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ENSURING YOUR RESEARCH IS DISSEMINATED:

Proactive Steps to Involve Your Community-Led and Patient-Centered Audience

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ABOUT TEXAS HEALTH INSTITUTE

Texas Health Institute (THI) is a nonprofit public health institute with a mission to advance the health of all. THI serves as a vital force in advancing systems-level solutions to address some of our state's most pressing public health and healthcare challenges. As a neutral convener, data-driven leader, trusted community partner, and the administrative backbone for several community- and state-level efforts, we consistently bring together diverse stakeholders to co-create and advance actionable, community-led solutions.

Public Health Impact Areas

- Advancing health systems transformation to increase access to whole-person and community-centered healthcare for all.
- Strengthening public health infrastructure to effectively meet population health needs and address public health crises of the 21st century.
- Promoting healthy communities to create resources, systems, and environments that provide health opportunities, free from barriers, for communities to thrive.

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TABLE OF CONTENTS

Introduction

WHY THIS APPROACH? WHY NOW?

Disseminating research findings back to the communities that inform and shape the work is more than just good practice—it is a matter of equity, accountability, and trust.

Too often, communities that have been historically marginalized or harmed by extractive research practices are left out of the final step: understanding how their contributions shaped outcomes and whether those outcomes led to meaningful change[1]. Today, public health, healthcare, and socio-political systems are increasingly strained by underinvestment, shifting policies, and persistent inequities. Public trust continues to erode, particularly among underrepresented communities. The need to practice ethical dissemination centered around the community has never been more urgent.

> *"A lot of the community is really tired of being surveyed and being assessed because we never get results back."*
>
> *– Gregory L. Casillas*

This project is a direct response to that need. It is built on the belief that dissemination is not the end of the research process; it is an opportunity to return value, reinforce trust, and advance equity by ensuring that communities are seen, heard, and informed in ways that matter to them.

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[1] Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health, 19*, 173–202. https://doi.org/10.1146/annurev.publhealth.19.1.173

OUR JOURNEY FROM BUILDING CAPACITY TO CENTERING COMMUNITY-LED DISSEMINATION

Since 2018, our team has worked to establish a statewide infrastructure for research that is rooted in community priorities and designed to build community power. What began as a collaborative effort to build community-engaged research capacity across Texas has grown into a robust network dedicated to advancing *community-led* research across the PCOR/CER continuum.

Through this work, we have supported and co-created projects that reflect community-identified priorities, emphasized multi-directional learning, and advanced equitable engagement practices. One consistent theme emerged across all the efforts: dissemination was often treated as an afterthought, rather than a strategic, relationship-centered phase of the research process. Disseminating results is not a “like to;” it is a “must have.” It needs to be planned for at the outset with intentionality and appropriate resource allocation.

We designed the *Ensuring Your Research is Disseminated* guide to help research teams, especially those rooted in community settings, plan their dissemination efforts with the same care, intentionality, and humility that is applied throughout the rest of the research and engagement lifecycle.

WHO THE GUIDE IS FOR

We recognize and appreciate the many researchers, practitioners, and institutions who have worked to evolve their approach along the community engagement continuum from outreach to shared leadership. We intend for the guide to serve as a next-step resource for those already committed to equity and partnership.

While we welcome all research teams into this conversation, this guide has been designed specifically with community-led researchers and community leaders in mind. Individuals grounded in their communities, guided by local priorities, and trusted to lead on behalf of those most impacted by the research. We believe that these leaders are uniquely positioned to redefine what dissemination looks like when it is rooted in trust, relevance, and respect.

To help clarify how this work applies across different models of engagement, Figure 1 provides an outline of key distinctions between community-informed, community-engaged, and community-led research approaches.

Figure 1: Comparing Research Dissemination Approaches

Criterion	*Community-Led Research*	*Community-Engaged Research*	*Community-Informed Research (Conventional)*
Community Member Role	Guides and leads the research and dissemination process from start to finish	Actively partners in some research and dissemination activities	Provides input but has limited or no decision-making power
Dissemination Leadership	Patients and community stakeholders lead dissemination efforts	Shared leadership between research team and community	Dissemination led primarily by the research team
Engagement Depth	Deep, ongoing collaboration and co-creation	Regular interaction and involvement	Occasional consultation or communication
Impact on Research Design	Community shapes research questions, methods, and outcomes	Research team incorporates community input	Research team designs and conducts research independently
Dissemination Goal	Broad and culturally tailored dissemination led by community	Collaborative dissemination, informed by community preferences	Traditional academic or clinical dissemination methods
Examples of Activities	Community advisory boards, co-authorship, community presentations	Joint workshops, focus groups, shared dissemination planning	Surveys, feedback forms, research summaries shared post-study

Note: This table is not intended to be exhaustive or prescriptive. It is designed to note the key differences across the levels of community participation and engagement to help differentiate between community-informed, community-engaged, and community-led research. We recognize that engagement exists along a continuum and that each research context may include elements that overlap or evolve.

HOW TO USE THE GUIDE

Our framework is organized into seven steps designed to educate and inform community-led researchers in planning dissemination activities that are trustworthy, relational, reciprocal, and that reinforce PCOR/CER foundational expectations. Each step of the framework builds upon the others. The steps can be used sequentially or independently, depending on where you are along the research continuum.

Each step includes:

Focus and Framing
A clear description of the core principle or recommendation behind the step and why it matters.

Reflective Questions
A curated set of questions designed to help researchers and teams critically reflect on their own practices, approach, and context.

Community Context and Insights
Observations and experiences from our team and community partners that help ground each step in lived realities, including challenges and lessons learned.

