



LEARNING JOURNEY 2023 REPORT

Lessons learned from a community-driven exploration to identify strategies to inspire communities of color to engage in advance care planning

October 2023

www.sfpcwg.org



SAN FRANCISCO
PALLIATIVE CARE
WORK GROUP



ABOUT THE SAN FRANCISCO PALLIATIVE CARE WORK GROUP

The San Francisco Palliative Care Work Group (PCWG) consists of leaders from diverse organizations across the city, representing governmental agencies, health systems, health plans, community-based organizations, and foundations. Its mission is to assist San Franciscans facing serious illness in leading their highest quality of life, for as long as possible, by accessing high-quality care that aligns with their wishes and values.

To realize this vision, the PCWG empowers individuals aged 65 and above, as well as those with serious illnesses, with the knowledge and tools necessary to actively engage in advance care planning and know why and how to access palliative care. While the ultimate goal is to broaden our outreach to all San Franciscans, the initial focus centers on addressing the needs of communities of color and LGBTQ+ communities, recognizing that these groups experience some of the most pronounced health inequities.

The PCWG is sponsored by the San Francisco Department of Disability and Aging and receives financial support from its members and philanthropic partners.

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ABOUT THE LEARNING JOURNEY REPORT

This report documents the lessons learned from the Learning Journey, a community-driven exploration that aimed to identify strategies for inspiring Latinx, Black and Chinese individuals to engage in advance care planning.

We have organized the report in three different ways to make it as easy as possible for you to access the insights that are most relevant to your needs. If you are interested in learning about the overall findings from all three Learning Journeys, please refer to the Summary of Learnings. If you wish to explore the lessons learned by each individual community, you can navigate to the Learning by Community section. Lastly, if you want to delve into the details of the process and lessons learned at each step, you access the Learnings by Phase.

By organizing the report in this manner, our aim is to provide you with easy access to the knowledge that will support your efforts to enhance access to advance care planning.

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Blue Shield of California	CPMC and St. Francis Medical Center	Open Door Legal
San Francisco Buddhist Center	CSU Monterey Bay	Self-Help for the Elderly
Californians For Safety & Justice	Curry Senior Center	Stupski Foundation
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Chinatown Community Development Center	Family Caregiver Alliance	UCSF MERI Center
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	Kaiser Permanente San Francisco Medical Center	Zuckerberg San Francisco General Hospital and Trauma Center
	Mettle Health	Urban Missions

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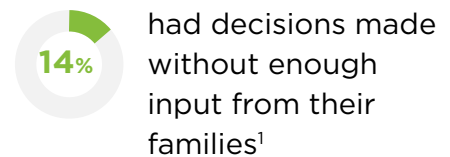
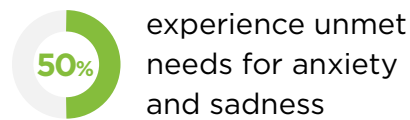
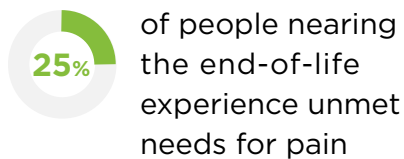
Stupski Foundation

San Francisco Department of Disability and Aging Services

Thriving in Place

BACKGROUND

Across the country, including the state of California, people with a serious illness or nearing the end of life often experience unnecessary suffering, including receiving care that is not consistent with their wishes or values.



Fortunately, there are two interventions designed to improve care for people in these circumstances: palliative care and advance care planning.



What is Palliative Care?

Palliative care (PC) is specialized medical care for people living with serious illness. It is focused on providing relief from the symptoms and stress of the illness. The goal of PC is to improve quality of life for both patients and their loved ones. It is provided by a specialty trained team of doctors, nurses, social workers, spiritual care providers, and others who work together with a patient's other doctors to provide an extra layer of support based on the needs of the patient. It is appropriate at any age and at any stage in a serious illness. Moreover, it can be provided alongside curative treatment.²



What is Advance Care Planning?

Advance care planning (ACP) is a process that supports adults at any age or stage of health in better understanding, documenting, and sharing their personal values, life goals, and preferences regarding medical care. ACP fills a critical gap by preparing patients for medical decision-making to help ensure they receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness.³

However, access to these interventions is limited. According to a study by the California Health Care Foundation (CHCF), only 40% of those with a serious illness said they had received palliative care, and only 34% said they had any of their wishes for desired treatment in a written document.⁴

Accessing palliative care and advance care planning is even more challenging for people of color and those who have a lower income. The same CHCF study found that Black, Hispanic, and Asian/Pacific Islander residents, as well as people with low incomes, are all less likely to have talked to a decision-maker or documented their desires for medical care at the end of life than white peers. Black, Hispanic, and low-income Californians are also more likely to have felt judgment or discrimination because of their race, income, or ethnicity. Black, Hispanic, Asian/Pacific Islander, and low-income Californians have a lower level of trust in health care providers than white residents as well.

Table One: Racial and Income Disparities: Engagement in Advance Care Planning and Provider Trust

	White	Black	Asian/ Pacific Islander	Hispanic	<150% Federal Poverty Level
Have not talked with a decision maker about the kind of medical care they would want at the end of life	56%	62%	70%	NA	62%
Have not documented wishes for medical treatment at the end of life	58%	68%	NA	76%	74%
Have felt judgment or discrimination from providers	14%	37%	15%	22%	32%
Have a lot of trust in providers	49%	39%	33%	32%	34%

Source: [Help Wanted: Californians’ Views and Experiences of Serious Illness and End-of-Life Care](#). California Health Care Foundation, October 2019.

While many barriers exist to the adoption of palliative care (PC) and advance care planning (ACP) throughout the country, such as general lack of awareness and lingering misperceptions of these services (for example, confusing palliative care with hospice), these barriers are especially pronounced in communities of color. These communities also face the following challenges:

- Poor provider communications, especially when talking to patients whose race/ethnicity is different than their own
- Unaddressed explicit and implicit bias between providers and patients
- Individuals’ lack of trust in the medical system, rooted in systemic racism
- Lack of trusted sources of information about PC and ACP
- Lack of consistent and equitable access to quality medical care

While we have some knowledge about certain barriers, there is still limited understanding of how to effectively overcome them, and often, communities are excluded from the dialogue

aimed at finding solutions. With the generous support of the Stupski Foundation, Hellman Foundation, and the San Francisco Department of Disability and Aging Services, the PCWG initiated community-led Learning Journeys. These journeys were undertaken to assess the current level of ACP awareness and adoption within San Francisco's Black, Chinese, and Latino/a/x communities. The aim was to identify culturally appropriate methods for increasing ACP participation through specific tools and activities.

