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Introduction

Palm Springs, California, is a retirement community with the highest prevalence of older people living with HIV (PLWHIV) in the nation



We obtained funding to engage the local stakeholder community (patients, caregivers, community-based organizations, providers, academics) around HIV and aging for future comparative effectiveness research.

Methods

Focus groups were 60-90 minutes in length and recorded for analysis. All participants received \$50

Following community based participatory research principles, study materials were created through a collaborative process involving the research team, which contained several older adults living with HIV, a 10-person steering committee of stakeholders, and a 10-person community advisory board of PLWHIV.

Participants were recruited using a study flyer distributed at community events, by word of mouth, and through our steering committee and community advisory board networks.

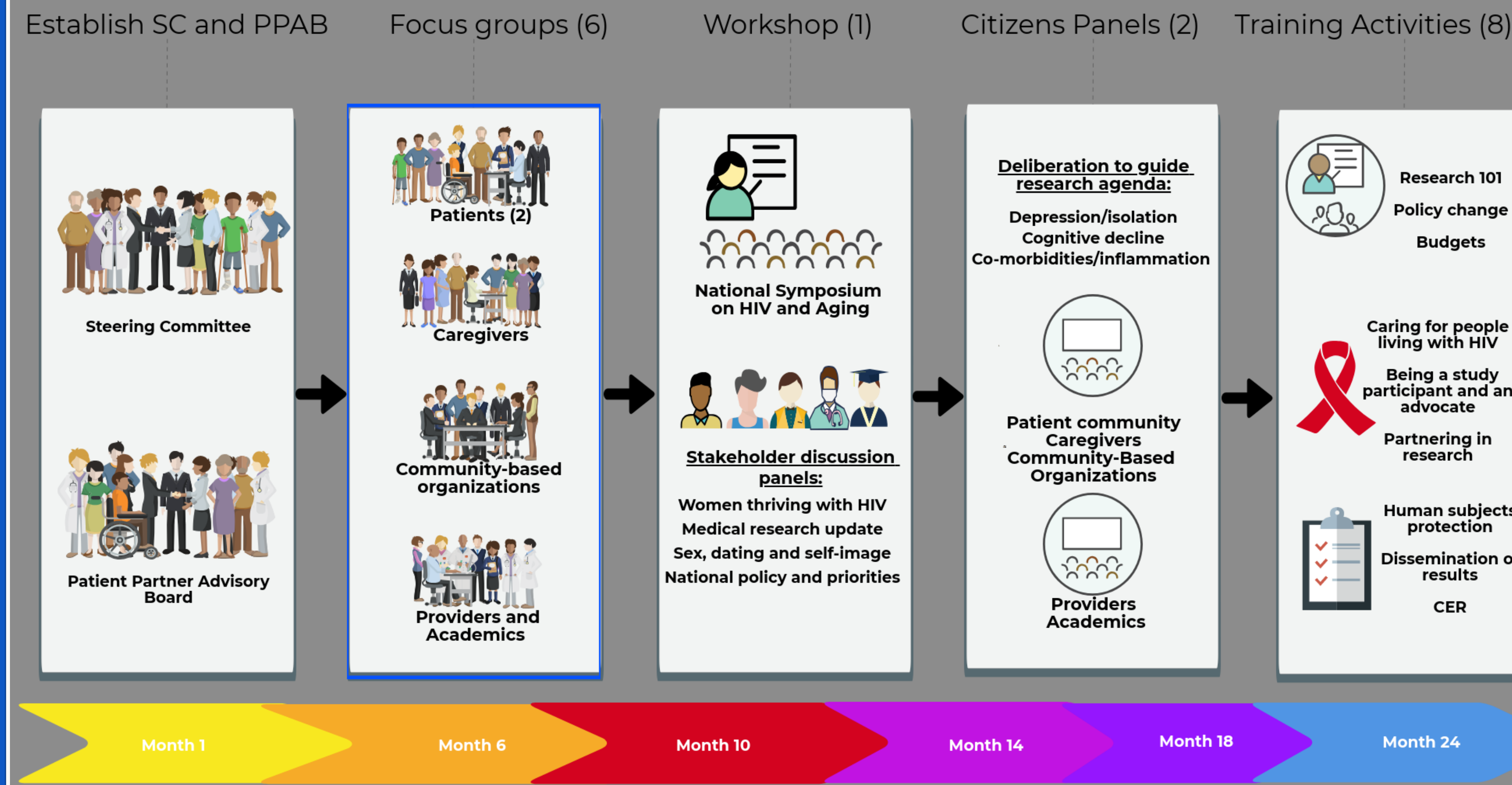
Results

Demographics of the 2 patient focus groups:

