

WHAT COMMUNITY MEMBERS SAY

Insights from a Patient Community Advisory Board

INTRODUCTION

In 2020, the California Department of Health Care Services (DHCS) and the Office of the California Surgeon General funded the California ACEs Learning and Quality Improvement Collaborative (CALQIC) with the goal of integrating Adverse Childhood Experiences (ACEs) screening and response within health care settings in a way that enhances relationships between patients and providers, helps connect patients to supportive services, and leads to better outcomes such as reduced disparities and more positive experiences with care.

In keeping with CALQIC's commitment to health equity and the integration of patient and community expertise, CALQIC created a Patient Community Advisory Board (PCAB) by recruiting and identifying 11 individuals who were representative of the patient population of clinics enrolled in the CALQIC. PCAB members were fairly compensated for providing consultation and sharing their life experiences. The PCAB aimed to optimize understanding of community and patient needs, concerns, and opportunities with regard to ACEs screening; develop culturally relevant materials for ACEs education; and assist in the translation of findings into interventions and practices appropriate for the patient population.

This document provides a summary of PCAB meetings and interviews. We have distilled some of the key points regarding members' preferences for care as it pertains to ACEs screening. PCAB input is informed by members' life experiences as patients, caregivers of patients and community members—including service providers— but members did not specifically participate in ACEs screening as part of CALQIC. While we report on data from a single group, there are recurring themes and ideas that resonate with prior evaluation and research findings and provide a rationale for the more frequent inclusion of patient advisory boards in program implementation and evaluation.

PARTICIPANTS

This summary includes perspectives from a total of 17 participants: 6 interviewees, 8 PCAB members, and 3 who participated in both. None of these participants received ACEs screening at a medical appointment as part of CALQIC activities.

OVERVIEW

In the early stages of CALQIC, prior to formalizing the PCAB, CALQIC staff designed and conducted semi-structured interviews with nine individuals. The aim of these interviews was to understand patient experiences and inform the creation of the PCAB and the structure of the subsequent facilitated meetings. Recruitment of participants occurred through an existing network via community engagement staff at University of California, San Francisco (UCSF), outreach on social media, referrals from clinics participating in the CALQIC learning collaborative, and referrals from UCSF staff working on other engagement initiatives. CALQIC staff sought to ensure representation from a range of geographic and racial/ethnic groups.

The interviews took place between May and June of 2020. Following the initial interviews, all nine participants were invited to join the PCAB. Six decided to join the PCAB initially, but due to conflicting schedules only three were able to stay on the PCAB. In addition to these three participants, CALQIC recruited eight additional participants using the same recruitment approach as the initial interviews. The final PCAB was comprised of 11 members, and this report provides an overview of the seven times they were convened by CALQIC between January and June 2021. CALQIC leadership facilitated the virtual 1-1.5 hour meetings in English and Spanish, with simultaneous English/Spanish translation for monolingual English or Spanish-speaking PCAB members.



The table below summarizes the characteristics of interview and PCAB participants:

TOTAL PARTICIPANTS* (n=17)		
Age	18-19	2
	20-29	0
	30-39	4
	40-49	4
	50+	5
	Unknown	2
Gender	F	16
	M	1
Race/Ethnicity ¹	Latin American	11
	Native American	2
	Asian	1
	Multi-ethnic	1
	Black/African American	2
Region of California	Northern	2
	Bay Area	8
	Central Coast	1
	Central Valley	1
	LA	4
	Southern	1

* Total participants included 6 who only participated in interviews, 8 who only participated in the PCAB, and 3 who were both interviewees and PCAB members

PCAB members included patients, caregivers, and service providers and provided expertise based on their lived experience as members of the community—however, none of them had specific experience receiving ACEs screening through CALQIC initiatives. In addition to members' lived experiences as patients or caregivers of patients, three members also had experience working in a health clinic or as a community health educator.

