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HIE Consent Consumer Engagement Summary Report

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Project Background & Methodology

Between August 2020 to June 2021, the Office of Health Strategy (OHS) contracted Health Equity Solutions (HES), a 501(c)(3) organization in the state of Connecticut, to conduct consumer engagement sessions to introduce consumers to Connecticut's Health Information Exchange (Connie) and facilitate discussion on the proposed Connie consent policy recommendations.

In efforts to foster a trusting environment that consumers would feel comfortable voicing the breadth of their questions, aspirations, concerns, and suggestions, HES served as a trusted community broker, outreaching with community organizations, explaining the project and value of the engagement, working with them to plan co-sponsored engagements, and facilitating sessions. Engagements were conducted as a series of two Zoom sessions lasting between 1 – 1.5 hours each and were recorded with participant consent for note taking purposes only. Consumers received a $25 Visa gift card per session in recognition of their time and participation.

The following report provides a synthesis of key consumer observations, questions, and recommendations about Connie and the proposed consent policy recommendations drafted by OHS. We hope that Connie will carefully heed consumer feedback and use these findings to inform the ways that Connie outreaches, communicates, and builds relationships with the diverse communities in Connecticut as the HIE becomes fully operational across the state.

Consumer Engagement Objectives

01 INFORM & EDUCATE

across sessions to build community knowledge of Connie, opt-out consent model, data sharing processes and benefits.

02 LISTEN to UNDERSTAND

perspectives, priorities, and concerns about data sharing, participation in Connie, and the consent model from diverse communities.

03 INVOLVE & RECOGNIZE

community and membership organizations as trusted sources of information, with a focus on engaging communities of color.

04 PROVIDE & AMPLIFY

opportunities for consumers to voice their needs, questions, and suggestions related to the health information exchange.

Consumer Engagement Snapshot

5 Community co-hosts

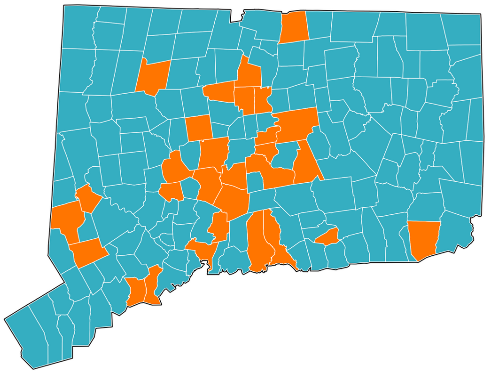
CHW Association of CT	CT Coalition Against Domestic Violence	LeadingAge Connecticut	NAACP of Middlesex County	PATH CT
17	9	9	14	12

61 Consumers Engaged (disaggregated by cohort)

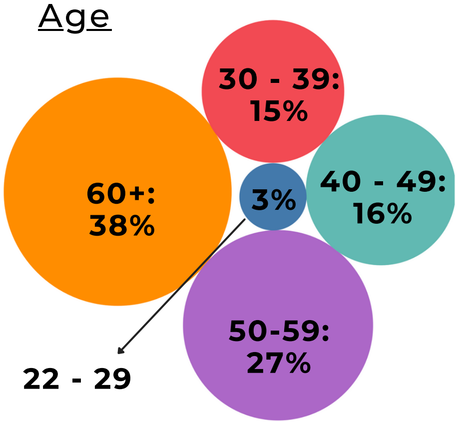
Engagement numbers

25 - Organizations contacted/outreach
13 - Organizations pitched
12 - Total consumer engagement sessions
80 - Completed interest forms
61 - Registered for sessions
57 - Attended session #1
35 - Attended session #2

Consumers represented 29 different towns

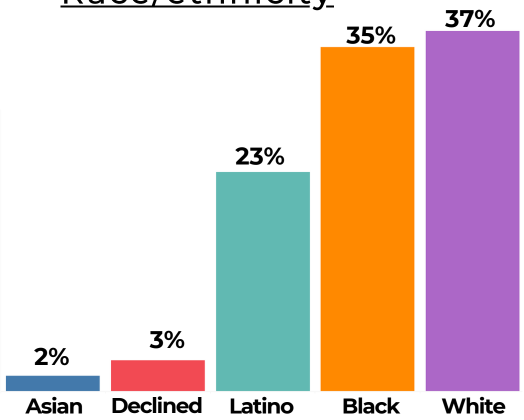


Age

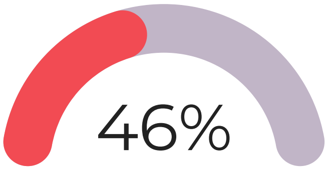


* missing: n = 1

Race/ethnicity



Participation



of consumers participated in both sessions

Consumer Engagement Limitations:

The qualitative data presented in this report represents a small sample size of consumers (n = 61). Organizing sessions with community groups during the pandemic presented a challenge due to competing priorities facing community organizations and consumers themselves. Many of the organizations we initially contacted did not have the capacity to participate, though they were interested and supportive of the project. Because HES was limited to virtual sessions during the pandemic, we were not able to connect with people who did not have access to computers and Zoom. Despite outreach efforts, we were unable to engage Indigenous and Asian residents as well as youth, as reflected in the data above. While we have identified themes from across sessions, the findings are by no means comprehensive.

Consumer Observations & Feedback:

Based on the discussions from the 12 consumer feedback sessions, we synthesized feedback into six main themes. The following section presents the consumer insights, recommendations and direct quotes related to each theme. For a list of the most commonly asked questions, see Appendix A.

Data Security & Mistrust

Top Concerns:

- Security breaches
- Identity theft
- Insurance stigma & data bias
- Enhanced vulnerability to harm

Consumer Recommendations:

Provide more detailed and accessible information tailored for consumers on the following:

- Connie's current security measures
- Consumer protections for anti-identity theft
- Plans for consumer recourse in the event of a security breach

"I'm concerned about that information on such a broad spectrum in the hands of so many individuals. I'm not saying Connie doesn't sound like a great opportunity. I'm just saying that in the midst of this great opportunity, what are we doing to think on the "what if" scenarios and somehow implement the supplement supports that would take away some of those legitimate concerns."

"My own health insurance was hacked, credit cards were hacked, they had to provide me with security – an anti identity theft protection put on all my accounts at the cost of my insurance company. Connie needs to consider that because they will be held liable for that."

Privacy & Access

"Currently when you go to the doctor's office you'll see a box that says specifically do not release my records for HIV, substance abuse, or others. It would be helpful with something like that [for domestic abuse victims]."

"It's hard when you receive medical services in your community because most people who work in that office are from your community. I'm having this issue in the clinic and I've reported as well because there is no confidentiality."

Top Concerns:

- The all-or-nothing level of access to a patient record for medical providers
- The uncertainty and limited understanding on levels of access afforded to peripheral health (e.g. medical assistant) and non-clinical (e.g. front desk) staff

Consumer Recommendations:

- Enhanced data sharing options enabling consumers to select different levels of sharing among specific providers on their care team
- Flexibility to redact or hide certain information in patient medical records
- Break-the-Glass feature requiring those not involved with patient care to justify access prior to viewing record
- Ensure documentation of abuse is under affirmative consent and provide additional means of protecting the sharing of this data with providers. (e.g. *Purple Ribbon Record.)

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*athenahealth features a separate carved-out record for documenting domestic abuse that is not freely shared among providers

Consumer Observations & Feedback:

Education & Outreach

Consumer Recommendations:

- Leveraging consumer engagement lessons learned from COVID-19 vaccination education & messaging
- Centering inclusive approaches & cultural and linguistic standards (CLAS) to responsively engage with diverse communities.
- Contracting with trusted community brokers and messengers for education
- Providing info to consumers via visual narratives, multimedia videos, infographics

"Connie is accountable so they need to engage consumers directly."

Communities to focus outreach:

- Immigrants
- BIPOC*
- Non-English speaking
- Elderly
- Adolescents & foster youth
- Rural communities
- Low health or technology literacy or access
- Domestic abuse victims
- Individuals with cognitive or physical disabilities
- Individuals with HIV/AIDS

"Mostly, I'm concerned about accessibility. How will people know how and where to access this information [on Connie] and how it is being explained. My grandmother would not" understand."

*Black, Indigenous, and People of Color

Consumer-Specific Use Cases

I"ll have the ability to do it and obviously I am computer literate enough to do it but people my age don't see what their medical record says and have providers update any errors."

