented to assist with privacy and security concerns
44	Connie Arnold (she/her/hers)	LGBTQI and persons with disabilities say:  1) Pay care providers a living wage;  2) Insure Innovative Differential Pay for HCBS recipient employers with severe impairments and disabilities' providers a higher pay level;  3) Provide rapid ressponse backup emergency and urgent care in all 58 counties and every city with care providers who have the essential skills to deliver needed services by the recipient employer (not patient) who requires services
45	Marty Omoto - CDCAN	Strongly support comments by Anthony and also by Cary - especially on the issues of the charter reflecting more individual healthcare experiences (patient/consumer) - something that was desperately needed when my older sister with DD, was alive and was constantly in urgent care or acute care
46	Michelle Rousey	Very concerned about how this information is going to be used and tracked. And who all has access? I'm extremely scared of this being just another way of tracking my every movement through the services I use.
47	Connie Arnold (she/her/hers)	California must not infrigement on disability and civil rights not falsely require recipients to waive their civil rights through any written signed consent!





48	Connie Arnold	The entire disability community is concerned about
	(she/her/hers)	Big Government tracking our lives!
49	Jonathon Feit	sounds great, thanks Kevin! Main thing is this,
		then: Claudia noted "federal standards." But there
		are SEVERAL of them, and not all of them are
		neatly aligned. There are also contravening state
		and county / local laws that for example
		REQUIRE the use of one standard or another, and
		it may not align neatly. There are in some cases
		ways of accounting for those, but it seems
		important to note that "federal standards" are not
		homogenous, and in some cases they are almost
		contradictory.
50	Marty Omoto - CDCAN	Question: can the presentations, when using
		abbreviations, always include on the same slide an
		explanation of the abbreviation used? This is
		important to make info accessible to others,
		especially to the general public. Just used
		abbreviations EHR and HIOin my CDCAN
		Reports I always explain the abbreviations to make
51	Dr Dobul Dhawan	the info more accessible. Thanks
31	Dr Rahul Dhawan	I appreciate being able to listen and comment for the public record. I am a PCP and specialist for
		MPM, the largest independently/owned MSO in the
		State. We are ready, willing, and able to volunteer
		our experience, expertise, and knowledge to serve
		on one of the groups to further assist the State in
		ensuring the best implementation possible for the
		people of CA. We are appreciative of all of the
		meaningful discussions our company reps have
		already had with the Administration
52	Connie Arnold	Are you planning your data tracking on the basis
	(she/her/hers)	that all seniors and persons with disabilities who
		receive home and community based services are
		all simply tracked as "patients" from a medical
		model rather than as p;eople? Are you twisting
		"person-centered" approach to turn us all into
		"patients" because someone needs home and
		community-based services (HCBS) because





53 54 55	Connie Arnold (she/her/hers) Connie Arnold (she/her/hers) Connie Arnold	managed care systems, home health agencies, nursing homes, and other healthcare programs are chasing financial gain from the 400 billion federal funding for HCBS services?  People of California don't want Big Brother government tracking!  No HCBS funding for any for-profit entities!  You are co-opting "whole person care" for your
55	(she/her/hers)	own gain which will drive up healthcare costs! Pay the direct care workforce a living wage!
56	Karen Ostrowski	We recently had the opportunity to provide an assessment to CHCF on HIE activity in 4 regions across the state to understand how these forms of HIE Rim has described play out at a regional level. As we note in the report, the dedication and creativity of folks in the field, who show up to work every day behind the scenes so that providers and their partners have the information they need, truly has a positive impact in peoples' lives. We are encouraged by the resurgence of demand for HIE and leadership from the State, but echo earlier comments about the need to build on the extensive work already done, particularly by the regional HIOs supporting communities.
57	drchr	What are the drawbacks of CTEN? One recently pulbished report was that providers have to access mutiple networks to get information on one patient
58	Terri Covarrubias - IEHP	May be too much in the weeds. But will this group discuss the universal health ID. The Master Patient Index has been problematic with overlays from other groups. Once propagated, that data is really difficult to rectify.
59	Michael Marchant (UC Davis Health)	We need to make sure the 'consumer mediated exchange' model does not negatively impact communities / constituents that do not have access to the technology to support that model and create larger inequities