¹ CALQIC collected data on race and ethnicity self-identification from PCAB and interview participants. This information was collected in an open-ended question format, which resulted in several groupings that were categorized as follows for the purpose of the table presented above:

- Latin American: Latina, Latin, Chicana, Mexican
- Native American: Native American/ Chumash/ Tongva, Lakota / Pomo
- Asian: Filipino
- Multi-ethnic: Tri-ethnic
- Black / African American: African American, Black

APPROACH

PCAB meetings focused on obtaining members' feedback given their experiences as patients, caregivers, community members, and health workers, on the following topics:

- Pamphlets and educational materials
- ACEs screening by phone or video
- Resilience questions that might be included in screening
- Fears and concerns about ACEs screening
- Perceptions on what the ideal clinical response looks like after ACEs screening
- Perceptions of Child Protective Services
- Patient scenarios for health care team training
- Health care team scripts and guidelines.

Interviews with participants overlapped with some of the PCAB meeting topics, as well as other topics such as: feeling safe and comfortable at a clinic; the provider's personal, cultural, and training background; considerations for communication and transparency when screening; and what should happen after the screening.

Audio recordings from the PCAB meetings and interviews were transcribed. RAND Corporation evaluators summarized the available data and organized the key points according to the following categorization:

- 1 Before ACEs screening
- 2 During ACEs screening
- 3 After ACEs screening

This report is based on interview transcripts, and as such non-verbal gestures (e.g., nodding in agreement) are not included in this summary. Additionally, although a wide range of topics were discussed during PCAB meetings, this report aimed to identify key themes as they pertain to ACEs screening rather than comprehensively addressing all comments. Quotes provided are exemplar quotes with the intention of illustrating key themes; they are not intended to be a comprehensive listing of PCAB comments.

1. BEFORE ACES SCREENING



Staff Diversity

PCAB members felt it didn't matter if their provider had lived experience with ACEs. As long as their provider was educated and trained in ACEs they felt comfortable. However, the PCAB mentioned several times the importance of racial and ethnic diversity among the health care team and that they would want providers to look like them or come from a similar background. One PCAB member suggested involving community members as formal "community liaisons" at clinics.

"Hire black, hire brown. They need people who know. I wouldn't want to get served from a 21-year-old white girl with no siblings."

– PCAB Meeting #4

"I feel like I could resonate with people of color more; most of my therapists were white, and they often didn't understand cultural differences or other experiences we had and they just didn't get. I have a therapist of color now, and it feels nice to have someone who understands me."

– Interview # 8

"When I was in a shelter with my son, a lot of people on staff were homeless one time their self. They were not tone deaf or insensitive to our needs. That is more important to me, because I want to speak with someone who knows what I'm going through."

– Interview #9

Patients want clinics to be calm, safe, and welcoming spaces.

Patients expressed that clinics engaging in ACEs screening should ensure that their space is calm, safe, and welcoming. The importance of the clinic space was brought up by more than half of the interview participants. Participants shared that being greeted warmly as you enter the clinic was important to them, as well as feeling genuinely welcomed instead of staff acting like they are too busy to pay attention to you. Making sure that the clinic is clean and tidy was also highlighted during interviews, and participants shared that the health care team should receive training to support this type of environment.

The PCAB shared many specific ideas about what makes clinic spaces feel welcoming and safe: suggestions on wall color, essential oil diffusers, music, materials for fidgeting or doodling pads, and using ACEs educational posters to decorate instead of traditional pharmaceutical advertisement posters. One PCAB member who reported having PTSD spoke to her need to be able to identify clearly marked exits when she walks into a clinic.

"I think that they should make sure they're greeting their patients, because a lot of times you walk in and no one even says, 'Hi.' When you go to Starbucks, they say hi to you. So sometimes you feel like your business isn't important right when you walk in the door."

– Interview #6

"I don't want to walk into a clinic and the walls are like cream off white. I mean, I want it to be like warm when you walk in there and comfortable."

– Interview #1

"So if I go up to a staff member and a staff member is not paying attention to me, is rude or just has ... If the staff is overworked and disorganized, you can tell [...] Because, that is kind of the first, that first impression will either throw someone off,... or it can be an interaction to build the bridge with somebody."

– Interview #3



PCAB participants provided very detailed and specific feedback on patient education materials as they reviewed specific handouts and fliers.

All participants across the PCAB meetings and interviews agreed that education is important. One participant offered that “knowledge is power” and that if patients do not have information on ACEs they would be less inclined to answer questions about it. This highlights the need for clinic staff to provide a clear rationale for screening in advance of administering the screening.