Action Steps and Planning Guidance
Practical suggestions for how to move from reflection to action, with tools and checklists where appropriate.

Together, these components are designed to support researchers in what to do, how to do it, and why it matters in ways that reinforce relationships, build local credibility, and advance the shared goal of community wellbeing.

RESOURCES AND REFLECTIONS

To complement this guide, we have developed an accompanying video featuring community leaders, researchers, and trusted partners who share their lived experiences, community perspectives, and aspirations. Organized around the seven steps, the reflections offer a human lens on the recommendations presented throughout this resource—helping to contextualize, deepen, and personalize the included insights and strategies. We encourage you to watch the video and share it with other researchers or community members. Use it as a starting point to ground the work with real voices and community realities.

This resource was co-created with input and leadership from community leaders and researchers who brought their lived experiences and expertise to this effort. We are deeply grateful to each contributor for their time, wisdom, and commitment. Throughout the guide and video, contributors are identified only with their informed consent and in ways they prefer, with safety and context in mind.

Step 1: *Engage Early, Build Trust Through Presence and Listening First*

FOCUS AND FRAMING

Too often, researchers engage communities only when a study is ready to launch or when data collection is about to begin. But community-led research starts with trust-building at every stage of the research journey.

> *“It is so important to create connection and community before you even envision a project, because to authentically envision a project with the community and with an organization, they've gotta be there from the very beginning.”*
>
> *– Kelly Ducheny*

Early, relationship-based engagement is about showing up before the project exists, and showing up consistently, not transactionally. This approach shifts research from being a one-sided extraction of information to a collaborative process rooted in trust, relevance, and mutual respect. Early and authentic engagement offers researchers, community members, and other stakeholders the opportunity to listen and learn before speaking, pitching, or planning.

> *“Not every community member cares so much about what is the question, but they want to know why you're asking. And that's, I think, one of the most important things to get across to community members, to participants, to make them feel engaged.”*
>
> *– Jamison Green*

Some opportunities to engage early and authentically include:

- Setting up introductory meetings with community-based organizations, businesses, community groups, religious spaces, and more
- Attending community fairs
- Putting up ads or flyers in community spaces
- Engaging in virtual community platforms

Listening first allows researchers to begin appreciating the community's context.

Consider asking:

- Why does the community operate the way it does?
- Where and how does the community gather?
- How is information exchanged, processed, and trusted?
- Who does the community look to for leadership, and what builds or breaks trust?

Understanding the community's context creates the foundation for whether or not to engage and how to engage in ways that are culturally respectful, community-informed, and contextually sensitive. These early steps also help identify which ideas are welcome, relationships need to be strengthened, and questions need to be co-developed.

> *"Wanting to ensure that work uplifts community narrative and contributes to solutions that your community cares about. Seems like it has to start from the very absolute beginning, in the creation of the work"*
>
> *– Sarah Bowman*

Importantly, early engagement is active. It is a strategic investment in long-term partnerships. It means showing up in community spaces, participating in local events, and allowing community priorities, not research timelines, to guide the pace and nature of the relationship. It also means building resources, compensation, and decision-making opportunities from the beginning for community members.

REFLECTIVE QUESTIONS

Use the following questions to reflect on your experience and readiness. Researchers, clinicians, and organizational leaders, write down your answers before engaging with community members. Community members, write down your expectations for these questions.

- What does it look like when a researcher shows up early and stays involved, even when no project is on the table?
- How have histories, past research experiences, or systemic harms shaped the way your community receives new researchers?
- What makes someone a trusted partner in your community?
- What do researchers often miss or misunderstand about your community before initiating a project?

COMMUNITY CONTEXT AND INSIGHTS

Take a few minutes to listen as Atlantis Narcisse and Kelly Ducheny, PsyD, two of our DAP members, share their reflections. Their stories illuminate the nuance of early engagement and what it looks like in practice.

Across our work, we have observed a pattern: researchers who take time to build presence, relationships, and commitments early are far more likely to co-create studies that matter to communities and sustain partnerships that last beyond a single project. Early engagement allows researchers to become familiar with local dynamics.

> *"When you come into this space, don't just come and get the information, but come back and bring it back to us and teach us how to teach it back to our community and then come back."*
>
> *– Atlantis Narcisse*

Consider asking the community:

- Where do people meet?
- What events are important?
- Who holds influence?
- What builds credibility and what undermines it?

We often refer to this approach as “learning by walking around,” a term borrowed from management practice that emphasizes immersion and observation. It is about learning with humility, not assuming expertise, and building trust through consistency, not charisma.

> *“And so all of the relationship building they did before, as they were in grad school, as they were making choices about anything else they were doing, that community memory can be long… that lays foundation in phenomenal, effective ways”*
>
> *– Kelly Ducheny*

Early engagement also helps build mutual capacity. Researchers practicing community-led research should invite community members into their organization to understand how research works, how data is collected and protected, how ethics are upheld, and what roles they can play. They should provide transparent and fair compensation, including for transportation, child or elder care, or time spent in consultation. They can also consider creating ongoing advisory roles, fellowships, or paid consultant positions that allow community partners to be embedded in your research environment.

> *"You've got to come in as an authentic partner and you have to involve the community in data analysis, because if you don't, you're getting little pieces that you can see, but you're missing really profound pieces that nobody's going to tell you about because you just don't get it."*
>
> *- Kelly Ducheny*

ACTION STEPS AND PLANNING GUIDANCE

Early engagement is a mindset shift, from outreach to presence, from pitching to listening, from assumptions to learning. It is the first, and one of the most essential acts of trust-building in any research relationship. When done right, it sets the tone for a research process, including dissemination, that is accountable, ethical, and deeply rooted in community priorities.

