



11th Annual CCTS BIOETHICS FORUM

Hosted by Tuskegee University

Ethical Co-Creation Toolkit

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Introduction

Strong community–academic partnerships are built intentionally through clarity, fairness, shared decision-making, and long-term commitment.

This Ethical Co-Creation Toolkit supports teams in moving from community-defined priorities to structured, ethical, and fundable action. The tools included here are practical and accessible for both community members and academic partners. They clarify roles, protect trust, strengthen engagement strategies, and align proposals with community values and funder expectations.

This toolkit is grounded in Community-Based Participatory Research (CBPR) principles, NIH guidance on community-engaged research and data management, the PCORI Engagement Rubric, and implementation science frameworks.

Attribution & Development Statement

This Ethical Co-Creation Toolkit was developed for the 2026 CCTS Bioethics Forum to support community–academic partnership development and ethical project planning.

The toolkit was designed by forum organizers using publicly available frameworks and guidance documents, including:

- Community-Based Participatory Research (CBPR) principles (Israel et al., 1998; Wallerstein et al., 2018)
- National Institutes of Health guidance on community-engaged research and data management
- The Patient-Centered Outcomes Research Institute (PCORI) Engagement Rubric
- Implementation science and sustainability planning frameworks

This toolkit does not reproduce proprietary instruments. External resources, such as the NIH Community Engagement Alliance (CEAL) Precision Outreach and Planning (CERPOP) Tool, are referenced and credited appropriately.

This toolkit is intended as a practical adaptation of established principles and is provided for educational and partnership development purposes.

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1. Partnership Alignment Worksheet

Clarifying Purpose, Roles, and Shared Expectations

Why This Matters

Strong partnerships begin with clarity. This worksheet helps community and academic partners align on purpose, expectations, and shared decision-making before writing proposals or submitting funding applications.

Section 1: Defining the Priority

1. What issue or concern are we addressing?
2. Who identified this issue?
 - Community members
 - Academic team
 - Both together
 - Other: _____
3. Why does this issue matter to the community?
4. Who is most affected?

Section 2: Shared Purpose

1. What change are we hoping to see?
2. What does success look like for community partners?
3. What does success look like for academic partners?
4. Are there differences in how we define success?

Section 3: Leadership & Decision-Making

1. Who is serving as community lead?
2. Who is serving as academic lead?
3. How will major decisions be made?
 - Consensus
 - Majority vote
 - Designated authority
 - Other: _____
4. How will disagreements be resolved?

Section 4: Communication & Transparency

1. How often will we meet?
2. How will updates be shared?
3. Who reviews materials before submission or dissemination?
4. How will we ensure community partners receive timely information?

Section 5: Ethical Commitments

1. How will community members be compensated?
2. How will contributions be acknowledged?
3. How will we protect community trust?

Final Reflection

Before moving forward:

- Do all partners feel heard?
- Is leadership shared appropriately?
- Is the community benefit clear?

2. Roles & Decision-Making Plan

Preventing Confusion and Protecting Shared Leadership

Why This Matters

Strong partnerships are built on clarity. Many conflicts arise not because of bad intentions, but because roles and decision-making authority were not clearly defined.

This template helps community and academic partners:

- Clarify responsibilities
- Define decision-making authority
- Prevent role overlap or power imbalance
- Strengthen accountability

Step 1: Identify Core Roles

Use the table below to define who is responsible for what.

Role	Person/Organization	Primary Responsibilities	Decision Authority (Yes/Shared/Advisory)
Community Lead			
Academic Lead			
Project Manager			
Evaluator			
Outreach Coordinator			
Budget Lead			
Data Manager			
Other:			

Step 2: Clarify Decision Categories

Not all decisions carry the same weight. Discuss the categories below.

A. Strategic Decisions

Examples:

- Finalizing research aims
- Selecting funding target
- Expanding project scope

Who has final authority?

- Community lead
- Academic lead
- Shared decision
- Advisory input only

B. Budget Decisions

Examples:

- Allocation of funds
- Compensation amounts
- Subcontracts

Who reviews and approves budget changes?

C. Dissemination Decisions

Examples:

- Conference presentations
- Community reports
- Publications

Who must approve before public sharing?

D. Data Decisions

Examples:

- Who can access raw data?
- Who stores data?
- Who approves secondary use?

Document agreements clearly.

Step 3: Address Power Balance

Discuss openly:

- Does one partner hold more institutional authority?
- How will we ensure community voices are not overshadowed?
- How will disagreements be handled respectfully?

Document your agreement here:

Step 4: Meeting Structure

- How often will leadership meet?
- Who sets the agenda?
- How are decisions documented?