Local community members were responsible for designing and executing these Learning Journeys, thereby enhancing our understanding of the unique local obstacles to ACP and fostering an environment conducive to community-driven tools and solutions. While the PCWG's overarching mission also includes promoting education about and acceptance of PC, the PCWG and our community partners made a strategic decision to concentrate solely on ACP for this initial Learning Journey to effectively allocate our resources.

Learning Journeys Overview

The Learning Journeys represented a collaborative, introspective, and systematic exploration in which community members and researchers worked together to identify strategies for overcoming ACP barriers and jointly developed educational initiatives to inspire people of color to actively participate in ACP. These community-led workgroups designed well-received events that increased ACP engagement over a relatively short period. Their objectives encompassed both implementing pilot events as part of the Learning Journey and inspiring their communities to build on the insights and pilot programs to sustain these efforts in the future. For instance, one local group, Self-Help for the Elderly, has incorporated the ACP engagement activity developed by the Chinese Work Group into their ongoing programs.

If ACP engagement events are widely adopted on a larger scale, it has the potential to significantly increase advance care planning within San Francisco's communities of color. This, in turn, could lead to a substantial increase in individuals from these communities receiving healthcare that aligns with their wishes and values, while also easing the burden of decision making on family members and caregivers.

LEARNING JOURNEY GOALS

The goals of the Learning Journeys were to:

- Understand the level of awareness and knowledge of advance care planning (ACP) within communities
- Listen and learn effective methods to inspire people to participate in ACP
- Foster deeper relationships with individuals in the community
- Develop culturally appropriate language, tools, and activities for ACP
- Test and refine acquired insights to facilitate future implementation
- Pilot workshops that, if successful, can be sustained over the years

LEARNING JOURNEYS STRUCTURE

The Learning Journeys were structured around three communities: Black, Chinese, and Latino/a/x. Each Community Work Group was staffed by a volunteer Work Group Lead, a Community Ambassador, and multiple volunteer Work Group members.

Community Ambassadors were recruited based on their strong connection to these communities, outreach capacity, and experience with community engagement and/or ACP. Committee members with deep community roots and extensive connections were invited to participate. Work Group Leads emerged from each group and received a modest stipend to work closely with the Community Ambassadors and help them lead the work of the committees.

A Program Manager and ACP experts supported the Learning Journey Work Groups, providing guidance and assistance during the process. The Program Manager and Community Ambassadors received a consulting fee, while the Work Group leads received an honorary stipend.

PCWG Steering Committee				
Program Manager	Black Community Engagement	Chinese Community Engagement Work Group	Work Group Latino/a/x Community Engagement Work Group	ACP, PC Experts & Evaluator
	Work Group Lead	Work Group Leads	Work Group Leads	
	Community Ambassador	Community Ambassador	Community Ambassador	
	Work Group Members	Work Group Members	Work Group Members	

LEARNING JOURNEYS TIMELINE AND PHASES

The Learning Journeys took place over a one-year period, between 2020 and 2021, during the height of the COVID-19 pandemic. Consequently, much of the work was conducted via Zoom, while some events were held outdoors or at trusted venues where people already gathered.

Four key phases helped to deepen the PCWG’s learnings:



During each phase, the Workgroups integrated the learnings and ultimately used them to design and implement the community engagement pilots.

SUMMARY OF KEY LEARNINGS

1 | A community-led learning process is not only feasible but also capable of eliciting interest, engagement, and action.

Over a one-year period, approximately 550 individuals from across San Francisco were engaged in learning how to facilitate advance care planning (ACP) within three communities of color. Three papers about the Learning Journeys, including the feasibility of a community-led process, have been published in peer-reviewed journals.

[“We’ve Got to Bring Information to Where People Are Comfortable”: Community-Based Advance Care Planning with the Black Community, Journal of General Internal Medicine.](#)⁵

[“Advocating for what we need”: A CBPR approach to advance care planning in the Latinx older adult community, Journal of the American Geriatrics Society.](#)⁶

[“At the end I have a say”: Engaging the Chinese Community in Advance Care Planning. Journal of Pain and Symptom Management.](#)⁷

2 | While approximately half of the people surveyed had heard about ACP, only one-third had actively engaged in ACP.

Community Member Survey Responses

Black Community	Chinese Community	Latino/a/x Community
<p>Action</p> <p> 33% have an advance care plan</p> <p>Awareness</p> <p> 60% had heard of ACP</p>	<p>Action</p> <p> 32% have a designated surrogate decision maker</p> <p>Awareness</p> <p> 50% of elders (>60) reported having heard about ACP</p>	<p>Awareness</p> <p> 31% had heard of ACP⁸</p>

3 | Co-developed community events represent a promising approach to fostering awareness and trust in ACP.

The key intervention that was tested—community-led education and engagement activities—can effectively create awareness and trust in ACP. Co-developed community events drew more than 400 people and led to increased ACP engagement. In two of the three communities, these results were clinically and statistically significant.

Summary of Outcomes from Community Engagement Activities

Black Community	Chinese Community	Latino/a/x Community
114 Attended	195 Attended	97 Attended
<p>ACP Engagement Score increased from 2.90 (SD 1.1) to 3.21 (SD 1.0), although not significantly (P=0.3).</p> <ul style="list-style-type: none"> 96% felt comfortable attending the events 98% would recommend the events to others 	<p>ACP Engagement Score increased from 1.7 (SD 0.84) to 2.03 (SD 0.85); P<0.0001 (clinically and statically significant).</p> <ul style="list-style-type: none"> 94% felt comfortable attending the events 96% would recommend the events to others 	<p>Overall ACP Engagement Score increased significantly (2.62 (SD 0.97) to 2.95 (SD 0.93); p = 0.05) (clinically and statically significant).</p> <p>Readiness to document wishes increased significantly (2.44 (SD 1.0) to 2.98 (SD 0.95); p = 0.003) (clinically and statically significant).</p> <ul style="list-style-type: none"> 85% felt comfortable attending the events 90% would recommend the events to others

4 | There are existing ACP tools that are linguistically and culturally tailored, and appropriate for use.

