



YOUTH ARE EXPERTS, TOO.

Strategies to Engage Young Adults in the Research Process



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Youth Engagement in IDHI

The Institute on Digital Health and Innovation (IDHI) in the College of Nursing at Florida State University is a co-lead of the **Adolescent Medicine Trials Network for HIV Interventions (ATN)**, the only U.S. research network that solely focuses on addressing HIV among youth. The ATN seeks to **center youth engagement** in the research process more than research has done historically. Youth engagement provides researchers with valuable insights into how young people interact with services, helping to **create more relevant, responsive, and accessible interventions**.

In 2021, the ATN merged and rebranded Youth Advisory Boards and the Youth Advisory Council from the ATN's iTech network into a **single sustainable group to better address the need for youth engagement through all parts of the research process**. Members were **formally hired as part-time university employees in a research consultant role** to better respond to evolving study needs, while also being able to offer youth additional resources and professional development opportunities.

This group has evolved into the present iteration under a new, self-determined name: **Subject Matter Research Consultants (SMRC)**.



Purpose of This Guide

The purpose of this document is to provide tips and tools to help researchers understand **how to ensure youth involvement in their protocols and to improve communication with young people**. As you read through this document, you are encouraged to reflect on this question.

How can your research continue to enhance the relationship between researchers and communities to increase impact and improve health outcomes?

Everyone benefits from partnerships between researchers and youth.

A 2022 review¹ of youth engagement in research found several personal benefits for both researchers and youth.



Youth reported:

- Feeling empowered
- Gaining new skills and knowledge
- Better career and learning opportunities
- Broadening their support networks



Researchers reported:

- Increased accountability
- Enhanced understanding of findings
- Gaining appreciation for engagement
- Pride in youth's professional and personal development

Community Engagement is Fundamental to HIV Research.

History of CABs

One of the earliest examples of community involvement in HIV research began in 1989 with the establishment of the first **federally funded and mandated community advisory boards (CABs)**.

Since then, CABs have become a regular feature for most clinical trials networks seeking to **improve the effectiveness and ethics** of research.