Quick Reflection Checklist

Before moving forward, confirm:

- Roles are clearly defined
- Decision authority is documented
- Budget oversight is transparent
- Data governance is discussed
- Dissemination approval is clarified

3. Compensation Planning Guide

Recognizing Time, Expertise, and Leadership

Why This Matters

Community members bring lived experience, cultural knowledge, trust networks, and leadership. That expertise has value. Compensation is not a gift. It is recognition of contribution.

Clear compensation planning:

- Builds trust
- Prevents misunderstandings
- Supports equity
- Demonstrates ethical partnership

Step 1: Identify Types of Contribution

Check all that apply:

- Advisory board participation
- Community leadership / co-investigator role
- Outreach coordination
- Recruitment support
- Data collection assistance
- Facilitation of community meetings
- Co-authorship / dissemination support
- Other: _____

Step 2: Determine Compensation Structure

For each role, document:

Role	Estimated Time Commitment	Compensation Type	Rate/Amount	Payment Schedule

Compensation types may include:

- Hourly rate
- Stipend per meeting
- Monthly retainer
- Contracted service agreement
- Subcontract with organization
- Gift cards (for advisory participation)

Step 3: Discuss Equity Considerations

Reflect together:

- Is compensation proportional to responsibility?
- Are community leaders compensated at a level consistent with academic collaborators?
- Are we compensating for preparation time, not just meeting time?
- Are payment timelines clear and reasonable?

Document any concerns:

Step 4: Administrative Realities

Clarify:

- How will payments be processed?
- What documentation is required?
- How long does payment take?
- Who supports vendor setup if needed?

Community partners should not carry administrative burden alone.

Step 5: Non-Monetary Recognition

In addition to financial compensation:

- Authorship credit
- Public recognition
- Conference support
- Capacity-building opportunities
- Letters of support
- Shared ownership of materials

Document agreements here:

Quick Ethical Check

Before finalizing:

- Compensation reflects expertise, not just time
- Payment process is clear and timely
- Community leadership is valued visibly
- Agreements are documented

4. Data Ownership & Governance Guide

Clarifying Who Owns, Accesses, and Shares Information

Why This Matters

Data is not just information. It represents people, experiences, and communities.

Without clear agreements about data:

- Trust can be damaged
- Communities may feel exploited
- Misunderstandings can arise
- Long-term partnerships may suffer

Step 1: What Data Will Be Collected?

Describe clearly:

- What type of data? (surveys, interviews, clinical data, observations, etc.)
- From whom?
- For what purpose?

Document here:

Step 2: Who Owns the Data?

Discuss openly:

- Does the university own the data?
- Does the community organization own the data?
- Is ownership shared?
- Is data governed through a formal agreement?

Record your agreement:

Step 3: Who Has Access?

Clarify:

- Who can access raw data?
- Who can access de-identified data?
- Are community partners given access?
- Who controls storage?

Document access levels here:

Step 4: How Will Data Be Used?

Discuss:

- Will data be used only for this project?
- Can it be reused for future research?
- Who approves secondary use?
- Will the community be informed of new uses?

Record agreements:

Step 5: Reporting & Dissemination

Clarify:

- Will results be shared with the community before publication?
- In what format will results be returned? (plain-language reports, meetings, summaries)
- Who approves public dissemination?
- How will authorship be determined?

Document agreements:

Step 6: Protecting Community Trust

Discuss:

- Are there cultural considerations?
- Are there sensitivities around certain data?
- How will privacy be protected?
- What happens if harm occurs?

Record safeguards:

Quick Ethical Check

Before moving forward:

- Data ownership is documented
- Access rights are clearly defined
- Secondary use policies are discussed
- Dissemination approval process is clear
- Community review is included

Optional: Formal Agreement

If appropriate, consider:

- Memorandum of Understanding (MOU)
- Data Use Agreement (DUA)
- Governance addendum

5. Community Advisory Engagement Checklist

A Self-Assessment for Ethical Partnership

Why This Matters

Community advisory structures should be meaningful.

This checklist helps teams evaluate whether engagement is:

- Early (not late-stage)
- Shared (not one-directional)
- Compensated (not volunteer-dependent)
- Transparent (not extractive)

Early Involvement

- Community partners were involved in identifying the priority.
 - Community partners contributed to shaping the research question or project aim.
 - Engagement began before proposal submission.
- If not, what is the plan to strengthen early engagement?

Shared Decision-Making

- Community members have a defined leadership role.
- Decision-making authority is documented.
- Community partners review major project decisions.
- Conflict resolution processes are agreed upon.

Compensation & Support

- Advisory members are compensated for time and preparation.
- Payment timelines are clear.
- Administrative processes are not burdensome.
- Non-monetary recognition is documented.

Communication & Accessibility

- Meetings are scheduled at accessible times.
- Materials are written in plain language.
- Language translation is available if needed.
- Virtual options are available if necessary.

