

COMMUNITY ENGAGED RESEARCH TRAINING

Day 1 - June 3, 2022

UCDAVIS

ENVIRONMENTAL HEALTH SCIENCES CENTER

How we'll spend our time today

1 Welcome to the Community Engagement Core

2 Overview of Community-engaged research

3 How to administer a community-engaged research project

4 Q & A and next steps

■ **Part 2: June 8, 2-5 pm**

1 Common pitfalls and challenges in community engaged research + strategies for prevention & repair

2 Research team goal setting and support plans (small group discussions)



California Native Lands Acknowledgement



An initiative of the Nevada City Rancheria Nisenan Tribal Council, California Heritage: Indigenous Research Project (CHIRP), and current residents of the Bear and Yuba River Watersheds.

<https://chirpca.org/ancestral-homelands>

A choice between two worlds.
Alyssa Walz. www.minewatchnc.org





NEWS
from NATIVE CALIFORNIA

SUBSCRIBE

35 YEARS OF INDIGENOUS CALIFORNIA STORYTELLING

News from Native California is a quarterly magazine devoted to the vibrant cultures, arts, languages, histories, social justice movements, and stories of California's diverse Indian peoples.

We strive to preserve the cherished knowledge of an older generation, provide opportunities for a younger generation making a place for Indian ways in the modern world, and illuminate the beauty of Native cultures to all of California.

<https://newsfromnativecalifornia.com/about/support/>



The mission of the Sacramento Native American Health Center, Inc (SNAHC) is to carry out the legacy of a healthy American Indian and Alaskan Native community based on cultural values delivered through traditional, transformational, innovative, accessible, and self-sufficient systems of health care.



<https://www.snahc.org/give-now/>

1. Welcome to the EHSC Community Engagement Core!

Who are we?

What is our role at EHSC?

How can we support your project?

The Community Engagement Core Team

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Our role at EHSC

The CEC is one of four EHSC cores

Our job is to help EHSC develop partnerships between environmental health researchers and the communities where they work

Our main geographic focus is the San Joaquin Valley, but our work also extends to other parts of California affected by wildfires, and workplaces nationally impacted by COVID

Our role in the Pilot Project Program

We assist pilot project grantees' community engagement efforts by offering a range of individualized support services

We facilitate the EHSC Community Stakeholder Advisory Committee (CSTAC), which helps set the EHSC's research priorities and reviews PPP proposals

EHSC

Community Stakeholder Advisory Committee

COMMUNITY- BASED ORGANIZATIONS

Representing stakeholders
most impacted by
environmental health issues

PUBLIC AGENCIES

Representing those
charged with protecting
public health from
environmental hazards

ACADEMIC RESEARCHERS

Epidemiologists,
Toxicologists, Exposure
Scientists, Engineers,
Clinicians, and more

Community Stakeholder Advisory Committee

Current members

Californians for Pesticide Reform (CPR)
Jane Sellen

Central California Asthma Collaborative (CCAC)
Kevin Hamilton

Central California Environmental Justice Network (CCEJN)
Nayamin Martinez

Community Water Center
Ryan Jensen

Comite Civico del Valle
Luis Olmedo &
Christian Torres

Leadership Counsel for Justice and Accountability
Phoebe Seaton

Environmental Justice Coalition for Water
Espe Vielma

Green Action Network / El Pueblo
Maricela Mares-Alatorre &
Miguel Alatorre

CA Dept of Public Health
Dan Woo &
Dilhara Ranasinghe

CA Air Resources Board
Trish Johnson

CA EPA Office of Environmental Health Hazard Assessment
Lily Wu & Amy Budahn

California Department of Food and Agriculture
Emad Jahanzad

CA Department of Pesticide Regulation

CA EPA Department of Toxic Substances Control
Yvonna Cazares

Marilyn Silva
Retired, Department of Pesticide Regulation

Jaymin Kwon
CSU Fresno Department of Public Health

How we support Pilot Program grantees

Help identify potential community partners and facilitate exploratory meetings (pre- or post-award)

Assist in the development of partnership agreements, including budgets, SOWs, and MOUs

Assist in IRB applications involving a community partner

Help community partners navigate UCD resources and administrative processes

How we support Pilot Program grantees

Help researchers maintain regular communication with community partners

Assist either party if needed in navigating conflict or unexpected developments

Help develop science communication materials for a variety of audiences

If project develops to Research to Action, RO1, or other NIH proposal, can provide assistance in proposal development

What you can expect from us

- Quarterly check-ins
- Additional support as needed to facilitate excellence in community engagement

What we expect from you

- Lay summaries of your project
- Copies of any partnership agreements and budgets (+notification if these are modified)
- Presentation of research to CSTAC (spring 2023)
- (EHSC progress reports include community engagement updates)
- Timely communications (with CEC + other research team members)

2. Pilot Project Introductions



Name and affiliation

Level of experience with
community engaged research

Brief overview of your project and any
community
engagement components

3. Community-Engaged Research

What is community-engaged research?