There are numerous websites and tools that support ACP, some of which are multilingual. However, only a few of them were developed with a cultural lens. Several multilingual and/or culturally tailored tools were identified and used in events throughout the Learning Journeys. These tools are listed in the table below.

ACP TOOLS IDENTIFIED BY THE COMMUNITY AND USED IN ACTIVITIES

	Black Community	Chinese Community	Latino/a/x Community
Conversation starters		Heart to Heart (adapted from Go Wish)	Go Wish
Tools to support all steps required for high-quality ACP	Alameda County Care Alliance Care Planning Workbook		PREPARE for Your Care
Advance Directives	PREPARE Advance Directives Alameda County Care Alliance Care Planning Workbook	PREPARE Advance Directives	PREPARE Advance Directives Five Wishes

5 | Despite the availability of some culturally and linguistically tailored ACP tools, communities still felt the need to create new culturally specific materials and activities to enhance relevance and foster engagement in ACP.









Local teams recognized the importance of developing additional culturally specific assets to introduce ACP and enhance its relevance. They created a variety of conversation starters to address the lack of familiarity or comfort in discussing ACP. They also integrated culturally-familiar visuals to bring local authenticity, relevance, and significance to the topic. For instance, the Chinese Workgroup designed a new priming tool called “The Precious Blessings: The Conversation,” which was specifically tailored for initiating discussions with Cantonese-speaking older adults, as well as their children and grandchildren. “The Precious Blessings” tool is now being used by Self-Help for the Elderly in collaboration with Dignity Health and the Asian American Medical Group.

Additional examples of successful priming tools include:

- Culturally- and linguistically-specific visuals, such as the reference to Día de los Muertos for the Latino/a/x community.
- Speakers who have a shared lived experience and/or are experts in ACP.
- Peer-to-peer discussions.
- Intergenerational discussions.
- Games, such as Heart to Heart and Go Wish.
- Movies, such as Extremis, or an educational video clip in Cantonese featuring a well-known movie/TV star from Hong Kong (see link [here](#))

6 | Engaging in ACP as a way to help families, caregivers, and loved ones is a compelling message that resonates with all communities.

One of the key learnings from focus groups across all communities is the notion that participating in ACP can foster unity and strength for families and loved ones, ultimately reducing family burden. Moreover, the idea that engaging in ACP can empower individuals with distrust of the healthcare system was found to be particularly compelling for the Black and Latino/a/x communities.

Perceived value of ACP	Black Community	Chinese Community	Latino/a/x Community
ACP unifies and strengthens families			
ACP reduces stress and tension within families			
ACP provides agency and upholds the wishes of those who lack trust in health care systems or personal networks			

7 | Similar strategies to engage people in ACP were identified across communities.

Four strategies to increase engagement in ACP were recognized by all three community groups:

- 1 holding events in trusted places
- 2 connecting to culture
- 3 providing skill-building in how to start conversations
- 4 fostering peer-to-peer learning and sharing

Additionally, the Black community identified financial planning as a critical aspect of ACP, while both the Black and Latino/a/x communities stressed the importance of tailoring events to specific sub-populations. The Chinese and Latino/a/x populations emphasized the significance of hosting intergenerational events and activities. Incorporating these principles will be crucial for driving future ACP engagement.

Facilitators to ACP	Black Community	Chinese Community	Latino/a/x Community
Hold events in trusted spaces, led by trusted community leaders	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Connect to aspects of culture	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Provide skill-building in how to start an ACP conversation with loved ones and doctors	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Peer-to-peer sharing and learning	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Enable intergenerational conversations	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Weave together financial planning and economic empowerment as part of ACP	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sub-populations, including LGBTQI+ and immigrant populations, may have different needs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

8 | None of these communities are monolithic.

Attitudes and priorities regarding ACP are influenced by various factors such as immigration status, generation, home country or region, religion, sexual preference, gender identity, and economic status. The working groups stressed that even within their communities, varied forms of targeted education and outreach are needed to effectively reach these different constituencies.

LEARNINGS BY COMMUNITY

BLACK COMMUNITY WORK GROUP SUMMARY OF KEY LEARNINGS

CURRENT LEVEL OF AWARENESS AND ENGAGEMENT

While 60% of Black community members have heard of ACP, only 33% have participated in some form of ACP



60% have heard of advance care planning

33% have an advance care plan

RECOMMENDATIONS FOR DESCRIBING THE VALUE OF ACP



Unifies and strengthens families



Provides agency and economic empowerment



Upholds the wishes of those who lack trust in health care systems

“In our community, we take care of each other because we have been left out of a lot of things. Insurances have ripped us off. So here again we’re talking about intergenerational wealth and social economic gains and disparities.

—Older Adult

RECOMMENDATIONS FOR DESIGNING COMMUNITY ENGAGEMENT ACTIVITIES

- Hold events in trusted spaces such as churches, senior centers, and local Black-owned businesses
- Events should be led by trusted community leaders
- Make time for peer-to-peer and/or intergenerational discussion
- Be mindful of historical trauma when bringing up illness, sudden injury, and death
- Weave in financial planning as it is seen as a critical component of ACP for Black San Franciscan's who are at risk of losing their homes due to a lack of proper estate planning
- Provide skill-building in how to start an ACP conversation with loved ones and clinicians
- Use PREPARE Advance Directives or the Alameda County Care Alliance Care Planning Workbook

Small Black businesses can host these intimate working and informational exchange groups. It is effective [...] and we have to put [information] in places where we know people will come. [...] That's who we are as a race.

—Community Leader

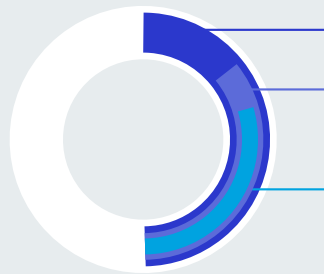
This is about family and making it easy for whoever needs care.