Use cases identified by consumers:

- Medication reconciliation
- Features supporting correction of medical errors found in EMR
- Language and gender preferences to support appropriate care
- Integration with care coordination & referral platforms
- Health equity

"I only know a few things in my medical record. My doctor asked me don't you know this, and sometimes I don't...[With Connie], I don't need to walk around with my medical record in my pocketbook...People didn't know what HIPPA was when it first came out so I feel it's something people need to get used to, that it's going to be there whether we like it or not. The information is there, we just need to find a way to communicate it to everybody that is a safe and secure way for everyone to get our information."

"The population we serve mostly have multiple providers or change providers frequently. This is a good step to keep all the information in the same place for providers to have access to them. Definitely I see us providing a lot of education in the community just informing them that this is available and how it will benefit them by keeping the information safe."

Consumer Observations & Feedback:

Opt-out Consent Model ☒

Consumer Recommendations:

- Review Connie consent options and updates annually with patients
- Clarify the types of data that are considered 'sensitive' and would fall under affirmative consent
- Create a consumer-tailored newsletter or portal notification to inform consumers of new data sharing use cases as they develop

Top Concerns:

- Consumers, particularly those facing the greatest barriers to access, will lack awareness about Connie consent options
- Opt-out model will not support principles of informed consent
- Consent will be an additional burdened on providers and take valuable patient time in already time-constrained visits

"I am very much against opt out system versus the opt in. Most people my age, and I am well over 80, just don't understand this thing...I know full well having seen things from my providers that they have things very incorrectly [in my medical records]. Once that is transmitted to other providers all hell will break loose."

"An overarching characteristic that has become very apparent as I listen is that opt-out...is basically bypassing the patient. And having spent years in clinical research and studying and following principles of informed consent, I think that having the only consent that anybody signs is to opt out, is not in line with that principle."

Funding & Sustainability

Top Concerns:

- Long-term funding plan
- Impact on independent providers & small practices
- Cost of participating pushed onto consumers

Consumer Recommendations:

- Provide detailed, publicly available and digestible information about Connie's funding plan
- Addresses potential unintended financial consequences to consumers such as increased cost of health care services

"You tell me that it's funded until September, you don't know how it's going to be funded going forward, just trust us, I have to opt out, not opt in, and if there are errors I have to get them corrected [myself]..."

"How do you see the impact of Connie on the prices of healthcare providers? Who covers the difference when prices rise due to upgrade costs of being part of Connie?"

Appendix A: Summary of Common Questions And Concerns By Theme

Data Security & Mistrust

- Who regulates Connie?
- Who is on the advisory board?
- How many other HIEs in the US and has there been documented security breaches?
- How do they ensure data is secure from hackers? What happens for consumers if there is a breach?

Privacy & Access

- How do you ensure confidentiality from those who should not have access including domestic violence (and other) abusers, clerical staff, other providers, etc.?
- How can my out of state provider gain access to Connie?
- How will Connie ensure ease of operability with regards to language, technology ability, reading level, visual impairment, etc.?

Education & Outreach

- How are consumers informed about Connie, automatic opt-in and how to opt out? How will they take into account CLAS standards and differentiate outreach to the youth vs the elderly communities.
- How does Connie plan to educate hard to reach communities including immigrant communities, congregate settings, foster communities, homeless, visual and hearing impaired?
- What is Connie's comprehensive education/outreach plan? Will there be training for providers and community-based organizations?

Reconciling Errors

- How can a patient reconcile errors they find in their complete medical record, including outdated information?
- Since information is coming from different providers with different platforms, how do you ensure accuracy of patient information?
- What is the process for ensuring health information is input correctly by providers?

Opt-out Consent

- Are providers responsible for ensuring patients know about opt in?
- How does automatically being opted-in follow the informed consent principles?

Funding & Sustainability

- How much does Connie cost to operate?
- How will Connie continue to operate once funding ends in September?
- How does Connie prevent costs of the exchange being passed on to providers or consumers?

Acknowledgements

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- Connecticut Coalition Against Domestic Violence
- LeadingAge Connecticut
- NAACP of Middlesex County
- PATH Connecticut

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