How can community engagement improve research?

How can it benefit community collaborators?

What is Community Engaged Research?



Collaboration with **community stakeholders** as full partners in **all** phases (formation, implementation and application) of research

Who are “community partners” in this context?

We prioritize **community-based organizations** that work directly with communities facing environmental justice and health disparities



As appropriate, other organizations (e.g., public agencies) can also be included.

Who are “community partners” in this context?

Working with community residents and advocates can improve the relevance, rigor and reach of projects.



Working with public agencies can enhance the policy impacts.

Working with both can improve multi-sector collaboration.

Community-Based Participatory Action Research (CBPAR)

"Community-based participatory action research (CBPAR) is **an applied collaborative approach that enables community residents to more actively participate in the full spectrum of research...**

(from conception – design – conduct – analysis – interpretation – conclusions – communication of results)

...with a **goal of influencing change in community health, systems, programs or policies.**"

Community-Based Participatory Action Research

CBPR helps address concerns of **exploitation** and **research fatigue** among members of disadvantaged, marginalized, stigmatized, and underrepresented communities **who have often been the subject of research studies.**

CBPR promotes **"research with"** rather than **"research on"** these communities and their members.

Principles of CBP(A)R

BUILD

on strengths and expertise within the community

FACILITATE

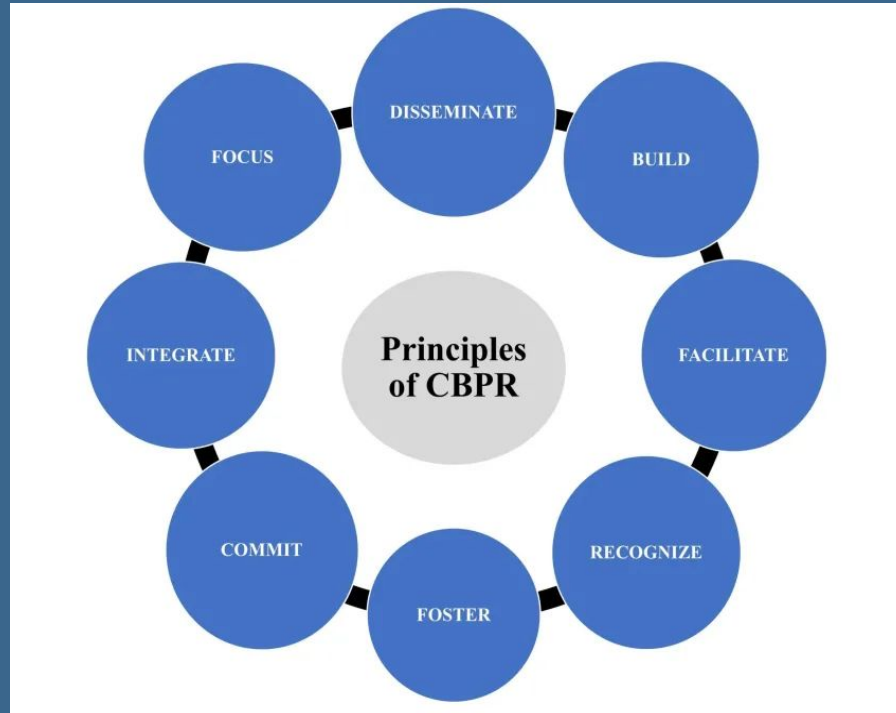
an equitable partnership in all phases of the research that aims to both empower and share power

RECOGNIZE

the community as a unity of identity with shared experiences related to environment, race, socioeconomic status, occupation, etc.

FOSTER

co-learning and capacity building among all partners



FOCUS

on public health issues relevant to stakeholder communities, including those influenced by social and economic determinants

COMMIT

to a sustainable, and when possible, long term investment in the partnership

DISSEMINATE

results to all partners and identify stakeholders who can influence change

INTEGRATE

knowledge generation with community action!

Community engagement on a continuum: from participant to partner



“Helicopter Science”

Community stakeholders have **no influence** on study topic or design.