—Older adult

CHINESE COMMUNITY WORK GROUP SUMMARY OF KEY LEARNINGS

CURRENT LEVEL OF AWARENESS AND ENGAGEMENT

While half of Chinese elders have heard of ACP, only 33% have participated in some form of ACP



50% of elders (>60) have heard of ACP

32% have a designated surrogate decision maker

80% of those who have a designated surrogate decision maker have discussed their values and preferences with their decision maker

RECOMMENDATIONS FOR DESCRIBING THE VALUE OF ACP



ACP unifies and strengthens families



ACP reduces family burden through providing surrogate decision makers guidance on decision-making

It should start from the younger people, to let [them] know about it and understand if they should prepare for their parents.

—Caregiver

RECOMMENDATIONS FOR DESIGNING COMMUNITY ENGAGEMENT ACTIVITIES

- Hold events in trusted places
- Tie activities to Chinese culture
- Use conversation starters
 - » Dialogue with people who have a shared lived experience and/or are experts in ACP
 - » Games such as Heart to Heart
 - » Video clips produced for a Cantonese-speaking target audience from Canton or Hong Kong, where most of the Chinese population in San Francisco originated. [See link here.](#)
 - » Conversation starters such as “The Precious Blessings” tool
- Make time for conversations
 - » Include peer-to-peer and/or intergenerational discussion
- Build skills
 - » Presentations from experts in ACP
 - » Guidance on how to start conversations with children/grandchildren, parents/grandparents, and doctors
 - » Orientation to PREPARE Advance Directive

R-was right about peer pressure, especially for seniors. When they hear “this person my age, my SRO neighbor, if he has done it, it must be a good thing, this will reduce their resistance.

—Community Leader

They might want to get prepared because they don’t want the family to worry about it.

—Older Adult

LATINO/A/X COMMUNITY WORK GROUP SUMMARY OF KEY LEARNINGS

RECOMMENDATIONS FOR DESCRIBING THE VALUE OF ACP



ACP reduces family burden through providing surrogate decision makers guidance on decision-making



ACP allows advocacy for oneself or loved ones; partially to overcome mistrust in the healthcare system

“ [...] if I leave something in writing, well my daughter will have more courage to be able to do what’s written. She’ll feel like, I believe she’ll feel protected, or that she’s fulfilling [my wishes].

—Older Adult

“ Giving the seniors information or some type of guide to provide their children would help facilitate the conversation.

—Community Leader

RECOMMENDATIONS FOR DESIGNING COMMUNITY ENGAGEMENT ACTIVITIES

- Incorporate trusted community spaces and culturally imagery
- Connect to culture through “deseos” or Día de los Muertos
- Include intergenerational discussion
- Include peer sharing and storytelling
- Redefine family for LGBTQ seniors; it does not need to be blood family
- Build skills
 - » Presentations from experts in ACP
 - » Guidance on how to start conversations with children, parents, and doctors
 - » Orientation to PREPARE Advance Directive

For LGBT seniors you know that we have a different sense of what family is to us, it may not be blood family.

—Community Leader

It’s also about empowering and advocating for what we need.

—Community Leader

Idon’t know how to talk with my children, [...] they are in denial.

—Older Adult

People at the senior center [...] maybe they don’t trust everyone there - but there’s an established sense of trust, about the space, and the people.

—Community Leader

LEARNINGS BY PHASE

LEARNING JOURNEY PHASES



PHASE 1

COMMUNITY LEADER INTERVIEWS & ASSET MAPPING

There were two key goals of the first phase: to hear firsthand the specific barriers and facilitators to ACP and to identify the culturally appropriate tools or activities that were already being used in the community. To accomplish these goals, the Program Manager and Ambassadors conducted interviews with 59 different community leaders and reviewed available ACP resources.

INTERVIEWEE COMPOSITION: LEADERS FROM DIVERSE ORGANIZATIONS

33	Community-Based Organization
12	Health Care
4	Faith-Based Organizations
4	Business
3	Government & Education
2	Law Firms

INITIAL LEARNINGS ABOUT ENABLERS AND FACILITATORS OF ACP

The first phase of community interviews unearthed considerations and recommendations for engaging people in ACP across all three communities. These themes expanded and deepened during additional phases of the Learning Journey.

Considerations:

- Intergenerational factors are important across all communities – whether in messaging about reducing familial burden, providing better financial sustainability for younger generations, or challenges vocalizing end-of-life needs with a younger generation
- None of these communities are monolithic – immigration status and generation, home country or region, religion, sexual preference, gender identity and economic status all impact attitudes and priorities regarding advance care planning

Recommendations:

- Find leaders outside the medical establishment to open the conversation (e.g., faith-based organizations, etc.)
- Partner with organizations with strong trust in community
- Host events at culturally appropriate venues
- Honor cultural and language patterns regarding how illness and death are discussed
- Be mindful of historical trauma when bringing up illness, sudden injury, and death.

CULTURALLY APPROPRIATE TOOLS AND ACTIVITIES IDENTIFIED THROUGH ASSET MAPPING

There are many websites and tools to support ACP, some of which are multilingual. However, there were only a few identified during this phase that were developed with a cultural lens. The tools that are multilingual and/or developed with a cultural lens were used in events throughout the Learning Journeys, as shown in the table below.

	Black Community	Chinese Community	Latino/a/x Community
Conversation starters	Hello	Heart to Heart (adapted from Go Wish)	Go Wish
Tools to support all steps required for high-quality ACP	Alameda County Care Alliance Care Planning Workbook The African American Spiritual and Ethical Guide to End-of-Life Care PREPARE for Your Care		PREPARE for Your Care
Advance Directives	PREPARE Advance Directives Alameda County Care Alliance Care Planning Workbook	PREPARE Advance Directives	PREPARE Advance Directives

**PHASE
2**

COMMUNITY MEMBER SURVEYS

In addition to talking to community leaders who represented the Black, Chinese, and Latino/a/x communities, the PCWG also wanted to learn from community members about their current level of engagement with ACP and potential barriers or facilitators to ACP. Surveys were developed within each community based on what each committee thought would provide the most important insights. The survey questions were different for each community. The Latino/a/x survey ended up reaching individuals who were not part of the target population, with only one third of respondents identifying as Latino/a/x. Therefore, the results of that survey were not used for population-specific learnings.

According to the survey results, while roughly half of people surveyed had heard about ACP, only one third of Black and Chinese community members had engaged in at least some aspect of ACP (identifying a decision maker or completing an advance directive).