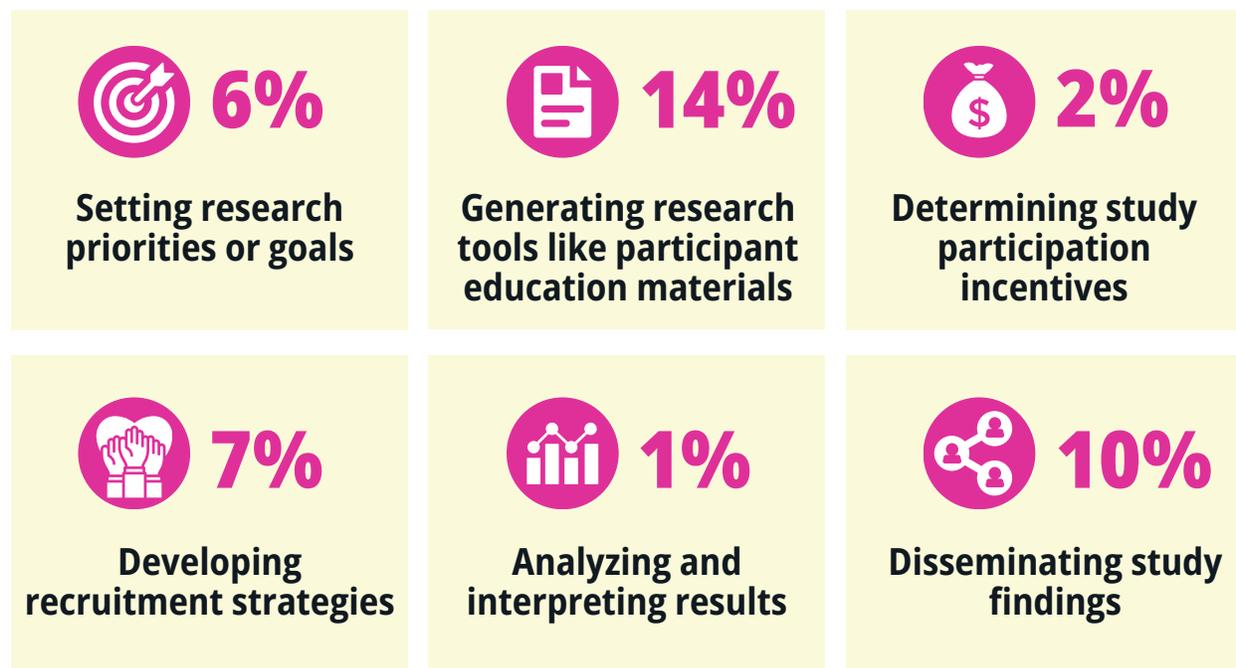
Barriers to Engagement

The effectiveness of community involvement in research is often **hindered by insufficient resources, training, or bureaucracy** necessary to make CABs and community-engaged methods more than just “a box to be checked.”

In order to fulfill the ethical obligations of academic institutions and address the gaps that shape research priorities – and, more importantly, impact the lives of the communities we serve – these barriers must be confronted.

Gaps remain when it comes to how community members are integrated into the research process.

A 2018 review² of community stakeholder engagement in HIV clinical trials found that studies were **most likely to engage stakeholders to develop protocols and recruit participants** compared to other stages of research. However, gaps remain in community engagement across the research process, illustrated by the percentage of studies that involves community stakeholders in these areas:



Stakeholder engagement is often conducted using researcher-driven, top-down methods such as interviews (40%) or focus groups (30%), and less likely to use these formats:



Before A Meeting

Research environments often present challenges for youth when it comes to communicating information in ways that are digestible and accessible, particularly for youth who might:



Be unfamiliar with academic terminology or concepts



Prefer more engaging forms of communication, like infographics or video



Have goals and expectations distinct from the project.

One way that researchers can support youth as informed partners in the research process is by taking the time to adequately prepare before meeting with youth. **This preparation creates an environment that fosters engagement, curiosity, collaboration, and meaningful questioning from youth partners.**

Whether a researcher is looking to review recruitment materials or gather input for their intervention's design, these strategies are a few ways researchers can facilitate improved capacity for engagement and collaboration.



“ How will this project align with young people’s personal goals? ”

Youth deserve the opportunity to accurately understand a study and its connection to their own interests, aspirations, and communities.

1 Clearly outline your study and why you're there.

Review the questions below to make sure you are prepared to present or answer questions related to different aspects of your research study.

Study Basics



- What is your research study trying to do? Why?
- What is the intervention?
- How is this intervention different from similar strategies?
- What type of data do you want to collect?
- Who are you recruiting, and where?

Importance



- What is the context for your study as it relates to health, policy, service delivery, and related research?
- Why should lay constituents care? How will your study affect the daily lives of youth or people serving youth?
- How does your study contribute to existing research or fill a gap in knowledge?
- What does your current engagement tactics look like? How effective have these been?

Challenges



- What issue or challenge do you seek to address with youth?
- What, if any, solutions have you already considered?
- What constraints or limitations does your team face for initial and/or additional solutions?
- What questions or asks do you have for youth?

2 Collaborate with the Youth Engagement Manager.

Beyond just adding your project to an agenda, the Youth Engagement Manager your organization's youth liaison can help review the appropriateness of content and provide additional ideas or feedback on how to engage youth effectively.



Promoting constituency among young stakeholders.

A common challenge in involving youth in research is the tendency to ask one or a very small number of young people to **represent the youth perspective as a whole**, something that often happens when a young person is invited to sit on advisory committees.

This burden can be addressed by giving young people the **time and resources to build their own representative voice** and practice good constituency.

Youth can practice thinking about constituency by participating in activities that encourage youth to consider both the similarities and differences between their own experiences and the experiences of those around them.

Constituency refers to the process of gathering ideas and representing the perspectives of a group of peers or people.

3 Set up youth for success ahead of the meeting.

Pre-meeting activities can help youth feel more prepared for discussion about your study and specific requests. They can also enrich feedback from other youth, especially if you're soliciting opinions that reflect youth perspectives.