Community **context influences** study design and research questions



Community stakeholders are **consulted**, may participate in **translation and dissemination of results**



Community stakeholders **frame questions and set research priorities.**



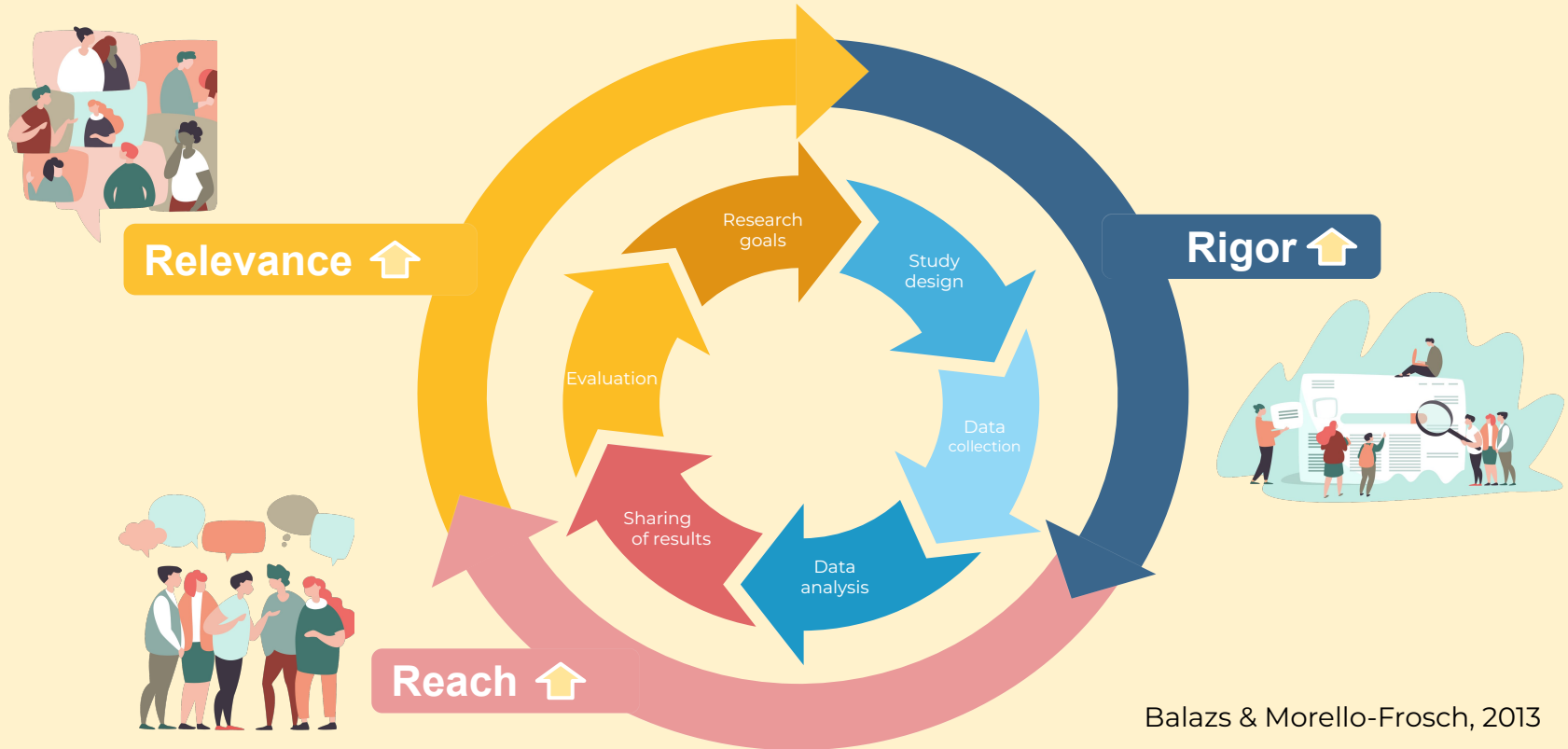
Community stakeholders **leverage study results & partnerships to promote social change**



CBPR

Community stakeholders are **full partners** in research, protocol design, fundraising, and data ownership

Community engagement can improve outcomes across the research cycle



Benefits of Community Engaged Research to Community Partners



Access to scientific resources and knowledge that help inform community advocacy and bolster legitimacy in political and public discourse.

Help shape the research agenda of universities to respond to community priorities.



Benefits of Community Engaged Research to Academic Researchers

Gain firsthand knowledge and insight of local partners

Build bridges between the university and broader community



Develop interventions with greater relevance and feasibility

Support the self-empowerment of disadvantaged communities to take part in the production and application of knowledge

The EHSC's intention is that the PPP will support both new science and new collaborations -- both of which we hope will continue beyond the grant term.

You're not just piloting the science, you're piloting the relationship to build into larger projects over time.

Pilots are short and budgets are small - think creatively about reciprocity and shared goals in both the short and long term.

If your pilot project doesn't currently include community collaboration, **we can help you develop relationships during your pilot award to support community engagement in your next steps.**

Partnership beyond the Pilot

Successful partnerships are long term investments in relationship- and trust-building.



Expanded access to **large funding opportunities** that require meaningful community engagement, including those where a community organization must be the lead applicant.

NIEHS **Research to Action (R2A)** grant encourages multidisciplinary environmental health projects that employ community-engaged research methods & translate research findings into public health actions.

Community engagement can also **translate to higher significance scores** on other types of NIH grants, such as R01s.