Community Member Survey Responses

	Black Community	Chinese Community	Latino/a/x Community
Respondents	66 Respondents 74% were Black/African American 39% were 65+	229 Respondents 100% were Chinese 79% female, 21% male Range of ages, education levels, and employment status	Of the 58 Respondents, only 13 were Latino/a/x; responses included for Latino/a/x population only 92% female
Engagement	60% had heard of ACP 33% have an advance care plan 50% who have heard of ACP have completed an advance care plan	50% of elders (>60) reported having heard about ACP 32% have a designated surrogate decision maker 80% of those who have a designated decision maker have discussed their values and preferences with their decision maker	31% had heard of ACP
Barriers/Enablers	58% of people 65+ learn about events from online source	33% uncertain on how to discuss ACP with loved ones 30% believe the “eleventh hour” is a good time to discuss ACP	23% are unfamiliar with ACP 23% don’t know how to discuss ACP

**PHASE
3**

FOCUS GROUPS

Ambassadors collaborated with researchers to develop the focus group protocol and questions, aiming to gain insight into the motivators for ACP usage. The goal was to understand how to overcome barriers and utilize community facilitators to ACP participation, as well as identify the types of activities that would engage communities in ACP. The ambassadors conducted six focus groups per community, for a total of 18 focus groups that reached 91 people. In the Chinese community, five out of six focus groups were conducted in Cantonese, and in the Latino/a/x community, three out of six were conducted in Spanish. Participants were recruited through each Workgroup using email and word-of-mouth outreach.

The PCWG Workgroup partnered with Sarah Nouri, MD, MPH, at UCSF. Dr. Nouri is an Assistant Professor in the Division of Palliative Medicine who studies equity in access to palliative care among racially, ethnically, and socioeconomically diverse populations. Dr. Nouri partnered with each Workgroup to develop a semi-structured focus group interview guide and analyze the focus group data.

Focus Group Participants

Populations	Black Community	Chinese Community	Latino/a/x Community
Caregivers	11	12	8
55+ and those with serious illness	9	11	10
Community-based leaders	9	11	10
Total focus group participants	29	34	28

CROSS-CUTTING THEMES AND PREVALENCE

While the examples and stories provided by each group differed, there were some consistent themes and beliefs.

	Black Community	Chinese Community	Latino/a/x Community
Perceived value of ACP			
ACP unifies and strengthens families	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
ACP reduces stress and tension within families	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
ACP provides agency and upholds the wishes of those who lack trust in health care systems or personal networks	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Facilitators to ACP			
Hold events in trusted spaces, led by trusted community leaders	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Connect to aspects of culture	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Provide skill-building in how to start an ACP conversation with loved ones and doctors	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Peer-to-peer sharing and learning	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Encourage conversations between parents, children, and grandchildren		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Weave together financial planning and economic empowerment as part of ACP	<input checked="" type="checkbox"/>		
LGBTQI+ and immigrant populations may have different needs	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>

Black Community Focus Group Learnings

PERCEIVED IMPORTANCE OF ACP

1. ACP unifies and strengthens families.

“This is about family and making it easy for whoever needs care”

—Older Adult

2. ACP provides agency and upholds the wishes of those who lack trust in healthcare systems or personal networks (e.g., people who are minoritized within the community based on race, sexual orientation, or gender identity) or who face competing priorities for survival and well-being (e.g., young Black men). Participants highlighted the critical role of ACP as a tool for agency among Black people identifying as transgender, since mistrust in both the healthcare system and biological family raised concerns among this population that their wishes would not be honored at death.

FACILITATORS OF ACP

1. Hold events in trusted spaces, led by trusted community leaders. Notably, trusted community spaces and leaders included not only social service organizations but also small Black-owned businesses where people gather, such as restaurants.

2. Provide skill-building in how to start an ACP conversation with loved ones and clinicians.

“I know trans women who were buried as men. So having [...] someone know that if you die, your wishes will be followed”

—Community Leader

“Young African-American males, they’re living day to day [...] They may not have anybody, they might just be out there hustling or whatever on the street [...] My clients, they got so much other intergenerational trauma and so much trauma from the community, the Black on Black to White on Black, the policy brutality [...]”

—Leader

“Small Black businesses can host these intimate working and informational exchange groups. It is effective [...] and we have to put [information] in places where we know people will come. [...] That’s who we are as a race”

—Community Leader

3. Include financial planning, which is viewed as a critical component of ACP because it preserves dignity and intergenerational wealth.

“In our community, we take care of each other because we have been left out of a lot of things. Insurances have ripped us off. So here again we’re talking about intergenerational wealth and social economic gains and disparities”

—Older Adult

Chinese Community Focus Group Learnings

PERCEIVED VALUE OF ACP

1. ACP reduces family burden and helps guide surrogates in decision-making.

“They might want to get prepared because they don’t want the family to worry about it”

—Caregiver

FACILITATORS OF ACP

1. Connect to cultural traditions such as the Five Blessings.

“It should start from the younger people, to let [them] know about it and understand if they should prepare for their parents.”

—(Caregiver)

“I think besides the senior [events] should also target their children. Because sometimes they will just use the excuse to talk to their children first. But their children might not understand what it is when they talk about it.”

—Caregiver

2. Provide supportive environments and tools to help older and younger generations have discussions about ACP. Chinese elders are not eager to discuss serious illness and end-of-life care with their adult children. Alternatively, adult children are motivated to figure out how to start the conversation with their elders, but lack the tools or strategies for how to introduce the topic of ACP.

“My grandmother is 100 years old. She is really healthy and [her children] all mentioned [ACP]. But as her granddaughter I don’t think it is appropriate for us to bring up this topic. Just like you said seniors don’t want to talk about this topic.”

—Caregiver

3. Support people in beginning conversations with doctors.

“My dad didn’t hear about it even after he had a stroke. No one mentioned it to him and he didn’t know where to find such information.”

—Older Adult

4. Take advantage of peer influence and peer-to-peer learning. Chinese elders prefer to discuss advance care planning issues with peers first, to learn their opinions generally, before discussing with family. They are also more likely to engage in ACP if someone else in their community has already done so.

“R-was right about peer pressure, especially for seniors. When they hear “this person my age, my SRO neighbor, if he has done it, it must be a good thing, this will reduce their resistance.”