> *"Researchers positioning themselves in advancing community-led efforts really need to be driven by listening first, both intently and actively, and not pursuing efforts with underlying assumptions."*
>
> *– Ankit Sanghavi*

Consider a few ways to put this step into action:

Co-Develop Community Agreements
Meet with community members early to define what a "trusted partnership" looks like. Co-create agreements that reflect shared values and revisit them at the beginning of each meeting. These are not guidelines; they are relational contracts.

Host Regular "Lunch and Learn" Gatherings
Create informal spaces for dialogue between researchers and community members. Use this time to build mutual understanding, share histories, and learn about each other's goals and barriers.

Support Priority-Setting Conversations
Facilitate listening sessions that elevate community priorities outside of a specific research proposal. Use these insights to shape future funding strategies and project development. Be sure to compensate community participants for their time and expertise.

Approach Early Engagement as an Investment
Like business development in other sectors, early engagement is an investment in future collaboration. For researchers, this is about creating authentic relationships. For communities, it is a form of economic development, a way to bring in resources, visibility, and opportunity when research is done well.

Step 2: *Align Community Values, Histories, and Ethical Principles*

FOCUS AND FRAMING

Building on the inherent value and importance of early engagement emphasized in Step 1, this step focuses on ensuring that community-led research dissemination efforts are rooted in the values, histories, and lived realities of the communities involved. Community-led dissemination is not just about sharing results, it's about doing so in ways that are culturally acceptable, respectful of past experiences, and aligned with ethical engagement principles such as those outlined in PCOR's Foundational Expectations for Partnerships in Research. These expectations, drawn from years of collective learning, provide a framework for fostering representative involvement, community leadership, and shared decision-making. Importantly, honoring community values is an ongoing practice that requires teams to revisit and refine their approaches over time to sustain trust, relevance, and impact.

> *"The first thing that comes to mind when I hear about mutual respect or community driven is that community members are in the leadership team or the research team and are involved in developing the research question and methodology."*
>
> *– Oralia Loza*

REFLECTIVE QUESTIONS

Reflect on the next four questions describing your community's values. As a patient or community member, take a few moments to write down your answers to the questions from your experience working with researchers and their organizations. If you are a researcher, clinician, or other stakeholder, write down how you would respond to a community member asking these questions.

- How have past experiences with outside institutions or researchers shaped how your community expects to be engaged?
- When you hear phrases like "mutual respect" or "community-driven," what do they mean in your context?
- What examples—good or bad—stand out to you where these principles were followed or ignored?
- What guidance would you give to researchers about how to make these principles come alive in your community's reality?

COMMUNITY CONTEXT AND INSIGHTS

Take a few minutes to listen as Oralia Loza, PhD, and Gregory L. Casillas, BS, MA, two DAP members, share their reflections. Their responses describe mutual respect and what community-driven means in shaping dissemination expectations.

Our guiding principle is to focus on the voices, expertise, and lived experiences of the people most affected by the issues we are tackling. This approach helps us build genuine trust with our community partners because it emphasizes transparency, ongoing dialogue, and shared decision-making. In fact, trust is earned; it grows when all partners engage openly, listen actively, and honor each other's perspectives. We also recognize the importance of team dynamics and intentional support. Effective collaboration means recognizing the diverse strengths everyone brings to the table, supporting one another, and creating spaces where people feel comfortable expressing questions or concerns. We all learn from each other. These components are just as essential as the research itself because they nurture an environment where innovation and empathy flourish side-by-side.

> *"There is a dynamic just being the researcher, coming in there with usually an education, which is not always held by everybody in the community. You also have the backing of an institution typically that you're doing research with. And that also has a measure of authority."*
>
> *– Madeleine Croll*

> *"If a researcher comes forward to participate in the community, they should be consistent in their intentions. That's part of being genuine."*
>
> *- Oralia Loza*

Building on this foundation, we have integrated two additional practices to enhance representative involvement. Representative involvement in community engagement refers to the process whereby selected individuals or groups are chosen to act on behalf of a larger community or population, ensuring that the perspectives and interests of that community are communicated and considered in decision-making processes. This involvement is distinct from direct participation by the whole community, aiming instead to balance inclusivity with practical deliberation through carefully selected representatives.[2]

First, we recognize the power of personal, indirect, or non-traditional mentorship, a process where patients and community members naturally share and translate research insights within their networks. This process takes place through social media and other virtual or in-person connections. This organic approach broadens our reach in meaningful ways.

> *"It's about showing up. It's about being committed to the project. It's about being committed to the community and the personal growth of the individuals"*
>
> *– Gregory L. Casillas*

Secondly, we prioritize clear, accessible communication. By using plain language that resonates with patients and stakeholders and non-technical jargon, our findings become more actionable and easier to understand. Patient and community leaders play a crucial role here, helping us craft messages that directly speak to their audiences.

> *"We know you're smart but use language that we understand... So I think it is if researchers or organizations aren't able to do that, it's really important to find the community members that are able to translate."*
>
> *– Gregory L. Casilla*

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[2] Rowe, G., & Frewer, L. J. (2000). Public participation methods: A framework for evaluation. *Science, Technology, & Human Values, 25*(1), 3–29. https://doi.org/10.1177/016224390002500101

ACTION STEPS AND PLANNING GUIDANCE

Consider implementing these two actionable examples:

Co-define terms and phrases
Convene a roundtable discussion with community members, researchers, and other stakeholders. Define the phrases “mutual respect” and “community-driven” for your work. Determine if the answers align with the community’s and research organization’s values.