Expanded opportunities beyond the Pilot



Challenges of Community Engaged Research to Academic Researchers



Disincentives for engaged scholarship in academia:
Work seen as “less legitimate/objective”
(especially for pre-tenure faculty, women,
academics of color)

Can be time and resource intensive

But, things are changing...



Challenges of Community Engaged Research to Community Partners



Over-extension in time and effort

Reduction of available resources for community organizing/ advocacy

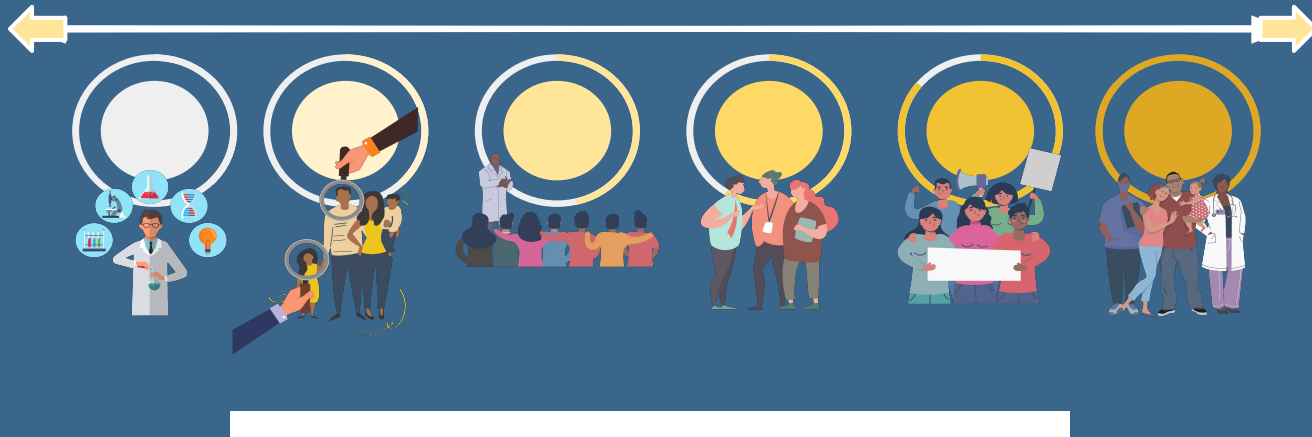
Potential for negative community impacts of the research based on negative/ inconclusive results



Assessing Community Engaged Research

Extent of community participation:

The quality and quantity of roles that community partners play in the project



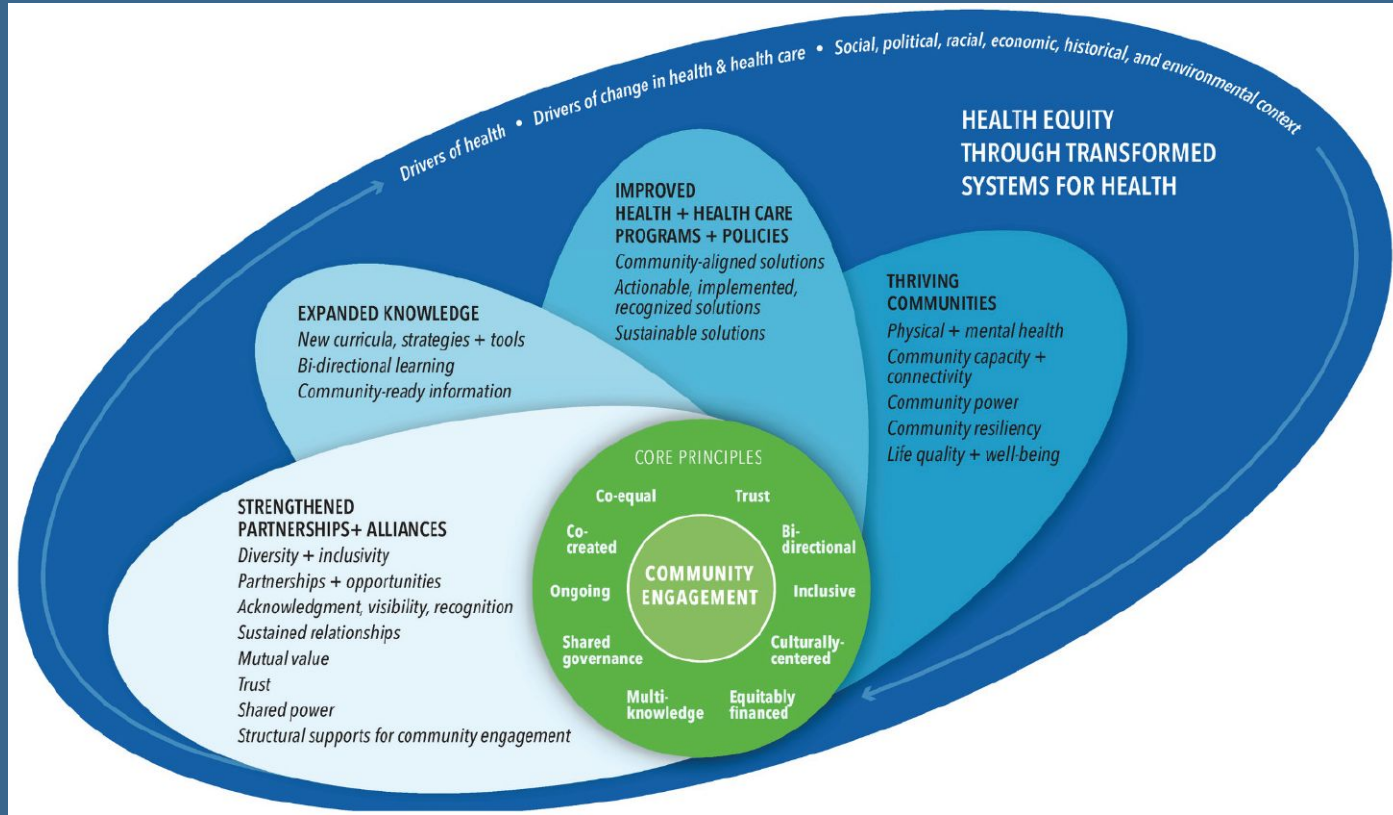
Assessing Community Engaged Research

Alignment
of the project
to its context



Assessing Community Engaged Research

From the community perspective





ACTIVITY:
**What does the community
engagement look like in your
current project?**

Discussion / Sharing Experiences

4. Administering community engaged research

Partnership agreements

Payments to community partners

Going through IRB with a community partner

Partnership agreements

We strongly recommend written agreements for all projects

A written agreement is **required** if the community partner is either:

- included as a researcher on the IRB application
- getting paid



Partnership agreements

The CEC can help you negotiate and write up your partnership agreements.

We request that you provide the CEC with copies of your partnership agreements and notify us of any modifications.



Partnership agreements

Types of partnership agreements include:

- Informal partnership agreement / Scope of Work
- Budget / contract / subaward
- Formal MOU
 - The terms of formal MOUs must be aligned with IRB requirements
 - ~4 month UCD approval timeline



Partnership agreements

Components of partnership agreement:

- Decision making process
- Nature of relationship
- Communication
- Ownership of data
- Timeline
- Roles and responsibilities
- Budget, if applicable





Payments to community partners

PIs are solely responsible for getting community partners paid

- EHSC / CEC cannot pay community partners directly
- Payments will go through your standard departmental accounting procedures
- Community partners will need to be added to the UCD system and issued POs or subaward agreements **before they can start work**



Payments to community partners

Payments may be issued to contractors/vendors, consultants, and subrecipients.

- Which category a community partner falls into is determined by nature and scope of their contributions to the work
- Each designation involves different administrative processes for payment
- UC Davis provides guidance on what types of work fall into each category



Payments: Vendor Status

A community collaborator is considered a vendor/contractor if all of the following are true:

- They do not collaborate on the design of the project/proposal, including the design of their own scope of work.
- Their work is measured against contract deliverables rather than project objectives.
- They do not make or contribute to project decisions.
- They are not expected to create or co-author publications.



Payments: Vendor Status

Documentation required for university to issue a PO:

- IRB Approval from UC Davis (if human subjects)
- IRB Approval from NIEHS (if human subjects)
- Community partner scope of work
- Community partner budget
- Payment term (default is 60 days, can request shorter)
- Any specific qualifications / resources of the community group



Payments: Subrecipient Status

A community collaborator is considered a subrecipient if any of the following is true:

- They collaborate on the design of the project/proposal, including the design of their own scope of work.
- Their work is measured against the project objectives, rather than contract deliverables.
- They make decisions as part of the project team.
- They create or co-author publications.



Payments: Subrecipient Status

A grant received by a UCD PI with a community subrecipient is referred to as an “outgoing subaward.”

UC Davis provides a toolkit with guidelines, tutorials, and a formal training for processing outgoing subawards. This will be handled by the PI’s accounting staff.

The CEC can help a community collaborator with their portion of the paperwork.



Payments: Subrecipient Status

Prior to receiving an outgoing subaward, community collaborators must be compliant with federal regulations.