- 18 patients, all male, 77.8 % white, 22.2% Hispanic
- Mean age 64.8 (range 55-76)
- 66.7% completed college or attended graduate school.
- Exercise, community involvement, and pursuing hobbies were behaviors that participants identified as contributing to resiliency.
- In addition, a supportive community, including friends, competent medical care, and other forms of social support and resources were common themes.

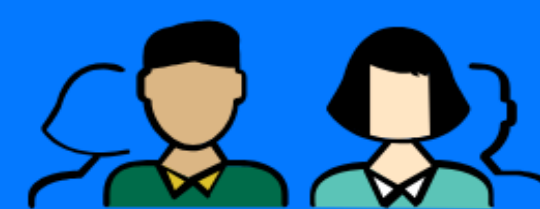
Results

Project Timeline



Stakeholders

Patients



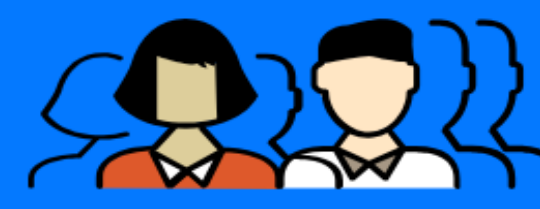
Pets: I just recently got a cat and it has really put me on a schedule. And a positive, more positive feeling. I'm not as depressed as I was. She makes me laugh. (54 Year old white male living with HIV)

Caregivers



Good Medical care: Here in Palm Springs area, I've found that it's been really good. I'm feel very glad that I was fortunate to be in LKA and gone to Borrego to their Stonewall Clinic...I felt very comfortable being there. But it would have been something else if—I went to another doctor...she was not great at all. I felt, like, stigmatized, I felt really bad about myself. I felt dirty, and they made me feel that way. So, there was a big difference in how they treated people and that made a difference in how I felt about myself. (57 year old hispanic male caregiver)

CBOs



Social support: Having many peers who have survived with or without HIV, so those social networks are absolutely resiliencies. They rely on each other understand each other, they find support with each other, they've had common experiences that they've gotten to share... Those are all forms of resiliencies that exist in the community. (58 year old white male CBO representative)

Providers /Academics



Health/ HIV education: They're very well health-educated in terms of 'what are the consequences' and knowing things like that, I mean, your average person doesn't know when to ask for an osteoporosis scan. You know, so I think that's definitely worth mentioning. (31 year old white female researcher)

Hobbies: For me, uh volunteer work and um I have a pretty big backyard so I've taken up some gardening and that's been very very helpful. And working in the front yard you meet all your neighbors walking by with their dogs. (66 year old white male living with HIV)

Exercise: Yes. So it's good cardio—good cardio workout but it's—you socialize. And you go to places like that and usually people are very friendly, especially at a dance—the people are happy and—because there's music. (69 year old hispanic male living with HIV)

Community: I think as we age, we need to make sure that we have at least a base of community. And if we don't, as we get older, I think it may be harder to find. (66 year old white male living with HIV)

Health/ HIV education: I have a lot of straight friends with health issues who are, they don't ask their doctors questions, they don't look anything up on the Internet, they take whatever's given to them. And the fact that we've been sort of trained to ask questions of our doctors...that's one of our resiliencies, that we've learned to be in charge of our health. (55 year old white male living with HIV)

Conclusions

- PLWHIV emphasized community, social support, good medical care, and pets as top resiliencies. Caregivers and CBO's agreed that social support and good medical care were important to healthy aging while living with HIV. Providers shared that health and HIV education were important resiliencies.
- PLWHIV discussed the important resiliencies, resources and behaviors that allow them to age healthfully with HIV.
- These results establish the importance of a focus on resiliencies rather than illness as people continue to live longer with HIV
- We are planning future patient focus groups which will include African-Americans, women, Trans people and the Deaf community to learn about their HIV and aging needs.

Acknowledgements



Steering Committee and Patient Partner Advisory Board

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