Learn from each other
Organize a monthly series of lunch (or dinner) and learning sessions. Set the time to accommodate stakeholder schedules. Community members, researchers, and research organization leadership should be included. Include a member of the responsible Institutional Review Board to help inform community trust and relationship building. Ethicists can provide insight into emerging technologies and practices. Co-identifying ethical and moral practices to include in current or future research is the outcome.

Step 3: *Honor Lived Experience and Ownership*

FOCUS AND FRAMING

A community's and community members' *lived experiences* are at the core of community-led research dissemination. The speed at which research results enter clinical practice and health policy is driven by passionate community members. This begins with valuing and honoring *lived experiences*. Shared decision-making and power, equitable compensation, and continuously improving community engagement practice strongly influence the rapid dissemination of research results.

> *"For people to feel really intellectually engaged and to feel a real partnership with the researchers, they have to understand that the researcher believes that what is being asked is important, and it will have an important effect that will benefit the community directly."*
>
> *– Jamison Green*

REFLECTIVE QUESTIONS

The "heavy lift" in answering the first set of questions is on the researcher and the research organization. Write down your responses for ongoing reflection. Intentionally return to these answers as your research project evolves.

- Are equitable compensation policies in place in your organization?
- What mental frameworks are present in sharing power?
- Is shared decision-making encouraged through the organization's practice and values?

For community members, ask yourself the following questions and write down your answers.

- In your experience, how has your community's time, knowledge, or lived experience been valued or overlooked by researchers?
- Can you speak to the impact that equitable compensation or power sharing has had (or could have) on community participation?
- What are some power dynamics that often go unnoticed by researchers, and how can they shift those dynamics intentionally?
- What would it look like for your community to feel like equal partners, not just participants in the research?

COMMUNITY CONTEXT AND INSIGHTS

Listen as Madeleine Croll, MA, and Jamison Green, PhD, two DAP members, share their reflections. Their stories illuminate the importance of actively listening to community members before starting a project.

Our first meeting in 2017 with transgender community members established the value of community knowledge and lived experience. Our first community agreement established listening with humility and respect to honor a person's lived experience. We co-developed five Public Health Training Center courses based on the community's priorities. Our first PCORI project was built on the lessons learned in creating the course. We worked to build trusting relationships, honoring lived experiences. We held eight regional meetings across the 254 Texas counties to reflect the distinct regional parts of the state. Identifying the steps to build trust in medical research was the primary outcome. Enrolling LGBTQ+ community members in the first longitudinal research project was one objective.

> *"I want to see more people in my community actively doing the research as a collaboration with institutions."*
>
> *– Madeleine Croll*

> *"We're experts in this from lived experience. We are resilient in our leadership."*
>
> *– Atlantis Narcisse*

In succeeding projects, we established early community engagement at the outset. This was crucial in developing the budget, identifying outcomes, and refining the methods. Our DAP's membership goal was to include 50% from the transgender and gender diverse community. We also recruited other members of the LGBTQ+ community to provide additional perspectives. Several community members were consultants. This project represents a new milestone — two community members serving as part of the seven-member leadership team.

> *"It starts from the very beginning... If the community is engaged in forming the research questions, interpreting the data, and shaping the language, the deliverable feels like it's with them... not just about them."*
>
> *– Mitchell R. Lunn*

> *"Equitable compensation is a big part of empowering the community to actually want to step forward and participate in research."*
>
> *– Jamison Green*

Equitable compensation is often overlooked in designing research projects. Researchers practicing community-led research should explore innovative compensation practices to level the playing field with community partners. Covering transportation, childcare, and other living expenses reflects responsiveness to community needs. Community members are ahead of researchers in providing this capacity for their own projects. Community members can help co-design ongoing compensation methods that comply with fiduciary and accounting standards. They can also identify research organization policies that exclude or limit community participation. The key is for all team members to honor, value, and own the community members' lived experience and expertise.

> *"Being fairly compensated for it doesn't just put, you know, joy in my face. It actually also oftentimes will put a meal on the table."*
>
> *– Madeleine Croll*

> *"Oftentimes you do get what you pay for. And if you invest in people a little bit more and show that you value them as more than just an expense to be jotted down in a research proposal, you're going to get a lot more out of it."*
>
> *– Madeleine Croll*

ACTION STEPS AND PLANNING GUIDANCE

Consider incorporating these practices into your work:

Honor community leadership and experience
Identify what policies exist and need updating to support community member compensation. Identify innovative community compensation practices that can be applied to the research organization’s policies.

Enable community member professional development
Provide opportunities for community members to learn research practices. Members can educate the Institutional Review Boards on trust and accountability practices to carry out their responsibilities. Cover the cost and compensate for the time for community members to take CITI Institutional Review Board (IRB) and Human Subjects certification courses. Increasing community knowledge of human research requirements and expectations can improve study participation. Better-informed community members amplify research results dissemination.

Step 4: *Ensure Research Deliverables are Accessible, Meaningful, and Reflective of the Community's Voice*

FOCUS AND FRAMING

It is crucial to ensure research findings are designed and shared in ways that truly connect with the people they are meant to help. This rings especially true when working with communities like LGBTQ+ and other marginalized groups, who have often been left out or misunderstood in traditional research. Sharing what we learn is about making information useful, relatable, and easy for the community to access and embrace. Community voices are essential at every stage of the process.