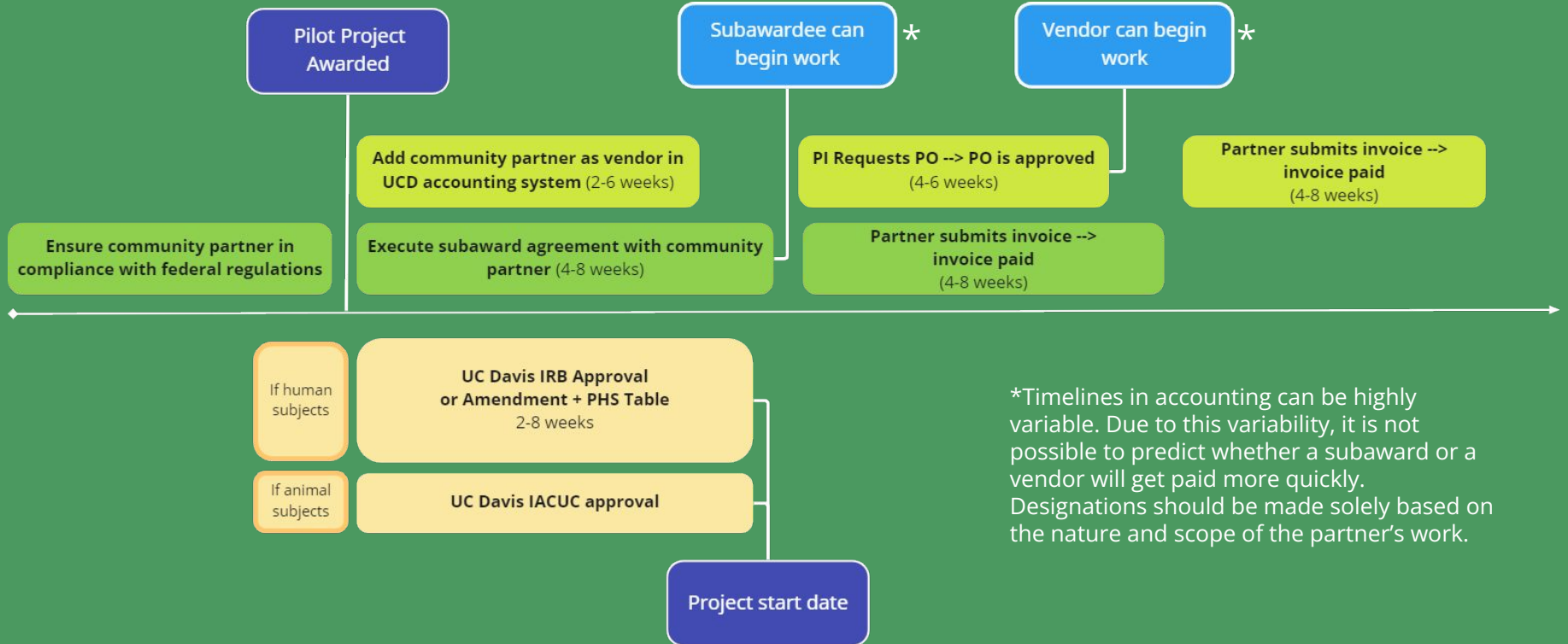
This includes:

- Registration in System for Award Management (SAM)
- A Unique Entity Identifier (UEI), which is requested through SAM
- Registration in eRA commons
- Any individual listed as key personnel must also have an eRA commons ID

Many larger community-based organizations will already be compliant or have a fiscal sponsor who is. **For those who don't, the EHSC can support them in applying.**