Send 2-3 teaser questions generally related to your issue.

Example: What do you know about the presence of methamphetamine among queer youth?



Ask youth to collect specific information beforehand.

Example: If you need feedback on app features that appeal to youth, ask the SMRCs to make a list of 3 to 4 apps that they enjoy using in their day-to-day life and what they like about them.



Send resources to lay the foundation for your discussion.

Examples: Share resources about the project or topic such as current events articles, videos about app design, webinars, lay summaries and/or journal articles.



During A Meeting

Structured institutions are often not designed to support a partnership approach with youth. Researchers and adult leaders must actively curate spaces and opportunities where young people feel validated and empowered to engage.

These recommendations are a few ways researchers increase equitable participation in meetings.

Check Your Adulthood.

Adulthood is a form of ageism that refers to behaviors or beliefs that adults have more value or potential contributions than children and young adults.

Adulthood is a serious roadblock for researcher-youth partnerships. It assumes that older adults are inherently superior to youth and young adults due to their amount of lived experiences, reinforcing the idea that young people must hold a certain amount of experience before they can contribute meaningfully. It can create a bitter, stressful, non-productive and even destructive atmosphere.

It is also important to **remember that many young adults who engage in research have earned degrees and hold professional experience related to research and public health**, bringing a wealth of experience that can be leveraged in addition to their perspectives as young people.

“ Young people will think what we’re asking them to do is too boring or not important. ”

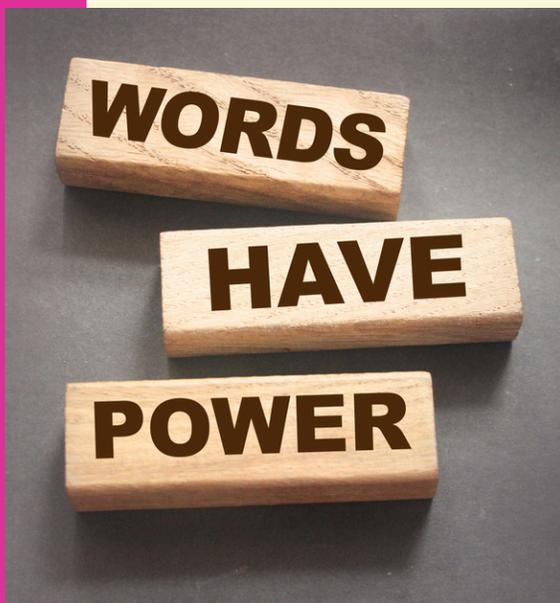
Researchers can step up to the plate as adult allies by:

- Acknowledging any biases that they might have coming into a partnership
- Supporting youth in taking ownership of the project and encourage creativity
- Not imposing judgments or ideas
- Being open-minded and willing to take risks
- Sharing power and accountability for successes and failures

4 Creating a safer environment.

At the start of the meeting, check in with your team and set ground rules to ensure youth feel respected and valued. Examples of ground rules include:

- **Sticking to the pre-established agenda so that everyone is on the same page.**
- **Having one speaker at a time and avoiding side conversations.**
- **Talking directly to youth with concise, lay language.**
- **Actively listen.**
- **Respecting pronouns and/or lived names.**
- **Avoiding language that can perpetuate harm or stereotypes.**
Example: “risky” behavior



Additional resources on harmful language

- [Facing HIV Stigma in Our Own Words](#) article on people-first language
- [NIAID Language Guide](#) for best practices around sexuality, race, and other identities

5 Diversify strategies for discussion.

Youth might not feel immediately comfortable speaking up in a traditional discussion setting with researchers and other adults, especially if the topic is new or complicated.

To encourage participation, structure discussion in ways that provide multiple opportunities to express ideas, offer comments, or share feedback.

- **Taking a moment to write down responses and share them with the group.**
- **Encouraging feedback through chat, email, or surveys, especially in virtual settings.**
- **Using interactive Zoom features like polling.**
- **Checking in for understanding and clarifications from time to time.**

Consider the setting for your discussion (is it in a wider team meeting, a meeting only for youth, or one-on-one conversation?) and adjust your approach to conversation, like the example questions in the next section, as needed to allow time for youth to reflect.

