

Save the Date!

ACCORDS & CCTSI Community Engagement Forum

October 22, 2025

12:00-1:00pm MT



Colorado Clinical and Translational
Sciences Institute (CCTSI)

UNIVERSITY OF COLORADO DENVER | ANSCHUTZ MEDICAL CAMPUS

Receive advice and guidance on your research project from experienced community members and academics

CCTSI/ACCORDS Community Engagement Consultations

Email Kaylee: Kaylee.Gordon@cuanschutz.edu for more information or to request a consult.

<https://www.cuanschutz.edu/cctsi/community/programs>



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Stay updated by joining our mailing list:
https://ucdenverdata.formstack.com/forms/pact_mailing

CCTSI Community Engagement Pilot Grants

Next RFA Posted November 2025

Email Kaylee: Kaylee.Gordon@cuanschutz.edu for more information.

CE-Pilots: <https://cctsi.cuanschutz.edu/funding/cepilot>



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ICYMI: watch previous Community Engagement Forums

[https://medschool.cuanschutz.edu/accords/educational-offerings/archive/seminar-series-\(2024-2025\)](https://medschool.cuanschutz.edu/accords/educational-offerings/archive/seminar-series-(2024-2025))



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What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a 'one-stop shop' for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally



ACCORDS Upcoming Events – mark your calendars!

Sept. 8 – Dec.15, 2025 Biweekly	Writing Seminar for Mid- and Senior Career Faculty: Developing and Teaching Skills in Scientific Writing <i>Registration opens next week!</i>
November 4 & 6, 2025 Elliman Conference Center	ACCORDS Introduction to Qualitative Research Workshop <i>Registration opens next week!</i>
September 8, 2025 December 8, 2025 March 8, 2026	ACCORDS Highlights
October 20, 2025 January 12, 2026 April 13, 2026	ACCORDS Grand Rounds
April 8 & 9, 2026 Virtual	ACCORDS D&I Science for Researchers Workshop
Annual Conference June 2026	Colorado Pragmatic Research in Health Conference Pragmatic Outcomes Research: Methods, Tools and Technology for Rapidly Changing Contexts



The background of the image is a blurred, close-up shot of green grass, likely wheat or a similar grain, with the blades creating a sense of depth and texture. The overall color palette is various shades of green, from light to dark.