—Leader

5. Almost 100% said that movies inspire conversation and that a card game would be a good way to have the conversation.

Latino/a/x Community Focus Group Learning

PERCEIVED VALUE OF ACP

1. Reduces family burden through providing surrogate decision-makers with guidance on decision-making.

“[...] if I leave something in writing, well my daughter will have more courage to be able to do what’s written. She’ll feel like, I believe she’ll feel protected, or that she’s fulfilling [my wishes].”

—Older Adult

2. ACP allows advocacy for oneself or loved ones, partly to overcome mistrust in the healthcare system.

“For those low-income communities, it’s hard to really trust, you know, put basically your life to a provider.”

—Leader

“It’s also about empowering and advocating for what we need.”

—(Leader)

FACILITATORS OF ACP

1. Incorporate trusted community spaces

“People at the senior center [...] maybe they don’t trust everyone there - but there’s an established sense of trust, about the space, and the people.”

—Leader

2. It is important to connect to culture. For example, language should frame ACP as “deseos” or “wishes.”

3. Support people in beginning conversations with children.

“I don’t know how to talk with my children, [...] they are in denial.”

—Older Adult

“Giving the seniors information or some type of guide to provide their children would help facilitate the conversation.”

—Leader

4. Peer sharing and storytelling is powerful and engaging for all Latino/a/x community members.

5. LGBTQI+ and immigrant populations may have different needs regarding ACP.

“For LGBT seniors you know that we have a different sense of what family is to us, it may not be blood family.”

—Leader

PHASE 4 COMMUNITY ENGAGEMENT PILOTS

The specific goal of this phase was to learn whether the community engagement activities increased the likelihood that someone would engage in ACP and what could be done differently to increase engagement in the future. Each Workgroup developed a different strategy for designing and piloting the community engagement activities based on their learnings from prior phases of the Learning Journey. There were approximately 4-6 events per community, with settings ranging from churches to community centers, restaurants, and senior centers, each with its own flavor, audience, and messaging.

The PCWG also partnered with Sarah Nouri, MD, MPH at UCSF to evaluate the pilots. Dr. Nouri used a modified version of a validated ACP Engagement Survey and a process that included pre- and post-surveys. The validated ACP Engagement Survey is scored from 1-5, but due to concerns from the Community Ambassador and Workgroup Leader in the Chinese community that people tend to choose a neutral response when presented with an odd number of options, the survey was modified to only include 4 response options (scored from 1-4, with 4 being the most ready). The Black community and Latino/a/x community Ambassadors and Work Group Leaders opted to make the same change for consistency.

The survey assessed readiness to:

- Talk to surrogates about care preferences
- Designate surrogates in writing
- Talk to doctors about care preferences
- Write down wishes regarding care preferences

The survey also included questions about demographics, participants' comfort level attending the event, and likelihood that they would recommend attending the event to others.



BLACK COMMUNITY ENGAGEMENT EVENTS

The Black Community Workgroup issued a Request for Proposal (RFP) to community members and leaders to design community engagement programs. The RFP offered training on ACP and serious illness communication, as well as a \$2,000 stipend to be used to develop their own ACP event. As a result, they created diverse programs ranging from citywide hikes to activities at local churches.

Events were tailored to the preferences of each organization. Based on original survey and focus group findings, all events were held in trusted spaces, framed ACP in terms of dignity and agency, and aimed to achieve cultural relevance through testimonials by community members and incentives such as meals catered by Black-owned restaurants.

Agency	Population	Location	Activities
Curry Senior Center	Seniors	Curry Senior Center Cadillac Hotel (Single-Residence Occupancy)	Testimonials by event facilitators followed by open discussion with participants; review of advance directive with opportunity to ask questions. Lunch and gift cards provided
Big+Black+Brunch	28-60	Hiking in SF	Urban hike followed by presentation and discussion about ACP led by local palliative care nurse. Healthy lunch was provided by a local Black-owned business
Third Baptist Church of San Francisco	Church Members	Third Baptist Church of San Francisco	Movie screening (Extremis) and discussion with testimonials facilitated by the church's health/wellness minister and local palliative care nurse. Raffle with cash prize included
Jones Memorial United Methodist Church	Church Members	Jones Memorial United Methodist Church	Testimonials by church congregants; ACP presentation and discussion by local palliative care chaplain who is also a congregant. Coffee, food, and gift cards provided
Alameda County Care Alliance	Church Members	Greater Life Church	Testimonial by a community member, prayer by a reverend, and information about ACCA's Advanced Illness Care Program by health care navigator. Included hot lunch and Target gift cards for participants

Black Community Work Group Pilot Outcomes

The ACP engagement score increased from 2.9 to 3.2, although this was not a clinically or statistically significant change.

Reach and Demographics	
Attendance	114
Age, average (range)	57 (12-88)
Race/Ethnicity, %	
Black or African American	74
Hispanic or Latino/a/x	10
Language at home	
English	83
Spanish	7
Gender, %	
Woman	54
Man	41
Non-binary	2
Sexual orientation, %	
Heterosexual	83
Bisexual/Pansexual	3
Gay/lesbian	4

Outcomes
<ul style="list-style-type: none">• ACP Engagement Score increased from 2.90 (SD 1.1) to 3.21 (SD 1.0), although not significantly (P=0.3).• 96% felt comfortable attending the events• 98% would recommend the events to others

Black Community Work Group Pilot Learnings

- Financial planning should be part of ACP.
- Black-owned businesses are trusted spaces for ACP-related discussions.
- Participants reported coming to events because they were invited or informed about events by trusted people like neighbors.
- Participants appreciated learning more information and described events as “inspirational” and “encouraging”.
- Organizations felt testimonials, peer-to-peer sharing of stories, and culturally competent ACP or palliative care experts were key to events’ success and specifically to building trust.
- Professional ACP trainers with cultural competency are important to dispel misinformation and provide trustworthy guidance.
- Incentives such as food, gift cards, and additional resources related to health care and adventures (such as secret hikes) are motivators to participate.



CHINESE COMMUNITY ENGAGEMENT EVENTS

The Chinese Community Workgroup decided to design their own events, building upon the learnings from Chinese Workgroup discussions and the focus groups. The key themes that informed the design of the events included the importance of intergenerational connection, connection to culture, peer influence, and peer-to-peer learning.

Intergenerational events

The desire for intergenerational events stemmed from focus group findings and committee member input. Many committee members noted that some Chinese American elders do not talk with their children about their wishes even after completing an advance directive.