Several participants in one meeting agreed that the ideal order would be to start with broad educational resources, then conduct the screening, and finish with the provider asking whether the patient would like more specific education and resources tailored to the patient’s situation and cultural background. One participant noted that all the educational materials now seem to point to websites and that sometimes patients have barriers in accessing the internet so adding a telephone number for questions would be helpful. Another suggestion was to play educational videos or presentation slides in waiting room areas, as many patients do not read print materials provided to them or have different learning styles that may be more receptive to a video format or peer educator.

Another participant shared that sometimes health recommendations made them feel guilty about all the things they should be doing and are not. They suggested that an acknowledgement by the provider about how recommendations are sometimes difficult to implement would be helpful. Related to language in educational resources, PCAB participants offered that some words were too broad (e.g., trauma), and some felt too deficit-based (e.g., dysfunction).

Lastly, participants also highlighted the importance of diversity in educational materials and wanted to see variation in how people are represented in posters and fliers. For example, one participant noted that in one pamphlet there was a drawing of a woman who was barefoot and that this could be an undignified representation.

“Going based on visual and the woman there [referring to educational pamphlet], my thought is, ‘Why is she barefoot?’”

– PCAB Meeting #2

“Education is key to empowerment. If we help people develop the language, we help people understand why we’re trying to do this and how it could affect them. Then they’ll understand why it’s so important and why it’s so important for them to share their experiences once we give them those tools.”

– Interview # 3

“I feel like it would be helpful to let them know what it’s for or why they’re asking those questions. Because I feel like people won’t be able to open up if they don’t know what it’s about, because it’s a very personal thing that they’re talking about.”

– Interview #4

“... Someone from the community that helps and understands the community can help better relay the info to community. People usually don’t pay attention to pamphlets; I throw them away.”

– Interview #8

2. DURING ACES SCREENING

PCAB participants emphasized transparency, patient-provider relationships, and communication with providers.

Participants shared that the patient-provider relationship is a worthwhile investment, and it may require several visits to establish trust. Establishing trusting relationships between the health care team and patients is critical. Participants explained that patients want to feel seen, like they matter. Providers can make a big difference by remembering a patient's name or giving a follow-up call just to see how they are doing.

The PCAB believes it is very important for patients to feel as if the provider knows something about them before they meet. They reported that even having the provider know their name indicates that the provider at least made an effort to look at the patient's health record before the visit.

One participant shared that if providers are going to conduct screening, then they need to be prepared to have the conversation that will follow screening, both in terms of time and training. Participants were aware of time constraints in medical visits, and one person suggested that providers be clear and upfront about the expectations for each visit and how much time was available so that patients would know what to expect from that medical encounter. Similarly, on the topic of transparency, one participant asked that providers be upfront and give people a 'heads up' about the ACEs screening. She compared it to getting a vaccination: if you get fair warning on a procedure like a vaccination, you should get the same for ACEs screening.

Additionally, a few PCAB members explained that they want the doctor to acknowledge the completed screening instead of just burying it with the rest of the paperwork. The issues of patient trust and comfort were brought up several times and were cited as factors that can help screening go smoothly.

One of the PCAB meetings focused specifically on the mechanics of conducting ACEs screening over the phone or during a video call. Participants in the group felt that it was too overwhelming to think of the questions and do the mental math to provide a number at the end. They emphasized that paper-based screening and giving people space to process was an important aspect of screening.

Lastly, some participants shared that inclusion of resilience questions is helpful for healing and a good bookend to screening.

"I know that they see lots of patients; but it's nice when you visit your provider and they actually recognize you and know who you are. Because they see so many, they have to look at the file to know who you are. I think it's just nice when they're a little more personable and try to get to know their patients."

– Interview #6

"I can remember the first times when I talked about my traumatic experiences, I felt ashamed. I felt sweaty. I felt like, 'What did I just do?' This shock [...] A raise of the eyebrow could make someone feel like, 'I shouldn't be talking about this anymore.'"