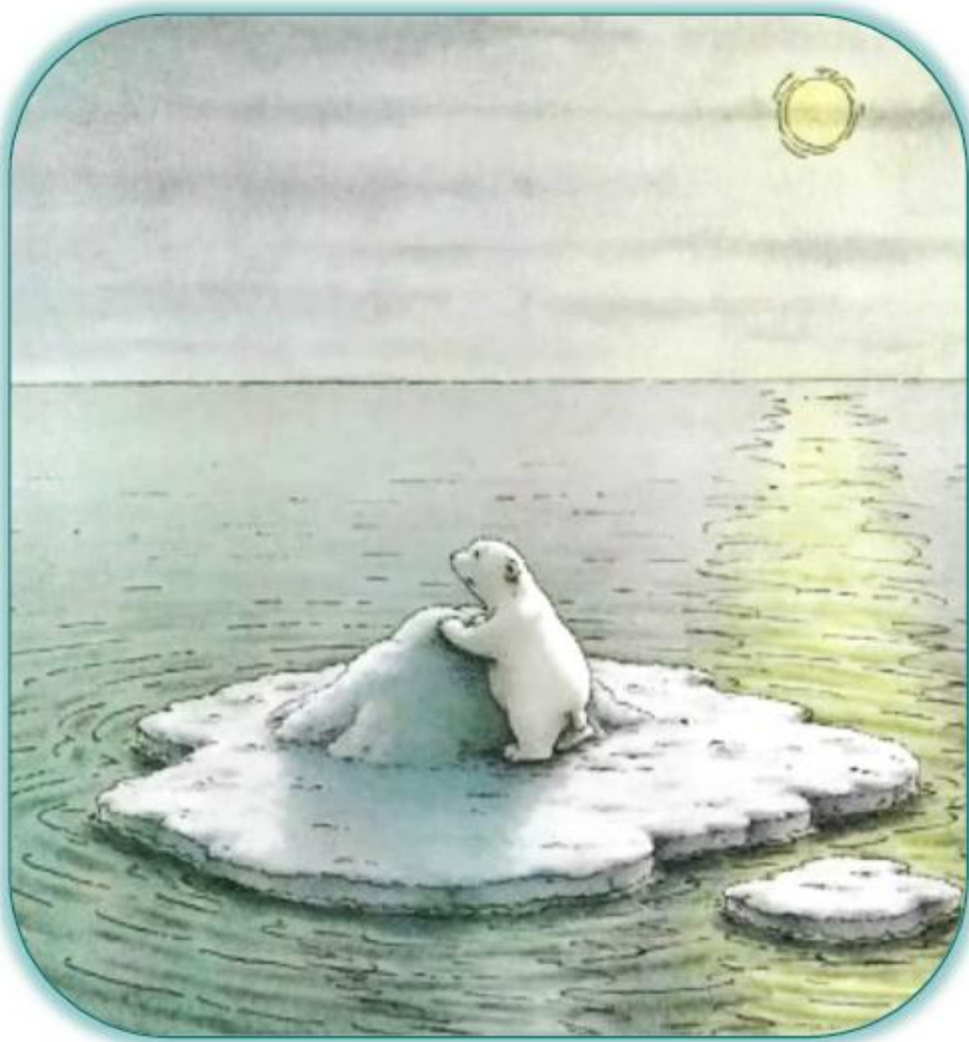
THE CASE FOR ETHICAL COMMUNITY-ENGAGED RESEARCH PRACTICE

The background of the image is a landscape photograph. It shows a sunset or sunrise over a desert. The sky is filled with orange and yellow clouds. In the distance, there is a range of mountains. The foreground is a flat, sandy area with some small, dark, scrubby bushes. A white rectangular box is superimposed over the upper half of the image, containing the title text.

WHY TRADITIONAL RESEARCH ETHICS FAIL US IN COMMUNITY

MATTHEW DECAMP

**University of Colorado
Center for Bioethics and Humanities**



Hans de Beer
Little Polar Bear

Little Polar Bear

LESSONS FROM A CHILDREN'S STORY

**Principles that serve us well
in one place – might not do
so well in another.**

A TRADITIONAL VIEW: RESEARCH “*PROTECTIONISM*”

Notable examples of research misconduct – from Tuskegee to Willowbrook to Guatemala and more – naturally led us here:

PRINCIPLE	PRACTICAL APPLICATION
Respect for Persons	Individual informed consent
Beneficence	Minimizing risks, maximizing benefits
Justice	Protection of the vulnerable: children, pregnant people, individuals who are incarcerated, marginalized groups....

AN UNINTENDED CONSEQUENCE?

RESEARCHER

- Over-focus on *individual* consent and harms, compared to group
- Barriers to recruiting people that represent the full range of lived experiences
- Researchers role is to protect “subjects”
- Results are returned at the end – if at all
- And more



PARTICIPANTS & COMMUNITIES

- Where do my data and samples go?
- What difference did it make?
- Should I trust researchers?
- And more



dilemma

By [Ewen Callaway](#)

27 April 2010



Havasupai people visited Tempe to say prayers over disputed blood

(Image: Jim Wilson/The New York Times/Redux/Eyevine)

A university has agreed to pay 41 members of a Native American tribe \$700,000 after using DNA for purposes it was not donated for. As well as ending a dispute between the Havasupai people and geneticists at Arizona State University in Tempe, the settlement highlights a **dilemma** facing much modern genetics research

Broad consent for research on diabetes...

**...eventual research on mental health,
substance use, and origins (while neglecting
the spiritual importance of blood)...**

HISTORICAL FLASHPOINT

**The Havasupai case eventually led o
legal settlement, the return of samples,
and multiple analyses of what went
wrong...but most importantly:**

BROKEN TRUST

<https://www.nytimes.com/video/us/1247467672743/blood-journey.html>

A CLOSER LOOK AT THIS CASE: *INFORMED CONSENT*

A focus on *individual* consent – while important – may overlook uniquely group-based risks.