Data & Dissemination Transparency

- Community advisors understand how data will be used.
- Advisors review findings before public release.
- Results are returned to the community in accessible formats.
- Authorship and recognition expectations are discussed.

Sustainability & Long-Term Relationship

- Engagement continues beyond the funding period.
- There is a plan to maintain communication after project completion.
- Capacity-building opportunities are shared with community partners.

Quick Integrity Check

Before moving forward, ask:

- Are we engaging for input, or for partnership?
- Would community members describe this as shared leadership?
- Are we building trust, or just compliance?

Document reflection:

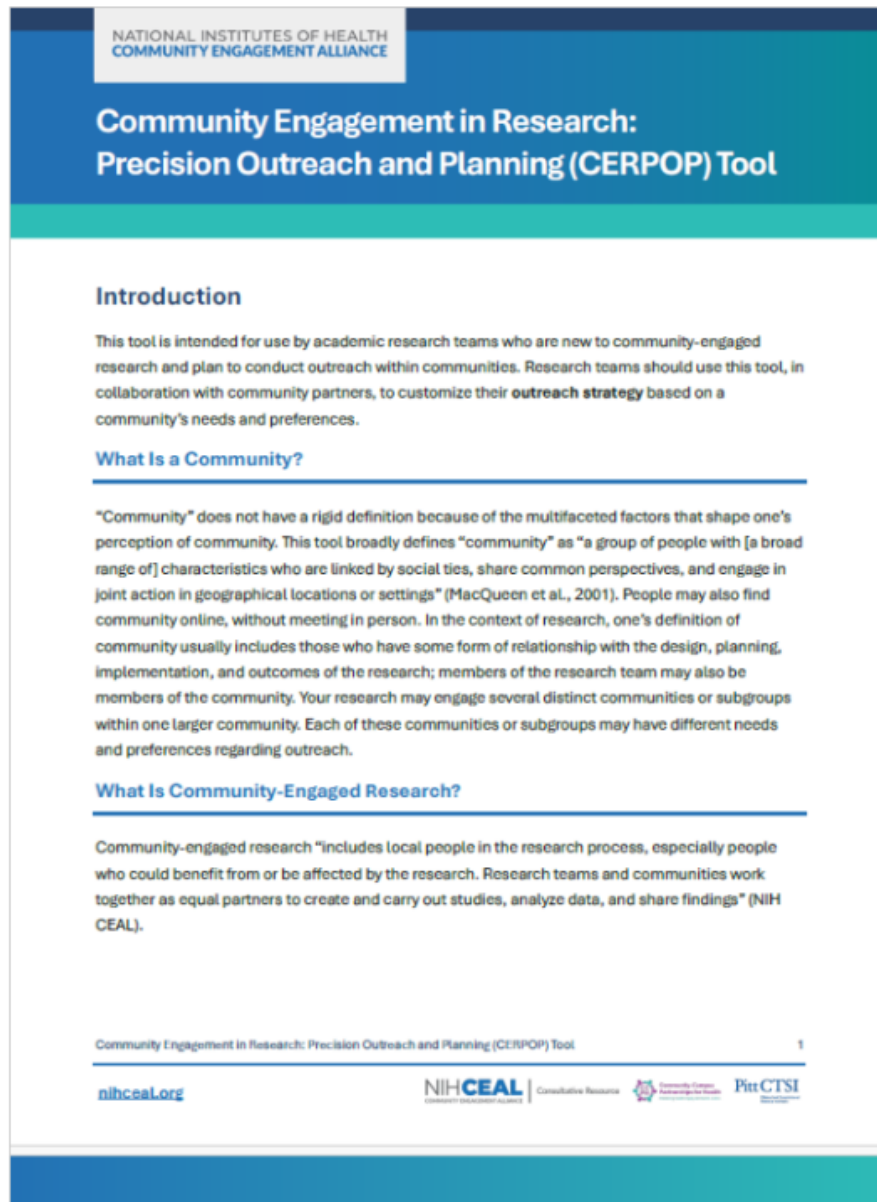
6. NIH CEAL Precision Outreach & Planning (CERPOP) Tool

External Resource

This nationally developed tool supports structured, tailored outreach planning. It helps teams define their target community, design engagement strategies, and document outreach decisions collaboratively.

For federal proposals, CERPOP strengthens engagement documentation aligned with NIH expectations. For foundation and corporate funding, it demonstrates tailored and community-informed outreach planning.

This resource was developed by the NIH Community Engagement Alliance (CEAL) and remains the intellectual property of its developers.



Access this tool at: <https://nihceal.org/resources/ceacr-precision-outreach-and-planning-cerpop-tool>

7. Community–Academic Concept Brief

A 1–2 Page Project Summary

Why This Matters

A concept brief helps teams clarify their idea before writing a full proposal.

It ensures:

- The community priority is clear
- The aim is specific
- The engagement approach is intentional
- Fairness safeguards are documented
- Sustainability is considered

Project Title

Short, clear, community centered.