> *"Being really careful about the words that you use, what you explain, the assumptions you make. And this is also why it's essential for thinking about language or the way that you're providing data or results, or a tool or a product that you can use based on data. Is really to have that iterative process with community, right?"*
>
> *– Lindsay Rosenfeld*

> *"Researchers need to explain to the community members who are engaging with them how they operate and exactly how they're how they fit into an institutional setting and what it is that they are aiming to achieve through interviewing them, through doing this research."*
>
> *– Jamison Green*

REFLECTIVE QUESTIONS

As a community member, you will have a unique view of how to effectively reach your community. Write your answers to these questions and share them with researchers and other stakeholders. As a researcher, consider how you would respond when a community member asks these questions. Write your responses down and reflect on them over time, especially between research studies. This is a good exercise in understanding who your "real world" audience is.

- Can you recall a time when a research finding or product was usable or made a difference in your community?
- What makes a deliverable feel like it was created with the community and not just about the community?
- What formats or languages are most effective for reaching different groups in your community?
- How can researchers ensure their work uplifts community narratives and contributes to the solutions your community cares about?

COMMUNITY CONTEXT AND INSIGHTS

Watch as Sarah Bowman, MPH, Lindsay Rosenfeld, ScM, ScD, and Mitchell R. Lunn, MD, MAS, three of our DAP members, share their reflections. Their stories illuminate the description of meaningful research deliverables, using plain language, and reducing the community's burden of dissemination.

Researchers practicing community-led research should meet community members in their spaces. The emphasis of meeting people where they are, both physically and virtually, was repeatedly highlighted in our discussions. This was the single most important priority we heard in our meetings, listening sessions, and discussions with stakeholders. Whether it is in community centers, advocacy group meetings, or family gatherings, showing up where people are can make a world of difference.

> *"Community-driven is really listening to the community and being out in the community and being there."*
>
> *– Oralia Loza*

Individual communities face plenty of hurdles in understanding research results. The LGBTQ+ community and other marginalized groups face a lack of research focused on community needs. Too few marginalized voices are research team members, much less, team leaders. This imbalance can influence the entire research process.

> *"Think with the community from idea generation to design to dissemination… That's how you make sure the work benefits the people it's meant to serve."*
>
> *– Lindsay Rosenfeld*

Another serious challenge is how research findings are shared with community members. This is especially important for people who took part in the research study. Too often, results are found in academic journals, behind paywalls. Unfortunately, these articles remain out of reach without access to electronic library accounts, or the researcher pays for the article to be published as open access.

> *"We use different formats… scientific papers for some, but also one-page summaries at an eighth-grade reading level, infographics, and even rotating slides for waiting rooms… Meeting people where they are matters."*
>
> *– Mitchell R. Lunn*

> *"Findings need to live in different spaces… sometimes published for government use, sometimes on platforms community members use every day. That mix makes the work accessible."*
>
> *– Sarah Bowman*

Presentations are important as well, but most LGBTQ+ and marginalized community members do not have access to the convening's materials in a useful format. They may also have limited knowledge of the research finding's results and terminology. As such, this creates a knowledge gap between research dissemination and community members. The consequences of this gap are that important insights become inaccessible to the very people who can benefit most from them. Clear, plain language and community co-designed packaging increase research dissemination. Dissemination materials should be rooted in community culture and communication styles.

> *"Community members should help interpret the data, not just provide it… That way findings make sense for them and can actually lead to change."*
>
> *– Mitchell R. Lunn*

> *“Even if there is a genuine attempt at community connection and community outreach, it's almost always external to the conference itself and does not involve free access to the conference. You almost always have to purchase a membership. You almost always have to pay hundreds of dollars to register. It's so out of reach for most community members that almost all of that is then happening in an academic vacuum.”*
>
> *– Ethan Coston*

In short, intentional co-design to disseminate research results is key to advancements in clinical practice and health policy application. When communities see themselves reflected, not just in the process, but in the deliverables, outcomes, and actions that follow, that’s when change begins.

ACTION STEPS AND PLANNING GUIDANCE

Consider the following actions in moving forward with your work:

Meet in the community
Meet with community members in their community space. Ask how best to disseminate research information, including results. Build a list of venues or places where community members meet. Show up in these places early and often, especially before starting a project. Determine the most appropriate means to share information in each type of venue or setting. Identify the digital divide and how to bridge the other side.

Partner with elder mentors
Identify community members who serve as elder mentors. Many communities have formal or informal programs for the younger generations to learn from their elders. Determine how best to provide information and in what format to elder mentors.

Identify rapid dissemination technologies
Create lists of community member Discord servers, Facebook groups, or other many-to-many dissemination and collaboration systems. Develop liaison opportunities with community members who lead these services. Host quarterly lunch/dinner-and-learn meetings to reinforce research partnerships. Attendees can learn from each other what works and what does not work.

Step 5: *Account for Cultural Relevance, Community Dynamics, and Trusted Venues*

FOCUS AND FRAMING

Disseminating research is about what you say, where you say it, and how you say it.

> *"If you're talking about research, I think that people are going to their trusted sources... People, when they're looking for research, are really looking for this communication that they can understand. So instead of talking in the scientific language, we're often speaking of. What people are looking for is how it translates to them and how does it impact their community directly."*
>
> *– Stacey Griner*

This step is about meeting people where they already are, in spaces they feel comfortable and connected to. Without thoughtful dissemination, even the most important findings risk being overlooked or ignored. Community members should lead in getting the word out. They understand cultural relevance, grasp community dynamics, have access to trusted venues, and can passionately drive research results into action.

> *"We need to be more responsive to being genuinely led by community as well. And in order for that to happen, I think that critically, all research projects need to be, ideally from the beginning, genuinely, genuinely, collaboratively led."*
>
> *– Ethan Coston*

> *"I see dissemination miss the mark all the time. We broaden the message so much that we lose the specific needs of the trans and gender diverse community... Culturally tailored materials would make a huge difference."*
>
> *– Stacey Griner*

REFLECTIVE QUESTIONS

Community members can use the following questions as an opportunity to think about how to connect and share information in a culturally relevant manner. For researchers, answering these questions with community members will help your message be heard, trusted, and acted upon.