60	Sharon Wolff	I believe that the universal health ID concept has
		been blocked at the federal level by Rand Paul for
0.4	01 14/ 155	a number of years now.
61	Sharon Wolff	https://healthinformatics.uic.edu/blog/unique-
		patient-identifier/
62	Sharon Wolff	https://aspe.hhs.gov/white-paper-unique-health-
		identifier-individuals
63	Jonathon Feit	BRAVO!!!!!!!!!!
64	Jonathon Feit	THANK YOU!!!!
65	Jonathon Feit	'@Jonah
66	tien@eff.org	We see a lot of concern from patients about how
		personal health data is shared, and hope that the
		committee will address the need to create patient
		trust and sustain it, visibly and transparency—
		especially with respect to behavioral health data.
67	Connie Arnold	Just a comment, in another state, a person with a
	(she/her/hers)	disability, a doctor needing 5 hours of care with
		home and community based services to live in the
		community from the "come and go" provider
		system, was denied it, forced into hospital and in
		3/4 of a year they charged the government
		\$750,000 for his care. He couldn't leave the
		hospital or they wouldn't provide care, he didn't
		want to live in a hospital, he was forced to move
		into a nursing home to get care!
68	Connie Arnold	Kevin McAvey are you with law firm of Manett in
	(she/her/hers)	L.A.????
69	Connie Arnold	Kevin McAvey, what is your role here?
	(she/her/hers)	
70	Connie Arnold	Get your money from the Mental Health Services
	(she/her/hers)	Act!
71	Connie Arnold	Kill You Kaiser is what my friend calls Kaiser!
	(she/her/hers)	
72	Connie Arnold	Read the California State Auditor's IHSS report
	(she/her/hers)	dated February 25, 2021 and the
		recommendations!
73	Michael Marchant (UC	'@DeeAnn - the CDPH data used for CV!9 IZ cards
	Davis Health)	did not take into account the phone / email were
	·	not required data elements for the providers





		reporting IZ data - big disconnect on intent vs implementation
74	Connie Arnold (she/her/hers)	Oh and more on Kaiser South Sacramento, I'm helping a senior in her 80's who cannot get LTSS paperwork signed by Kaiser doctor for severe impairments she has and had to file a grievance and that is a joke!
75	Connie Arnold (she/her/hers)	Kaiser ROI shutdown and wanted her to go through ROI to IHSS paramedical form!
76	Lane, Steven MD MPH	With regard to Public Health data and exchange, a tremendous amount of work has been done nationally to define current challenges and develop recommendations. CDC and ONC recently cosponsored a Public Health Data Systems (PHDS) Task Force which developed a host of recommendations that were transmitted back to ONC and CDC for action: https://www.healthit.gov/sites/default/files/facas/2021-07-14_PHDS_TF_2021_Recommendations_Report_0.pdf
77	Connie Arnold (she/her/hers)	California State Auditor IHSS report dated February 25, 2021 report stated 19,000 IHSS recipients going without care every month in 2019, more now, and yet no increase of IHSS provider pay to living wage!
78	Connie Arnold (she/her/hers)	We don't want or need CalAIM or managed care made mandatory and you are wrong
79	Connie Arnold (she/her/hers)	NO MANDATORY MANAGED I DON'T CARE ENTITIES! STOP SAYING WE ARE ALL PATIENTS FOR LIVING IN THE COMMUNITY WITH HELP!
80	Connie Arnold (she/her/hers)	How are you all financially benefiting?
81	Connie Arnold (she/her/hers)	Corruption!
82	Connie Arnold (she/her/hers)	Conflicts of Interest! Get out of California!





83	Michael Marchant (UC Davis Health)	'@paul - I think the need is to know where the data is and provide access / consent - not STORE the data
84	Connie Arnold	We have NO TRUST of YOUR INDUSTRY or
	(she/her/hers)	TRUST YOUR TRACKING SYSTEMS!
85	Connie Arnold (she/her/hers)	Good luck with your paper trust!
86	Michelle Rousey	Concerned that for home and community services
		like home care we are being considered as patients
		when were not a patient but someone with a
		disability who needs assistance in our homes.
		What does all of this mean towards you having a
		uniformed system for getting and retaining our
		health charting etc.
87	Colleen Petersen	Those providing direct patient care know what data
		elements they can/cannot share, though the forms
		may differ from practice to practice opting in/out are
		part of most new patient paperwork.
88	Ayanna McGee	Thank you all for providing this presentation. Will
		this recording be available to view after the
		meeting?
89	Connie Arnold	See the mismanagement of Mental Health Services
	(she/her/hers)	Act (MHSA) funds in a recent 2021 California State
		Auditor's report!!!! You don't even know where the
		billions spent on the homeless went or what
		outcomes happened!
90	Lane, Steven MD MPH	With regard to Patient Demographic data, this data
		class is well specified in the US Core Data for
		Interoperability Version 1, which is currently
		required for exchange, as well as the recently
		published Version 2. Additional demographic data
		elements have been proposed and "leveled" and
		will be added progressively to the USCDI as they
		achieve appropriate maturity. Our CA efforts
		should track and fully leverage these evolving
		standards. https://www.healthit.gov/isa/uscdi-data-
		class/patient-demographics
91	Connie Arnold	We don't support Big Pharma either!
	(she/her/hers)	