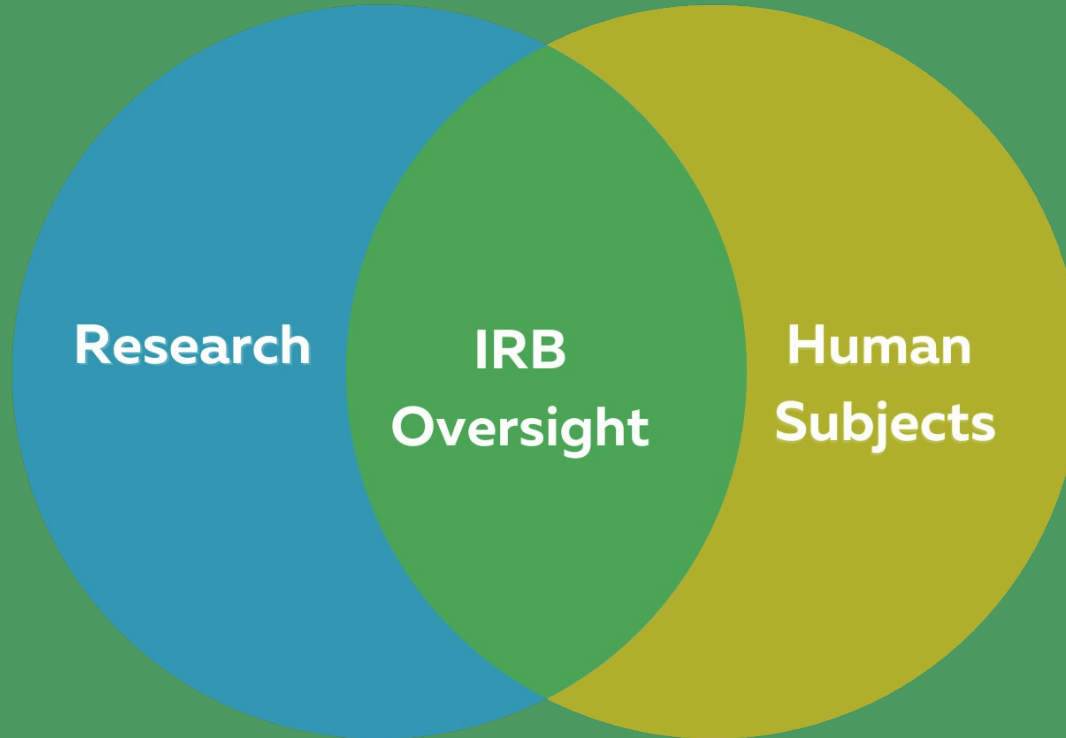


Payments: Timeline



IRB with a community partner

Institutional Review Board



3 types of IRB review

Full board review

Studies involve more than “minimal risk”

Examples:

Interventions involving physical or emotional discomfort or deception

Studies involving sensitive data or vulnerable populations

Expedited review

Not greater than “minimal risk:

Examples:

Collection of biospecimens by non-invasive means

Studies that do not involve vulnerable populations

Exempt review

Studies involve less than “minimal risk”

Example:

Research with de-identified records or anonymous surveys

Studies that involve normal educational settings using normal practices

What is research?

Research is a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge

If the intent of an activity is to contribute to testing a hypothesis, drawing conclusions, and contributing to generalizable knowledge, **these activities are categorized as research.**

Translating and disseminating findings alone is not “research.”

Source: https://research.oregonstate.edu/sites/research.oregonstate.edu/files/irb/comparison_research_v_non_research_v01292018.pdf

What is human subjects research?

A human subject is **a living individual**

- about whom an investigator conducting research obtains, uses, studies, or analyzes **data or biospecimens** through an intervention or interaction with the individual

-OR-

- whose **identifiable, private information** is used, studied, analyzed, generated

Source: <https://grants.nih.gov/sites/default/files/human-subjects-research-infographic.pdf>

Examples of human subjects research

- Collecting blood
- Conducting a survey
- Changing participants' environment
- Administering medicine
- Interviewing
- Collecting data
- Conducting a focus group
- Testing a new educational technique
- Administering a psychological test

Source: <https://grants.nih.gov/sites/default/files/human-subjects-research-infographic.pdf>

HUMAN SUBJECTS RESEARCH ACTIVITIES

VERSUS

NON-HUMAN SUBJECTS RESEARCH ACTIVITIES

Recruitment

Obtain informed consent

Inform potential participants about a study, including:

- Providing potential participants with IRB-approved materials, including copies of informed consent documents
- Providing potential participants with information about contacting investigators, or obtaining permission for investigators to contact them

Data handling

Access to identifiable private information

Access to coded, de-identified data

HUMAN SUBJECTS RESEARCH ACTIVITIES

VERSUS

NON-HUMAN SUBJECTS RESEARCH ACTIVITIES

Data collection

Perform an intervention (i.e. take measurements, administer a treatment, collect a biospecimen, or alter the environment for research purposes)

Engage in protocol-dictated communication or contact (i.e. asking someone for a specimen, conducting interviews, or administering questionnaires)

Obtain identifiable private information

Permit the use of facilities for an intervention or interaction with subjects (i.e. provide a location for conducting surveys or collecting blood samples)

Release identifiable private information to investigators

Dissemination

Author a paper, journal article, or presentation describing a human subjects research study

IRB with a community partner

If a community partner will be engaging in human subjects research, they must be included on the researcher's IRB.