For Indigenous people, these risks implicate the communities as a whole, which thus transfers potential risks onto the group. If group risk is not adequately disclosed to the tribal member who is consenting to participate in a study, then we must ask if consent is truly informed or if it is being obtained from an under-informed participant.

Underlying many of the complex issues touched upon here is a fundamental lack of acknowledgement of risk to groups in standard informed consent procedures. While the focus has been on tribal groups, these concerns extend to other, non-Indigenous groups as well.

--*Krystal S. Tsosie*

Claw, K. G. et al. A framework for enhancing ethical genomic research with Indigenous communities. *Nat. Commun.* 2018;**9**:2957.

Tsosie KS, Yracheta JM, Dickenson D. Overvaluing individual consent ignores risks to tribal participants. *Nat Rev Genet.* 2019 Sep;**20**(9):497-498

THE ALTERNATIVE: FROM RESEARCH “*PROTECTIONISM*” TO RESEARCH “*RELATIONSHIPS*”

What might some supplemental ethical principles be?

PRINCIPLE	PRACTICAL APPLICATION
Humility	Being aware of one’s own limitations
Solidarity	Asking not just “what” – but “why” and “how” our actions demonstrate unity
<u>Social</u> Justice	A fundamental concern with promoting social fairness by addressing root causes – not over protectionism

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FROM PRINCIPLES TO PRACTICAL GUIDANCE

1. Be clear about the purposes of engagement and the community you want to engage	6. Recognize diversity <i>within</i> the community
2. Become knowledgeable about the community – including past engagement experiences	7. Mobilize community assets
3. Build and maintain relationships and trust	8. Release control and be flexible
4. Recognize self-determination of the community	9. Foster collaboration and long-term commitment
5. Establish a partnership	10. Demonstrate trustworthiness

SEE ALSO:

CTSA Principles of Community Engagement (2nd edition). See: <https://ictr.johnshopkins.edu/wp-content/uploads/2015/10/CTSAPrinciplesofCommunityEngagement.pdf>

CDC Principles of Community Engagement (3rd edition). See: https://www.cdc.gov/pcd/issues/2025/25_0189.htm

Principles of CBPR. srael BA, Schulz AJ, Parker EA, et al. Review of community-based research: assessing partnership approaches to improve public health. Annu Rev Public Health. 1998;19:173–202.

A COUPLE EXAMPLES

1. Be clear about the purposes of engagement and the community you want to engage	YES, but – community first (“when you have a hammer....”)
2. Become knowledgeable about the community – including past engagement experiences	“About” but...immerse
6. Recognize diversity <i>within</i> the community	Be wary of labels (e.g., in writing up a paper)
8. Release control and be flexible	Your timeline v. the community timeline and competing priorities
10. Demonstrate trustworthiness	Show up

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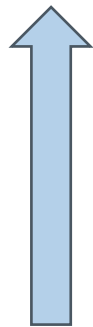
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A WORD OF CAUTION

In ethics, there is an important distinction between...

INSTRUMENTALISM	INTRINSIC VALUE
“Means to an end”	Inherent worth independent of outcome



YES – engagement leads to better research questions, improved recruitment and retention, and better dissemination/implementation/uptake.

BUT – without humility, solidarity and social justice, overemphasis of this and failure to recognize inherent value can verge on **Exploitation**