– Interview # 3

"If they feel that they can't open up because it just hurts them too much, we need to be patient about them and just let them handle it for themselves. Such as we have to wait for the right time when they want to express their traumatic experience."

– Interview #4

"Pay attention to that questionnaire. Because you're having me sit down and spending 20 minutes filling it out, then I think you can spend that 20 minutes checking every checklist and every entry. Then you will know where I'm coming from."

– Interview #7

"The surprise can make a patient uncomfortable. Explaining is very helpful. That would be like giving someone a shot without explaining why."

– Interview #9



3. AFTER ACES SCREENING

"You don't necessarily want to just like shift into, 'I'm going to help you mode and I'm going to pile a bunch of resources.' And a bunch of warm handoffs on, 'Okay, well I know you said you dealt with this. So then this means we're going to like put you on this track to try and help you with that.'"

– Interview #2

"I think if you give them a list to go home with, they may never look at it again because they're traumatized."

– Interview # 6

"I've had a couple experiences with CPS and it wasn't so bad. And I think that that needs to be conveyed, because in my community, people think CPS and they think they're going to take my kids, you know?"

– PCAB Meeting #4

PCAB members all agreed that the post-screening response needs to provide guidance and involve co-planning

instead of providing a list of places to patients and families. Families want to be involved in the process of considering next steps, and providers need to be mindful and respect patients who may decide to not pursue certain types of resources or referrals offered.

Participants were asked about their perception of Child Protective Services (CPS). They explained that families are often fearful of CPS due to the perception that the only thing they do is "take your kids." However, several PCAB members shared their own positive experiences with CPS, and they felt that those types of experiences need to be shared and disseminated more widely. Less anxiety and stigma surrounding CPS, they explained, would allow people to access good resources that they may be missing out on due to fear.

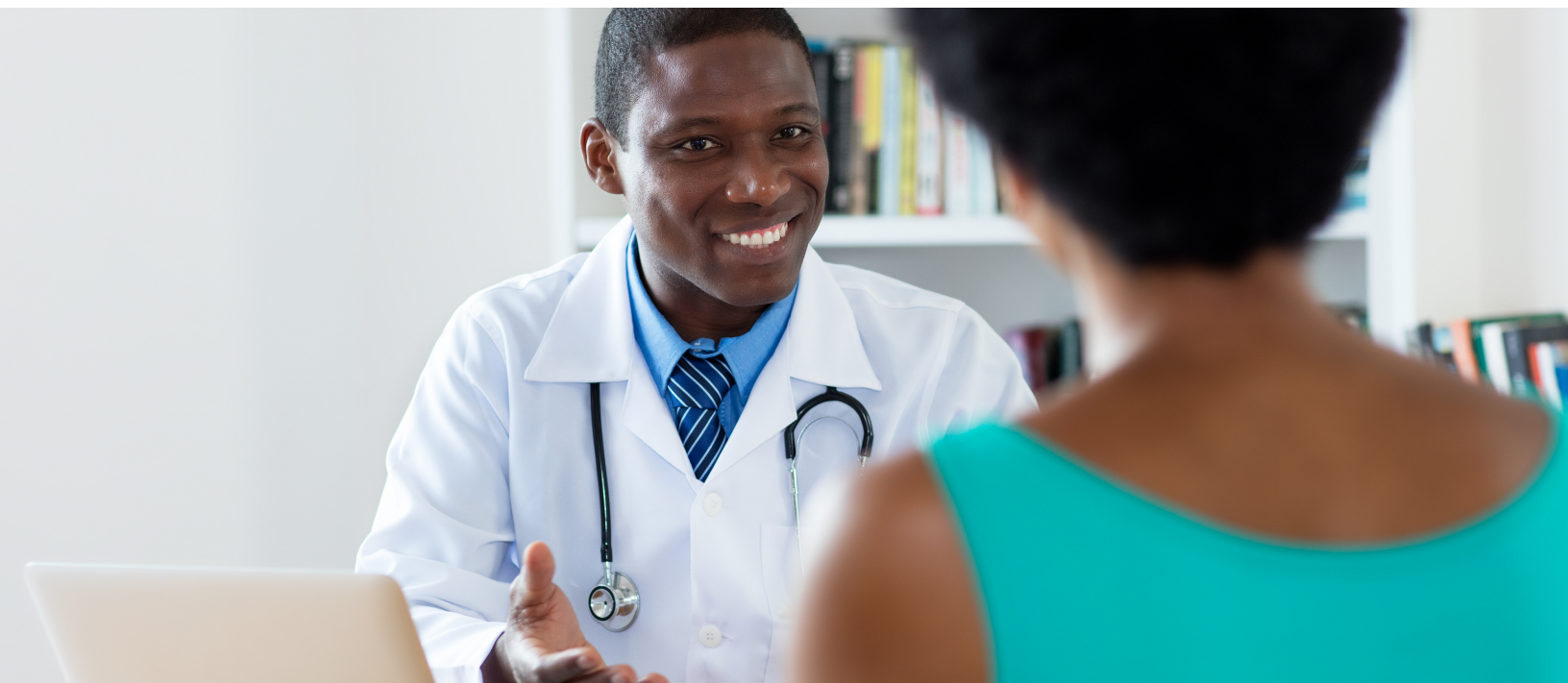
One participant shared that they had once disclosed ACEs to a doctor and that they felt that the doctor overstepped in their response, as the doctor disclosed information to the patient's parents and began referral processes without patient consent. PCAB members said providers need to be respectful, work with the patient, and give them time to process and heal, instead of taking a task-oriented response to a positive screen.

