

HARP-PS

HIV & Aging Research Project Palm Springs

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PCORI

The Patient-Centered Outcomes Research Institute is a non-partisan, independent research sponsor federally funded through the Affordable Care Act. PCORI helps people make informed healthcare decisions, improving healthcare delivery and outcomes. They fund and promote evidence-based information from research guided by patients, caregivers, and the broader healthcare community. PCORI strives to make science accessible.

pcori.org

UC Riverside

The University of California Riverside School of Medicine was founded in 2013 as the first new public medical school west of the Mississippi in 50 years. Through its Center for Healthy Communities, UCR promotes research to improve the health of the culturally and economically diverse communities in Inland Southern California, especially those that are medically underserved.

Focus Groups

The first round of focus groups to determine our future research projects has been successfully completed. Members from five broadly-defined community subgroups were identified and invited to generate ideas, discussing specific topics relating to HIV & healthy aging. The questions were determined through discussion with the Stakeholders Steering Committee and the Patient Partner Advisory Committee. The groups were patients, caregivers, providers, academics, and community-based organizations. Questions, and the most frequent answers, are highlighted in the charts on page three.

HARP-PS will host additional citizens' panels to further discuss and refine the ideas produced in the first round. If you are interested in participating and were not part of one of the earlier groups, please contact Chris Christensen (sidebar).

Members of the Patient Partner Advisory Board





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Reunion Project 2.0

The Reunion Project was conceived as a way to gather community and provide useful current information for long-term survivors. It has been held in cities across the US, and well received.

For its second visit to Palm Springs, the Reunion Project 2.0 was sponsored and produced wholly by HARP-PS. The format was changed from a day of lectures with everyone present in a single room, to breakout discussions on specific topics with time for audience input. From the four topics presented, attendees could participate in three: Women Thriving with HIV, How to Thrive-Body, Mind, & Spirit; Dating & Self-Image; Medical & Research Update. After lunch Brandon Brown and Jeff Taylor presented information from the focus groups held by HARP-PS, followed by a report from the National Roundtable and a panel discussion with members from each of the stakeholder groups (patients, caregivers, providers, academics, community-based organizations) on stage to answer questions. Finally, a rousing plenary was delivered by Cleve Jones, noted activist and founder of the AIDS Memorial Quilt.

National Roundtable

With the Test Positive Aware Network, HARP-PS co-sponsored a National Roundtable focused on HIV long-term survivors. HIV educators, researchers, providers, and advocates gathered for the day and evening before the Reunion Project 2.0. The event provided an opportunity for people to network and learn about each others' projects, strengthening their work collectively and individually. The diversity of opinion and breadth of knowledge was stimulating and impressive. Participants were excited by the cross-disciplinary possibilities of the group. Events such as this are a huge help to furthering the work of participants, and the larger population of PLWHIV. Many expressed the hope that this will become an annual event.



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Achievements to Date-focus groups

Question Set A: Health issues

- 1. What are the top 3 major health issues affecting people who are aging with HIV?

Question Set B: Resiliencies

- 1. What are some of the resiliencies that allow people to age healthily with HIV?
- 2. What are some of the resources that you draw upon to navigate your health?
- 3. What are some of the choices that people have made to live healthily

Question Set C: Research

- 1. What should be the top priority topics for research on HIV and aging in CV?
- 2. How should these priority research topics be chosen?
- 3. What HIV and aging topics do you think are understudied?
- 4. What are the problematic aspects of research participation?

Focus groups-Top hits by all stakeholders

Question Set	Topics
Health issues	<ul style="list-style-type: none"> Cognitive function, dementia, memory loss Depression and isolation Financial strain
Resiliencies	<ul style="list-style-type: none"> Exercise/gym Socializing/having friends Support groups (online and in person) CBO services (DAP, The Center)
Research Priorities	<ul style="list-style-type: none"> HIV and co-morbidities HIV and neurological function (memory loss, neuropathy)

Sharing Information

These topics came up in groups and generated active discussion. They are included here to enlarge the discussion. The Kick ASS Manual, produced by Let's Kick ASS Palm Springs includes a series of short pieces on these topics and others. <https://www.lkaps.org/the-lka-manual>

What do we mean by “culturally competent care”? Why is it important?

HIV has primarily been a disease affecting marginalized communities. Society marginalizes people on the basis of race, gender, sexuality, language, religion— the list goes on. A person needing HIV care might be multiply marginalized. Culturally competent care for long-term survivors addresses the trauma they've experienced living through the epidemic and their various psycho-social needs (not only medical). This helps to get and retain them in care, improving medical and socio-behavioral outcomes.

Basic Needs

Nutritious, freshly-prepared food is essential for health and well-being. Home-delivered meals can make a huge difference in quality of life for people managing a chronic illness.

Housing is healthcare. Long a rallying cry, this is a fundamental truth. It's extraordinarily challenging for people to remain in care if they do not have stable and secure housing.

Access to behavioral and other health programs: Access to programs relies on several factors. People must know the programs exist, be able to get to the programs (transportation) and they must believe that the program is relevant for them.

Holistic and Alternative Health Modalities

Since the earliest days of the epidemic, people affected by HIV have been interested in “alternative therapies.” Used today in combination with ART, many people find these therapies increase their quality of life. More research is needed to evaluate the therapies, which include grounding, medicinal cannabis, and forms of Traditional Chinese Medicine such as acupuncture, acupressure, and herbs.

Experts on longterm survivor issues from around the country gather for a National Roundtable hosted by HARP-PS