- Where do people in your community already go to access information or have important conversations?
- What are some examples of trusted messengers or spaces (physical or virtual) in your community, and why do they matter?
- Can you describe the types of places or events where research dissemination has missed your community? What could have worked better?
- How can researchers become more attuned to the everyday realities and priorities that shape where and how your community receives information?

COMMUNITY CONTEXT AND INSIGHTS

Take a few minutes to listen as Stacey Griner, PhD, MPH, and Ethan Coston, PhD, two of our DAP members, share their reflections. Their stories illuminate the importance of understanding how community members receive information and what this looks like in practice.

Our literature search and community discussions confirmed important ideas to successfully disseminate research results, with community members taking ownership to inform the community in accessible spaces. These include:

- Leading with an inclusive team to ensure diverse perspectives and cultural competence are always centered in the work.
- Shifting from community-informed or community-engaged approaches to community-led dissemination, allowing the community to tailor messaging culturally

and broadly. Encouraging community members to disseminate the results in a manner that is culturally relevant.
- Identifying a mix of physical and virtual channels, libraries, community centers, private Facebook groups, Discord channels, and other trusted online spaces where community members are active.
- Culturally tailoring the dissemination materials to address the community's unique needs and preferences. Writing the materials using language and terms the community understands.
- Providing capacity building for community organizations and advocates so they can share information effectively within their networks. This is a great way for universities and research organizations to host learning and community professional development in the community using community venues.
- Remaining flexible and responsive to the changing social and political environment—what works in one area might not in another.
- Budgeting for translations to reach a broader audience.
- Screening materials to ensure accessibility for all community members, including those with vision or hearing challenges.

Creating an effective dissemination plan is about more than just sharing information—it is about empowering communities to own and spread knowledge in ways that resonate deeply with them. Researchers practicing community-led research should take the time to explore and engage in the physical and virtual spaces the community values. They should collaborate closely with community members to co-create plans that are inclusive, culturally relevant, and accessible. This method, thoughtfully applied, ensures everyone involved already knows what to expect because they have been part of the process over time.

> *"I have seen transform work happen when you have developed partnerships before starting the process, or the project, with the people you work with. I've started my partnerships years before I begin projects because I want to get to know people, but also because my work is informed by the needs in the community. If you have a partnership, there's also more buy in from the community."*
>
> *– Stacey Griner*

> *"Research needs to be genuinely led by community from the beginning… not just monthly check-ins but steering the ship together. That's how you learn where people really get information."*
>
> *– Ethan Coston*

ACTION STEPS AND PLANNING GUIDANCE

Consider stimulating collaborative action in creating a PCOR/CER dissemination framework and process in the following ways:

Dissemination is a two-way street
Meet with individuals and groups of community members in their space. Identify how you, as a researcher, can stay more informed on everyday community realities and priorities. Community members should identify the ways and means to keep researchers informed of community dynamics.

Informed dissemination
Assemble a cross-section of people with knowledge and skills in creating trusted messages. Develop a format to consistently disseminate research findings. The Pride Study is one example of a research program sharing a 1-page synthesis of a study’s findings. While the dissemination means are varied, such as infographics or webinars, the core message for each study’s findings drives home how researchers are giving back to the community.

Access community spaces
Develop creative ways to immerse yourself in important community venues. Find the community restaurants and other venues. Consider how to use neighborhood dinners to increase dissemination access. Explore ways to engage, increase awareness, and build relationships while also identifying venues to share research findings.

Step 6: *Healing, Accountability, and Ethical Research Grounded in Trustworthiness*

FOCUS AND FRAMING

In an era where social media accelerates the spread of information with both positive and negative effects, and socio-political landscapes shift rapidly, it is impossible to work in isolation from these forces. LGBTQ+ and other marginalized communities face significant and growing challenges. The principles of doing no harm and fostering trust apply to many communities and it calls for actively safeguarding the dignity, safety, and autonomy of the communities we serve. Whether addressing social justice, immigration, genetic diseases, vaccinations, or women's health, prioritizing harm reduction and trust-building is critical to meaningful, ethical, and moral engagement.

> *"The research community causing unintentional harm and intentional harm and there being consequences, those consequences often look like community not stepping forward anymore"*
>
> *– Rocky Lane*

> *"There's been a long, extractive history... research taking and not giving back. That's why so much mistrust exists; it's a protective mechanism... and it's valid."*
>
> *– Rocky Lane*

This step illustrates why research dissemination must embed these commitments from the outset. It can shine a light on what matters most to people, to help move the resources, attention, and support in the right direction. When researchers get it right, we create safer, more inclusive spaces and build lasting relationships necessary for real impact.

> *"Being in the community with us, coming in prepared, and showing they know where they can genuinely be of support."*
>
> *– Rocky Lane*

> *"When researchers come to work with a community that historically has been underserved or misrepresented in, or left out of, research process. Researchers should acknowledge that"*
>
> *– Oralia Loza*

Healing, accountability, moral, and ethical research grounded in trustworthiness are important considerations in not only upholding trust but strengthening the foundation for lasting, equitable change.

REFLECTIVE QUESTIONS

As a member of a community, especially one that is marginalized, write your answers based on your lived experience. Do not try to speak for other members in the community since you can only share your experiences. Researchers and other stakeholders should consider how you would respond to a community member sharing their experiences. Even if you are a researcher and a member of a marginalized community, be careful not to generalize your experiences to that of the community.