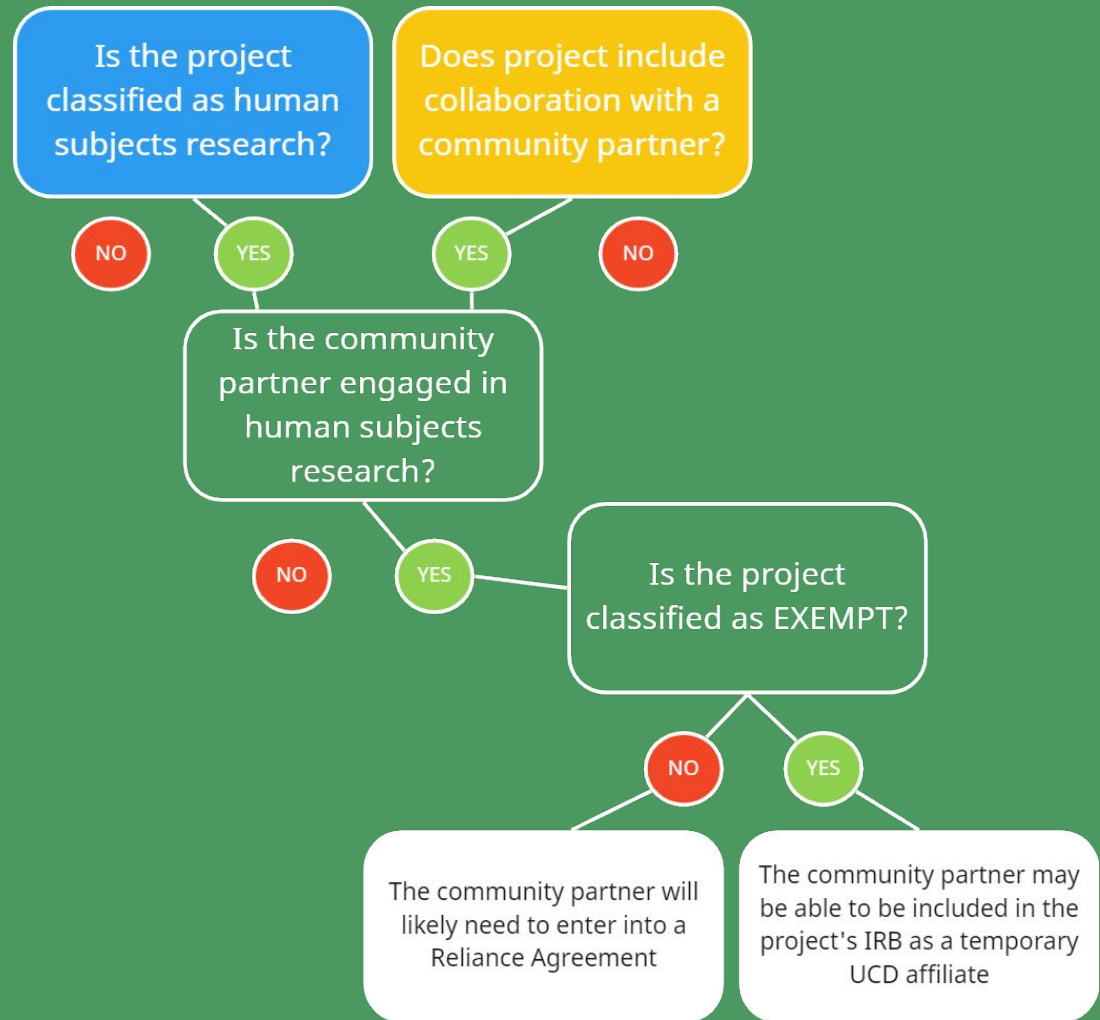
UC Davis IRB Policy is to not allow non-university employees on the Research Personnel List.

Available options for including a community partner on an IRB:

Temporary Affiliate Form (TAF)

Reliance Agreement

IRB with a community partner



Temporary Affiliate Form (TAF)

Can only be used for projects classified as EXEMPT by IRB.

Cost: Free

TAF is a process created to grant external constituents (visiting faculty, concurrent students, vendors, and others) access to UC Davis computer resources.

By registering for temporary access, affiliates have access to the UC Davis network, a ucdavis.edu email address, and a unique username and password which is used to verify identity and enable subsequent access privileges to various parts of the network.

Term: 1 year, renewable

*TAF (Temporary Affiliate Form): https://servicehub.ucdavis.edu/servicehub?id=it_catalog_content&sys_id=e729e15d1b9798103f4286ae6e4bcb3e
To create a TAF: <https://computingaccounts.ucdavis.edu/cgi-bin/taf/index.cgi>*

Reliance Agreements



Reliance Agreements allow **independent investigators** partnering with UC Davis researchers to rely on UC Davis IRB for review and oversight of **non-exempt human subjects research.**

Reliance Agreements

An **Independent Investigator** is one whose home institution does not have an IRB.*

Cost:

\$2974 for initial review

\$1620 for continuing review

Contact: hs-irbreliance@ucdavis.edu

*An **external investigator** is one whose home institution does have their own IRB.

Special Considerations for IRBs with Community Partners

- Importance of intentionality around power imbalances
- Include community partner in assessing risk, particularly community-level risk and risks associated with dissemination of findings
- Planning for modification is important but also introduces potential uncertainty around informed consent and predicting risk

Special Considerations for IRBs with Community Partners

- Start early, as the process can take longer with multiple collaborators
- Some non-academic entities may have their own ethics review process that the research will need to go through
- Consult with CEC and IRB if you need to go through the IRB process before you have a partner identified

5. Q & A

and next steps

- Please fill in training evaluation (sent by email)
- CEC will reach out to set up quarterly check-ins for individualized, project-specific support
- Supplemental support materials will be provided before Part 2 on June 8