CONCLUSIONS & RECOMMENDATIONS

The PCAB meetings and interviews provided community members' perspectives on topics related to ACEs screening. Participants commented on the clinic environment in the context of ACEs screening, emphasizing the need for spaces that felt welcoming and safe in terms of both infrastructure and staff diversity and behavior. They pointed to the importance of patient-provider relationships, preferences regarding how information and education should be shared, enough time for conversations and acknowledgement of the screening, and the overwhelming nature of screening over the phone.

Below are some recommendations that follow from the findings summarized in this document:

- 1 Prioritize décor, cleanliness, and attentive staff at the front desk and waiting area.** Creating warm environments and making patients feel welcome from the moment they step through the door can be conducive to increasing trust, which could make screening more acceptable to patients. This can be done with clean, fresh smelling spaces, organized countertops with no clutter, colored walls, uplifting or educational posters that portray a wide range of groups and backgrounds, and attentive staff.
- 2 Strengthen diversity, equity, and inclusion initiatives as they relate to clinic staff, hiring practices, and printed materials.** PCAB members highlighted how sometimes they do not feel like the person sitting across from them understands their background and situation. Furthermore, educational pamphlets and flyers should depict individuals and situations that patients can personally identify with. Commitment to diversity may increase levels of trust with the people the clinic serves, which may increase likelihood of acceptance of ACEs screening.



3

Provide clear rationale for the ACEs screening and its importance prior to administering the screening. Participants discussed how they might feel more inclined to complete the screener if they were provided with more information on what ACEs are and why it is important to screen for them. Participants also noted that general education and information prior to screening would be helpful, and then follow-up with more education that is tailored to each person's responses after the screening. Developing clear workflows of which medical provider gives the information, which information, what format of delivery, at what point in time, and in which setting or location would ensure that all patients receive enough education to help them feel comfortable when screened for ACEs.

4

Nurture patient-provider relationships. PCAB participants expressed how knowing and trusting their doctor would make screening a more comfortable process. Patients noted that when doctors remember their names or include them in the decisionmaking process, they feel seen and valued.

5

Always acknowledge the screening. Participants explained that if they spent time filling out the form, they expect some form of acknowledgement from the doctor instead of just filing it away with the rest of the paperwork. This acknowledgement is important even if patients report zero ACEs, or if the provider already knew about the patient's ACEs.

This report illustrates the value of incorporating patient and community perspectives in understanding how best to serve their needs. The PCAB provided important and unique expertise to the clinical implementation of ACEs screening. Overall, PCAB members used their life experiences as patients, caregivers, and community health workers to provide advice on how to conduct and respond to ACEs screening in a manner that feels safe and valuable to patients. When done in this manner, PCAB members agreed that ACEs screening can be a useful tool that provides families the opportunity to feel validated and receive help they need.