Connection to culture: "The Precious Blessing: The Conversation"

The Chinese Community Workgroup developed a new engagement conversation aid based on the Five Blessings, which is a millennia-year-old concept reflected upon by many families during the new year. One of the Five Blessings is kao zhong ming, or the desire to have a peaceful death in old age. The Committee developed this novel, culturally tailored ACP tool through an iterative process with community members and by drawing on their personal and professional experiences working with Chinese elders.

"The Precious Blessings: The Conversation" takes the form of a pamphlet with questions for reflection and discussion about preparing for medical decision-making and for conversations that support surrogates for decision-making (Figure x). The pamphlet art features "Grandma Blessing," a happy, comfortable grandmother surrounded by her family, plants, and cat.

Peer influence and peer-to-peer learning

To help explain the importance of ACP, the Chinese Community Work Group found an existing movie about the importance of ACP featuring a well-known Hong Kong actor, Mr. Chow Chung. In addition, peer-to-peer learning was a key part of follow up conversations using **"The Precious Blessing: The Conversation"** tool.

Chinese Community Work Group Events

Agency	Location	# Events	Model (same for all)
Self Help for the Elderly	Senior Centers	4	<ul style="list-style-type: none"> • Intergenerational • Screening of a 6-minute video clip about the importance of ACP starring a well-known Hong Kong actor, Mr. Chow Chung • Facilitated group discussions using “The Precious Blessing- the Conversation” tool • Review of the PREPARE Advance Directive in Chinese (which was identified during the Asset Mapping) • Facilitated by the Chinese Community Ambassador who is an experienced ACP facilitator
Chinatown Community Development Corporation	Senior Housing (in person) SRO (streaming via zoom)	4	
Buddhist Center	Online	2	

Chinese Community Workgroup Pilot Outcomes

The ACP engagement score increased from 1.7 to 2.1, which is clinically and statistically significant.

Reach and Demographics	
Attendance	195
Age, average (range)	62 (14-103)
Race/Ethnicity, %	
Asian	98
Chinese speaking, %	96
Gender, %	
Woman	80
Man	20
Sexual orientation, %	
Heterosexual/Straight	94
Bisexual/Pansexual	4
Something Else	2

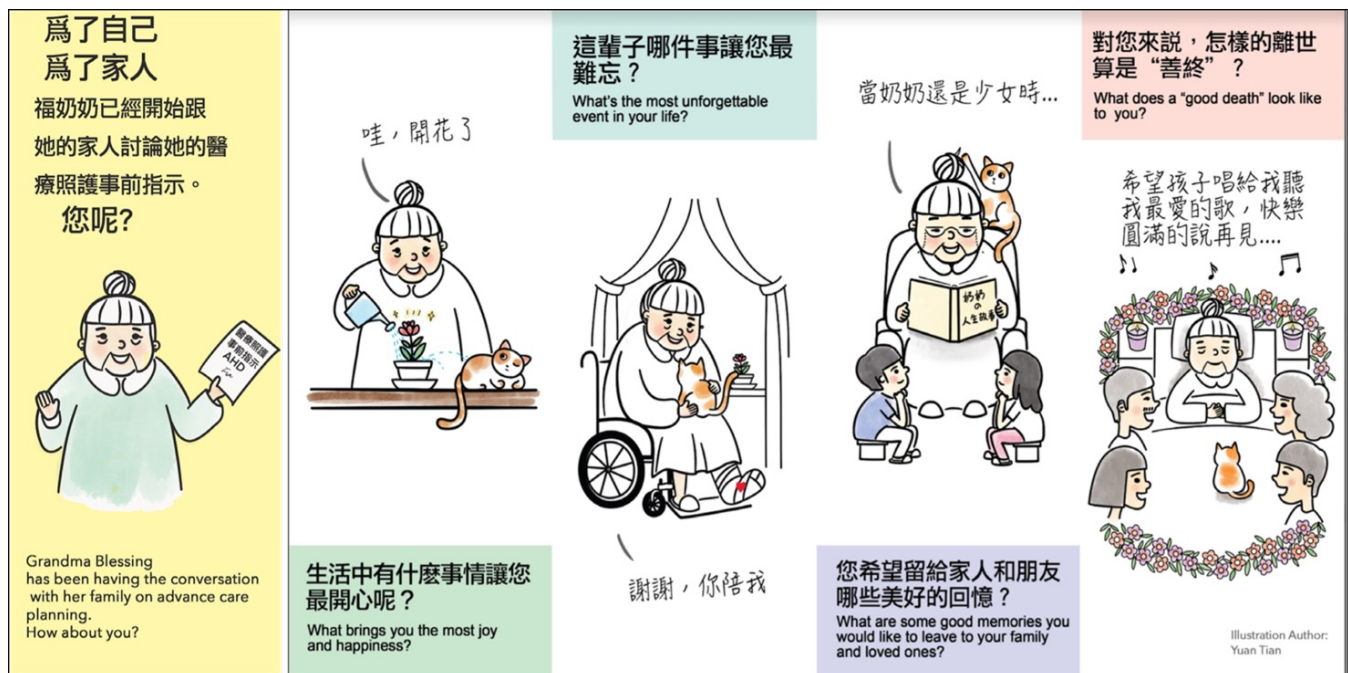
Outcomes
<ul style="list-style-type: none"> • ACP Engagement Score increased from 1.7 (SD 0.84) to 2.03 (SD 0.85); P<0.0001 (clinically and statically significant). Similar when stratified by in-person vs online events • 94% felt comfortable attending the events • 96% would recommend the events to others

Chinese Community Workgroup Pilot Learnings

- Participants loved sharing their personal stories. Several participants requested more time for dialogue and peer-to-peer sharing in future events.
- The “younger” elders in their 60s and 70s seemed to be the most engaged, while elders in their 90s and over 100 years old mostly expressed that they already had satisfying informal conversations with their children about their wishes. These “younger” elders were very curious about all aspects of ACP, asked many questions, and offered helpful comments to others.