- How has research intentionally or unintentionally caused harm in your community, and what were the consequences?
- What does trust look like, feel like, or require in your community, especially when working with outside researchers?
- Can you describe what accountability means to your community in the context of research?
- What do researchers need to understand about historical trauma, cultural mistrust, or community fatigue with extractive engagement?

COMMUNITY CONTEXT AND INSIGHTS

Take a few minutes to listen as Rocky Lane and "J" John Oeffinger, two of our DAP members, share their reflections. Their stories illuminate historical trauma, cultural mistrust, and research community fatigue, and thoughts to overcome these in practice.

“Do no harm” means actively avoiding negative consequences and promoting positive outcomes. To “foster trust” is to build genuine, respectful relationships grounded in honesty and understanding. It means showing up early, being transparent about intentions, and listening with humility.

> *“Trust depends on the space… is it truly safe? In-person or online, we look for signs: do researchers make themselves vulnerable… do they share something personal to signal we can too?”*
>
> *– “J” John Oeffinger*

> *“[Trust] looks like, getting your hands dirty. That you're in the community, working with us.”*
>
> *– Rocky Lane*

Since our initial 2017 Community Agreement, these principles have been central to our work, particularly in a divided and complex social environment.

Our approach incorporates:

- Prioritizing cultural competence by involving project members with lived experience or history supporting transgender and gender diverse communities.
- Committing to inclusive language reinforced through training and open conversations.
- Creating physically and virtually safe, affirming spaces, adapting quickly when circumstances like the pandemic required new approaches.
- Protecting confidentiality and privacy as foundational, non-negotiable practices.
- Leveraging trusted, ongoing relationships as the backbone of community engagement.
- Fostering transparency, accountability, and open communication in every step.
- Ensuring all participants share power in decision-making, moving from community-engaged to community-led.
- Recognizing and respecting cultural diversity, especially when working across regions and backgrounds.

We also need to separate individual stakeholders from their organization in our thought process. An individual researcher might hold themselves accountable for their ethical research practices and trustworthiness. However, the researcher’s organization values may not align with the moral and ethical conduct of medical research. This disconnect can influence a community’s view of the research as untrustworthy. The result is decreasing participation in research studies. This will be a challenge in the years ahead.

Embedding “do no harm” and “foster trust” is fundamental in creating community relationships. It honors individuals’ dignity and rights while building a stronger, more equitable society, even amid polarization.

> *“You're building trust by saying, I've done my homework and I know where I can be of support.”*
>
> *– Rocky Lane*

> *“Partnership goes a long way in building credibility, reinforcing trust, and most importantly, making sure that the research reaches the ones who are going to be most impacted.”*
>
> *– Ankit Sanghavi*

Every project team and every research organization must consider how they are ensuring their work causes no harm and actively builds trust with the communities they serve. These are ongoing commitments. Prioritize learning, listen deeply, and co-create with communities, not for them. Only by embedding these principles can you transform research and outreach from transactional efforts into genuine partnerships that affect lasting, positive changes.

> *“Research has often undervalued the community… our voice, our participation, even our power in the work. Too many times, we’re invited to speak, but what we say isn’t truly listened to.”*
>
> *– Rocky Lane*

> *“Community members need to see themselves in the research results. If they don’t, the mistrust grows. If they do, it can heal some of that trauma.”*
>
> *– “J” John Oeffinger*

If you are truly looking for healing, accountability, and ethical research grounded in trustworthiness, you must continuously engage in the hard work to make this happen. Engaging as such means making yourself vulnerable to better understand another person’s perspective.

ACTION STEPS AND PLANNING GUIDANCE

Consider the following examples to help spur ideas on how to look for solutions:

Reducing unintentional harm
Convene a working team of community members, researchers, organization leaders, and other stakeholders. Consider recruiting someone who can bring ethical and moral knowledge and/or experience to the table. Ask and answer the questions as a group, "How has research, intentionally or unintentionally, caused harm to the community? What are the consequences? What are the solutions? How will we act and put possible solutions into practice?"

Create trust and reduce harm
Create a working team with the same mix of stakeholders as in the previous example. Develop a shared understanding and agreement on what trust looks like, feels like, and is required for community-led research, including working with outside researchers. Consider what organizational policies need to be addressed to create trust between the community and the research organization, and who will be accountable for ensuring the policies are updated and practiced by all parties.

Implement policies, practices, and incentives to bridge knowledge silos
Two problems researchers and community members face are siloing knowledge and lived experience. An earlier PCORI project explored the impact COVID-19 was having on transgender and gender diverse people. We looked at how an individual, community, and organization dealt with mental health, employment, and housing. Historically, these three areas have been treated individually. This project looked for intersecting elements, treating all three as one system. Think about how research teams can design studies that look for intersections beyond just the research question.

Implement policies, practices, and incentives to reduce trauma and create "safe spaces"
Explore if your research team members understand the impact of historical trauma, cultural mistrust, and how this contributes to community fatigue on medical research and dissemination of research results. Even the dissemination of research results can trigger trauma in the person sharing the information. Find out how you can create safe spaces where people thrive.

Step 7: *Sustain the Engagement and Commit to Long-Term Change*

FOCUS AND FRAMING

True community-led research dissemination is not a one-time effort or a box to check at the end of a project, it is part of an ongoing, long-term commitment to partnership, trust, and lasting change. Each step we've discussed—engaging communities early, honoring histories and values, fostering shared leadership, ensuring accessible deliverables, strengthening capacity, and protecting communities from harm—builds the foundation for lasting change. Sustainability means embedding these principles into every stage of research. It also means recognizing that the real measure of success is whether communities continue to benefit long after a single project ends. Tools like Health Impact Assessments, Environmental Impact Assessments, and Equity Impact Assessments can help weave together and ensure research efforts leave a legacy of trust, relevance, and positive change.