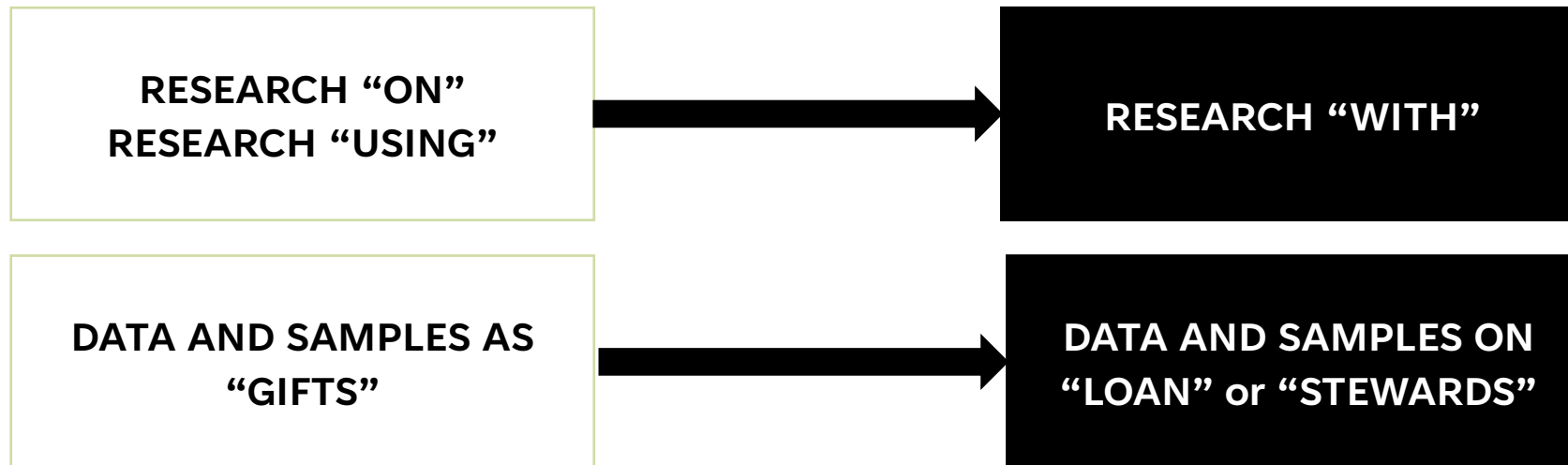
ANOTHER WORD OF CAUTION: *TODAY'S REALITY*

In the move toward relationships of trust and added principles, we must still be cautious of where good intentions can lead, today more than ever.

For the sake of...	...we may wish to...	...but we might risk...
Respect and solidarity	Be “in community”	Being uninvited – sometimes, virtual is easier, better and safer
Social justice	Post recruitment wide and far, in community and online	Unintended disclosure of identity, safety, or privacy risks
Transparency and trust	Disseminate data and results freely and openly	Unauthorized secondary uses that harm community

FROM'S AND TO'S

Subtle changes in language can be very important in orienting us to the ethics of community engagement:

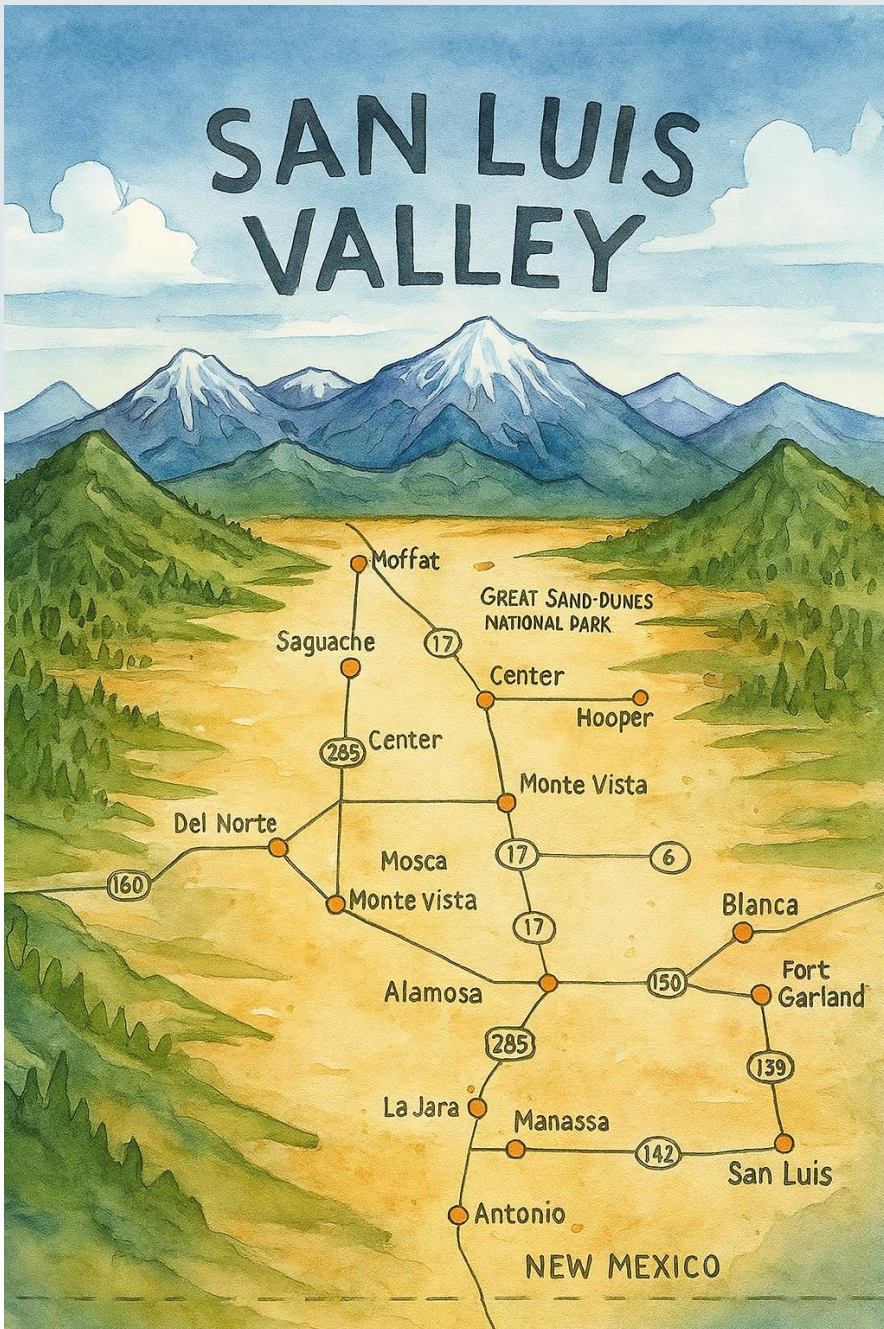




**THIS WORK IS
PERSONAL: REAL-WORLD
ETHICS IN COMMUNITY-
ENGAGED RESEARCH**

LISA LUCERO
COMMUNITY ADVOCATE &
RESEARCH PARTNER





A COMMUNITY OF DEEP MEMORY

- Historically rich, deeply under-resourced
- Community memory of unethical research practices:
 - Researchers who never returned
 - Trauma explored but never healed
 - Stories and data taken with no community benefit
- Layering historical trauma and poverty creates risk of economic coercion in research

“People may participate not out of trust, but because they need the gift card.”

THE CURRENT CLIMATE: TENSE, WATCHFUL, WOUNDED

- Increased fear of surveillance, targeting and being used
- Examples we've seen:
 - COVID-era studies with no follow-up
 - Mental health surveys without acknowledgment of trauma
 - Data collected *on* communities, not *with* them

Community Questions:

- Why are you collecting this data?
- Where will it live?
- Who benefits?
- Will we see the results?

“This caution is not paranoia; it’s protection earned through experience.”





COMMUNITIES ARE CONNECTED

- Community advocates talk across towns, regions and the state
- Example: declined a project due to the involvement of a PI with a harmful history

“The PI may have moved on, but the harm stayed behind.”

- Ethics > Funding
- Quote to funder:

“If more money in the SLV leads to more inequity, burn that [expletive] before it gets into my community.”

TWO ROADS: ONE THAT FAILS, ONE THAT HEALS



A Failure:

- National research team lacked:
 - Communication plan
 - Understanding of local history
 - Local representation
- Result: triggering questions, no follow-up, community felt used
- Mistrust built through *small violations of relationship*

A Success:

- Trust was built before research began
- Community co-designed questions
- Community chose how data would be used
- Returned with results *and* resources
- Result: ownership, not just participation

WHAT THIS ALL COMES DOWN TO

Matt's principles + lived experience:

- If you're not staying after the data is collected, don't come
 - If your questions may reopen trauma, slow down
 - If you wouldn't do it in your neighborhood, don't do it in mine
- “Ethics aren't a checkbox, they are relationships.”
- See people as partners, not data points
 - When people feel seen and safe, research can heal, not harm
 - Do that and you're welcome in my community



THANK YOU

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