- Participants’ reasons for attending events included curiosity, wanting to increase their knowledge about ACP, and wanting to plan for the future—for either themselves or their families.
- Participants liked learning more about ACP (an “unfamiliar” topic), and “sharing with other participants”; they described events as “a rich experience,” “clear,” and “useful.”
- While some participants noted that talking about death and therefore ACP is “uncomfortable,” they also expressed appreciation for the events as spaces to prepare for these “taboo topics.”
- Event facilitators shared that giving participants time to discuss ACP with their peers, reviewing the PREPARE advance directive, and using culturally appropriate materials such as the video testimonial were the most effective elements.
- Event facilitators noted that event evaluation in the form of surveys distracted from the event content, and was particularly cumbersome for the oldest participants, many of whom had literacy and visual challenges and required one-on-one support to complete the surveys.
- Gift cards motivated attendance and survey completion.

Figure 1: The Precious Blessings: The Conversation





LATINO/A/X COMMUNITY ENGAGEMENT EVENTS

The Latino/a/x Workgroup formed a Design Team to develop and implement ACP pilot events and build capacity with community partners. The Workgroup conducted outreach to community members through their own networks and focus group participants to recruit Design Team members. Potential designers applied for the opportunity and were selected based on their connection to the Latino/a/x community and experience with ACP. They underwent a 2-hour “train-

the-trainer” workshop led by an experienced palliative care nurse manager at a local community hospital. The workshop included watching the movie *Extremis*, engaging in discussions about “quality of life” and “a good death,” and reviewing ACP tools including *Go Wish* and *PREPARE for Your Care*. Each designer received a \$750 stipend to create, market, and host the event.

The Design Team members decided to facilitate the pilot events themselves, with support from the Community Ambassador and local ACP experts such as nurses, physicians, or attorneys, who were identified through the committee members’ networks. The key themes that informed the design of the events included the importance of ACP as means of advocacy and relief of family burden, and the importance of connecting to culture, including using culturally specific words like “deseos” or “wishes.”

The Latino/a/x Work Group commissioned Latinx artists to develop new artwork that was used throughout the outreach process and at the events. The art aimed to incorporate cultural imagery, including references to Día de los Muertos, and to highlight the community’s diversity by including graphic representations of LGBTQI+ families and people with disabilities.



Latino/a/x Community Work Group Events

Agency	Population	Location	Activities
On Lok	Seniors	30 th Street Senior Center	<ul style="list-style-type: none"> • Introduction to ACP • Go Wish • Testimonial by a community member • Step by step support in completing an advance directive • Latino/a/x food, music and art
Family Caregiver Alliance Calle 24 Latino Cultural District Healing and Social Change	Intergenerational	Mission Cultural Center for Latino Arts	<ul style="list-style-type: none"> • Video about how to start the conversation • Panel with a local doctor and an attorney presenting about the importance of ACP • Step by step support in completing an advance directive • Latino/a/x food, music and art
Aguilas	LGBTQI+	Aguilas (LGBT Center)	<ul style="list-style-type: none"> • Format included food and music, along with a very interactive agenda. • Event was structured around a series of questions and scenarios, with participants responding in writing (for themselves) and with one another in pairs and groups • Themes included Your Values, Conversations, Your Representatives. • At the end of the event, participants filled out their advance directive document and identified who they would speak to about being their surrogate
El/La Para TransLatinas	TransLatinas LGBTQI+	Regular meeting at TransLatinas and a private party at the host's home	<ul style="list-style-type: none"> • The first event was a presentation about the importance of ACP for Trans people in particular, and included discussion among participants; this conversation was recorded and viewed by over 800 people worldwide in the following weeks • The second was a "house party" where the host invited friends and acquaintances to enjoy homemade tamales, learn about ACP, and discuss end of life issues in an intimate setting

Latino/a/x Community Workgroup Pilot Outcomes

The ACP engagement score increased from 2.6 to 2.95, which were clinically and statistically significant.

Reach and Demographics	
Attendance	97
Age, average (range)	59 (16-87)
Race/Ethnicity, %	
Black or African American	4
Hispanic or Latino/a/x	86
Asian	8
Spanish-speaking %	55
Gender, %	
Woman	63
Man	34
Transgender	3
Sexual orientation, %	
Heterosexual	63
Bisexual/Pansexual	8
Gay/Lesbian	27
Something else	2

Outcomes
<ul style="list-style-type: none"> • Overall ACP Engagement Score increased from 2.62 (SD 0.97) to 2.95 (SD 0.93); P = 0.05 (clinically and statistically significant). • Readiness to document wishes increased from 2.44 (SD 1.0) to 2.98 (SD 0.95); p = 0.003 (clinically and statistically significant). • 85% felt comfortable attending the events • 90% would recommend the events to others

Latino/a/x Community Work Group Pilot Learnings

- Language is important—each group of designers landed on the language of “wishes” or “deseos,” which resonated with community members and was an inviting framework for the pilot events.
- Peer sharing and storytelling is powerful and engaging for all Latino/a/x community members; storytelling is a beloved practice used to pass on history, impart ancient wisdom, teach life lessons, and share family traditions, memories, and secrets.
- Death is part of daily life in many Indigenous and Latino/a/x cultures (e.g., Pan de Muerto, flor de muerto, altars in people’s homes, dreaming about and talking to the departed, along with songs, poems, books, and stories about death). Death is often seen as the backdrop of life—a diamond against a dark background shines the brightest.
- A known venue and trusted staff, along with the opportunity to reunite with friends for a conversation, provided incentive for people to participate.
- Bringing together all the elements of an event—venue, food, outreach, curriculum development, ACP expert coordination—is accomplished more easily by agency-embedded staff.

- While event content varied, event facilitators reported that games, testimonials, and experts (i.e., attorneys, doctors) were the most impactful aspects of the events, and that PREPARE for Your Care and Five Wishes were well received.
- Event facilitators believe that engagement would be highest if events were embedded into regularly scheduled gatherings by partner agencies.
- The \$750.00 stipend was not sufficient to cover the time and costs associated with the events.

NEXT STEPS

The Learning Journeys laid the groundwork for ongoing efforts in impactful community-based ACP within Chinese, Latino/a/x, and Black communities in San Francisco.

The next step is to integrate these key learnings into ongoing community engagement programs through continued collaboration with community partners.

Additionally, the PCWG will work towards increasing awareness and engagement with other aspects of serious illness care, including:

1

Building awareness of palliative care, its benefits, how it is different from hospice, and how to access it.

2

Empowering people to advocate for their preferences and needs within the healthcare system, particularly when encountering implicit or explicit bias.

3

Establishing connections to existing services, including caregiver support.

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