> *"How trust feels is somebody coming back and saying, 'thank you so much for sharing a very personal part of your life or very personal part of your story.' Here's the follow up of what we learned, and here's what we're going to do with this information."*
>
> *– Rocky Lane*

> *"When your findings, your results, are ready to share, there is a sense of what to expect because everyone who mattered has been involved from the early stage of the process to the way through of completing research."*
>
> *– Ankit Sanghavi*

REFLECTIVE QUESTIONS

Answering the final four questions should illuminate a path forward. Community members should write their answers, looking forward to a future with change in health outcomes and health policy. Researchers and other stakeholders should write their answers thinking about the long-term health impact on the communities they work with.

- What are your hopes for how research can support your community's long-term goals and well-being?
- If you could imagine the ideal research partnership from beginning to end, what would it look like?
- How should community voices be heard and honored, not just in the research process, but in how results are shared and used?
- What is one aspiration you hold for how future research can contribute to the change your community is working toward?

COMMUNITY CONTEXT AND INSIGHTS

Take a few minutes to listen as Ankit Sanghavi, MPH, BDS, a DAP member, shares his reflections. He outlines his aspiration for how future research can build trust, honor lived experience, and leave communities stronger and more resilient than we found them.

Bringing it all together, embracing a community-led dissemination model is a strategic commitment to equity, respect, and real impact. By centering the voices and needs of communities, we move beyond traditional top-down approaches and foster trust, relevance, and meaningful engagement. This model ensures that research findings are co-shaped, accessible, and actionable for those who matter most.

> *"There could be harm done in research, and we don't want to do that as researchers coming in or as leaders that's bringing in researchers into our space. We are not here to be saved or solved. We are here to be partnered with and co-create."*
>
> *– Atlantis Narcisse*

> *"My aspiration is that research becomes a tool for empowerment, not extraction... something done with the community, not to the community."*
>
> *– Ankit Sanghavi*

ACTION STEPS AND PLANNING GUIDANCE

Your next actions are up to you as a member of a community, researcher, organizational leader, or stakeholder. Several ideas to consider moving forward:

Policies, practices, and community impact
Explore policies and practices that are in place to elevate and listen to community members. Help ensure they will be heard and their lived experience will be honored. Explore how to implement this across the research organization. Ask if the organization's leadership is willing to hold the organization accountable. This is not short-term work but will take place over time. The key is to start.

Systems-level change
Explore community priorities that future research can change to support what the community is working toward. Plan how it can be sustained and what resources are needed. Find out if community members and researchers have the professional and personal skills to carry out this research. If not, search for professional development opportunities that can be added for both community members and researchers.

Now is the moment to put this into practice. Research must move from intention to implementation by partnering authentically with communities every step of the way, honoring their expertise, and sharing power in how knowledge is communicated and used. The collective future of research depends on it.

> *"When research is done with the right intent, it can bring visibility, elevate overlooked stories, and leave communities stronger and more resilient than before."*
>
> *– Ankit Sanghavi*

Limitations and Observations

We recognize that this guide, while grounded in practice and lived experience, is not comprehensive. This section acknowledges what may have been overlooked, underdeveloped, or is still emerging in our collective understanding of ethical, trust-centered dissemination. These reflections are invitations to expand the conversation and sharpen the work as it moves forward.

While this guide focuses on the role that researchers and community leaders can play in advancing ethical, trust-centered, community-led dissemination, it is important to recognize that many of the changes called for here cannot be fully realized without institutional support and broader systems change. Universities, research institutions, funders, and policy leaders all have a critical role to play in enabling the kind of flexible, relationship-based work that is central to true community partnership. Without shifts in institutional policies, funding structures, and incentive models, even the most well-intentioned researcher may face institutional and other systemic barriers to putting these changes into action.

Additionally, while the guide and recommendations are informed by years of experience and relevant to a wide range of communities, no single approach can universally apply to all settings. Each community has its own history, power dynamics, cultural values, and lived realities. Trust-building must be rooted in these local contexts. As such, this resource should be seen as a guide, not a prescription, and we strongly encourage users to adapt and co-design their approach with each community they engage with.

We also recognize that while this guide provides suggested actions and reflective questions, not all of the ideas will be feasible for every team or project. Real-world constraints, such as limited time, staff capacity, or funding, may require researchers to assess feasibility and identify barriers before implementing certain practices. Doing so is not a failure of commitment; it is part of the honest and necessary work of navigating competing demands with integrity.

Finally, it is important to acknowledge that the landscape of community-engaged research is not monolithic or a constant. Community needs, political environments, and public trust are all shifting and ever evolving. What is relevant today may need to evolve tomorrow. *Ensuring Your Research is Disseminated* is meant to be a starting point, not an endpoint. It is part of an ongoing process of learning, unlearning, adapting, and growing—individually, organizationally, and collectively.

A Closing Invitation

This work reflects our ongoing journey, a learning approach rooted in humility, accountability, and deep respect for community leadership. We offer this resource not as an outcome, but as a shared step toward building and advancing research practices that reinforce trust and contribute to equity in health and opportunity.

We invite you, our partners, whether you are a community leader, academic partner, or practitioner, to reflect on your own position, learning, and aspirations. We hope you will share your experiences with us and with others in this space, as we work together to move the needle on health and opportunity for all.

For more information about the community-led approach including strategy, policy, and communications highlighted in this resource, please contact communications@texashealthinstitute.org. For community engagement training and technical assistance, contact John Oeffinger at joeffinger@texashealthinstitute.org.