92	Janelle Lewis	Regarding the discussion of building trust:
93	Connie Arnold	What is happening to all of our privacy? Bourne
	(she/her/hers)	Identity?
94	Troy Kaji	Will committee address Fragmentation among
		state and local agencies, such as separate results
		portals for Prenatal screening results, Newborn
		Genetic screening results, and need to report CMR
		separately to each Local Health District
95	Janelle Lewis	There must never be coercion and must always be
		true informed consent in data sharing.
96	Mons Jensen -	Please understand more fully models of data
	Adventist Health	sharing before you assume that a central data
		repository is the only way to manage and share
		information. The internet is fundamentally based
		on a federated model where data is shared without
		the need for a central repository of currated data.
		Google, Amazon, and others are examples. These
		are based on technology to keep track of where
		data is, without having to hold or own the data.
		Health Information Exchange is foundationally
		based on a federated model of data sharing. And
		yes appropriate access management for security
		and access is necessary and included. Data is
0.7	L OL MONDU	retrieved at point of need, at time of need.
97	Lane, Steven MD MPH	'@ClaudiaWilliams, regarding the important role of
		the federal Information Sharing (Blocking) rules, it
		is important to appreciate that the scope of those
		rules expands from USCDI Version 1 to "All
		Electronic Health Information" as of 10/6/2022 for
		all three classes of covered actors - (1) Health
		Information Networks, (2) Providers, and (3)
		Vendors of Certified Health IT systems.
00	Troy Kaji	https://www.healthit.gov/curesrule/
98	Troy Kaji	What protections will be in place for patients at risk
		of being Public Charges, and therefore ineligible for pathway to citizenship?
00	Connie Arnold	1
99	(she/her/hers)	Please send me a copy of the Chat from today's meeting and a transcipt, video, and all document
	(3116/1161/11613)	presentations to ihss_advocate@yahoo.com
		presentations to mss_auvocate@yanoo.com





100	Michael Marchant (UC Davis Health)	'@jonah - so the statute says that there needs to be a plan / strategy to address unique MPI for state of CA as 'secure digtial identities'?
101	Connie Arnold	How can I download the chat???? This is a
	(she/her/hers)	disability accommodation issue?
102	Michael Marchant (UC Davis Health)	'@kevin - thanks for clarifying that its not for the state but private/public orgs
103	Connie Arnold	This is a matter of public information
	(she/her/hers)	·
104	Lane, Steven MD MPH	Regarding data sharing agreements, California stakeholders will also have the opportunity initially, and likely a requirement eventually, to participate in the national TEFCA. Much work has been done by The Sequoia Project to collect public input for the development of a draft Common Agreement (https://rce.sequoiaproject.org/common-agreement-work-group/) which will result in the publication of the first version of the national common agreement in Q1 2022. https://www.healthit.gov/topic/interoperability/trusted-exchange-framework-and-common-agreement
105	Connie Arnold	https://www.chhs.ca.gov/data-exchange-
100	(she/her/hers)	framework/
106	Michelle Rousey	Make sure you pen the groups to regular consumers
107	Karen Ostrowski	Also contributing to the urgency is communities that are transitioning from WPC to CalAIM. Many are currently contemplating changes to their data governance frameworks, including making modifications to their existing data sharing agreements. They can't wait for this work, but also are closely watching to understand the downstream impacts and how this will be operationalized.
108	Connie Arnold	Outnumbering stakeholders by moneyed interests
	(she/her/hers)	is not real inclusion
109	Jonathon Feit	'@Steven Lane: Do remember that HISTORICALLY I've heard this is evolving the Sequoia / CommonWell agreements had required authorization from the patient. That





		DOES NOT work in EMS environments due to (a) altered mental status, (b) children, and (c) unconscious patients. "Break glass" may be insufficient due to "dirty data" it's not just about permission, it's also about accuracy in looking up John / Jane Does.
110	Jonathon Feit	VOLUNTEER FOR SUBCOMMITTEE JONATHON FEIT
111	Jonathon Feit	(please confirm that you're seeing these. Raising hand, too.) Thanks!
112	Terri Covarrubias - IEHP	Thank you all. This is exciting to be part of a solution to a large problem. All will benefit from this. :)
113	Connie Arnold (she/her/hers)	51% public representatives or more and fewer financially interested parties
114	Jonathon Feit	thanks!

**Total Count of Zoom Chat comments: 114** 

**Total Count of public comments: 123**