Community-Defined Problem (Significance)

In plain language:

- What is the issue?
- Who is affected?
- Why does it matter now?
- What evidence or lived experience supports this concern?

Keep this to 1–2 short paragraphs.

Specific Aim

State one clear aim:

The goal of this project is to _____
in order to _____
for _____.

The aim should be measurable and realistic.

Target Population

- Who specifically are you working with?
- How is this population defined?
- How were they identified?

Engagement & Outreach Strategy

(You may reference CERPOP here.)

- How will community partners be involved?
- How will outreach be tailored?
- What level of engagement is planned?
- How will feedback be incorporated?

Approach (What You Will Do)

Briefly outline:

- Key activities
- Timeline (high level)
- Who leads each activity
- How progress will be tracked

Bullet points are encouraged.

Expected Outcomes

What will change?

Short-term outcomes:

- _____

Long-term outcomes:

- _____

How will success be measured?

Equity & Fairness Safeguards

- How are community partners compensated?
- How is decision-making shared?
- How is data ownership handled?
- How will results be returned to the community?

Sustainability Strategy

After funding ends:

- What continues?
- Who maintains the effort?
- Can this integrate into existing systems?
- Is policy or institutional change part of the strategy?

Funding Alignment

Which funding lane fits best?

- Federal research (NIH, PCORI, CDC)
- Federal implementation (HRSA, state health departments)
- Foundation
- Corporate philanthropy
- Health system or payer support

Why is this a good fit?

Final Readiness Check

Before submission:

- The aim is clear and measurable
- Community leadership is visible
- Engagement is structured
- Budget implications are considered
- Sustainability is addressed

8. Budget Planning Checklist

Ensuring Your Budget Reflects Your Values

Why This Matters

A budget is more than numbers. It reflects:

- Whose work is valued
- How responsibilities are distributed
- Whether fairness commitments are real
- Whether the project is feasible

Personnel Costs

- Academic lead time
- Community lead time
- Project manager
- Evaluator
- Outreach staff
- Administrative support

Ask:

- Does compensation reflect level of responsibility?
- Is community leadership compensated proportionately?
- Is preparation time included?

Community Compensation

- Advisory board stipends
- Meeting honoraria
- Travel reimbursement
- Childcare support (if needed)
- Interpretation/translation services

Ask:

- Are compensation timelines realistic?
- Are administrative processes clear?
- Are indirect burdens minimized?

Outreach & Engagement Costs

- Printing and materials
- Venue rental
- Technology platforms
- Transportation support
- Food/refreshments (if appropriate)

Ask:

- Does the outreach plan match the engagement strategy?
- Are community access barriers addressed?

Data & Evaluation Costs

- Data collection tools
- Software
- Analysis support
- Data storage/security

Ask:

- Are resources allocated to ensure data privacy?
- Is community review of findings supported?

Indirect & Administrative Costs

- University indirect costs
- Organizational administrative fees
- Subcontract arrangements

Ask:

- Are indirect costs transparent?
- Are community organizations fairly supported through subcontracts when appropriate?

Sustainability Planning Costs

- Training
- Capacity-building
- Integration into existing systems

Ask:

- Does the budget prepare for continuation beyond the grant?

Final Budget Integrity Check

- Budget reflects shared leadership
- Compensation is equitable
- Engagement costs are realistic
- Evaluation is supported
- Sustainability is considered

9. Sustainability Planning Worksheet

Ensuring Long-Term Community Benefit

Why This Matters

Ethical co-creation requires thinking beyond the funding period.

Sustainability planning ensures:

- Community benefit continues
- Trust is maintained
- Infrastructure is strengthened
- Partnerships remain intact

What Continues After Funding?

Describe:

- What activities continue?
- What outcomes persist?
- What community structures remain?

Institutional Integration

Can this effort be integrated into:

- Health department programs
- Health systems
- Community organizations
- Schools
- Policy initiatives

If yes, how?

Capacity Building

Did the project:

- Train community members?
- Develop leadership skills?
- Strengthen organizational infrastructure?
- Create reusable tools or materials?

What remains after funding ends?

Policy or Systems Change

Did the project aim to influence:

- Organizational policies
- Institutional practices
- Public policy
- Funding streams

What changes will persist?

Future Funding Strategy

Is the next step:

- Federal submission
- Foundation support
- Corporate philanthropy
- Institutional adoption
- Fee-for-service model
- No further funding required

Describe next funding milestone:

Community Commitment

Discuss openly:

- Does the community want this work to continue?
- Are they prepared to remain engaged?
- What support is needed?

Final Sustainability Check

- Long-term benefit is clear
- Institutional support is identified
- Community leadership remains visible
- Follow-up funding or integration plan exists

References

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research.
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