6 Be inquisitive rather than making statements.

Questions that might be simple to researchers might be too specific or challenging for youth, who might need more time to process the information and reflect before responding.

Approach the discussion with genuine curiosity using questions that are low-stakes but allow youth to express their thoughts openly.

- **What surprised you most?**
- **What is the most important thing you learned?**
- **What is the most interesting thing you learned?**
- **What do we think others should know about this issue?**
- **What should we spend more time learning?**
- **What do you want to do about this issue now that you have learned more?**

7 Ensure that youth can have an impact on decision-making.

Research teams do not have to plan entirely around youth feedback, but team members should demonstrate an active effort to incorporate youth's interests, feedback, and contributions into key discussions and decisions.

- **Openly discuss everyone's goals and incorporate youth's goals into your team's plan. What brings youth to the table? How can you support their goals and interests?**
- **Avoid coming in with predetermined solutions before you have a chance to collaborate with youth.**
- **Revisit assumptions about youth's interests and their ability to contribute meaningfully to decision-making.**

The importance of being culturally humble.

Cultural humility is the ongoing process of **reflecting on and critiquing our own biases and actions, while learning from and respecting a range of perspectives.** It's about engaging authentically with others, recognizing that we all have room to grow.

Research on cultural humility shows their importance in fostering trusting relationships with youth and fostering youth's identity development.

For further reading on cultural humility and mentorship, review [this resource](#).



Some ways to build cultural humility with youth:

- Build an understanding of young people's experiences.
- Exercise self-reflection and explore feelings that come up.
- Recognize your own and other's power and privilege.
- Build your comfort with not knowing and open the door to learning.
- Adapt the existing culture and co-create new traditions with youth.

8 Be transparent about your decisions.

One of the best ways to demonstrate that youth are a valuable part of the decision-making process is practicing transparency.

Transparency is demonstrated when motives, methods, and limitations are clearly and openly communicated. It fosters trust and respects youth as active partners in the research process.



Explain the reasoning behind a decision or process.

How will your group come to a consensus?
What are the barriers or constraints that you operate under?



Address mistakes or areas for improvement.

What factors contributed to a mistake?
What specific steps will you take to address a problem?



Provide honest feedback on youth input.

How do you plan to incorporate their input? If something cannot be implemented, honor young people's contributions by explaining why an idea wasn't feasible.



Review decisions and next steps as a group.

If you've assigned youth a follow-up task, check-in to see if they need any additional support, such as a one-on-one meeting to clarify any questions that arose afterward or to review progress.

After A Meeting

Part of moving away from asymmetrical and extractive models of community partners is honoring a relationship beyond its function for a specific event, meeting, or project. Researchers should plan to **incorporate sustainability practices and spaces to maintain relationships, motivation, and action with youth.**

By taking the time to **follow-up with youth after a meeting or share exciting opportunities in the future,** researchers can demonstrate to youth that their contributions are not only valued within the scope of their project but also as individuals with full lives – whether they have goals for attending medical school, active projects in their communities, or simply expanding their horizons.



9 Share the impact of youth contributions.

Sharing the outcomes of their contributions can motivate youth to stay engaged and manage expectations for future involvement, even in cases where their input was not used. Be sure to report back in a timely manner, whether by joining a meeting or through a follow-up email.

- **How has youth input changed the way you thought about different parts of your project?**
- **Have you gotten additional community input since your discussions with youth?**
- **Have you made changes to the materials/intervention in language or design?**
- **What barriers or challenges prevented you from fully implementing youth recommendations?**

10 Share other opportunities.

Engagement should lead to an expanded support network for youth.



Involve youth in dissemination activities, such as developing social media content of your findings.



Invite youth to collaborate on other projects.



Share more learning opportunities like conferences, workshops, and community forums.

11 Work towards co-authorship.

Researchers should maintain ongoing collaboration with youth throughout the entire research process, particularly when **preparing for peer-reviewed publications**. Involving youth in this process ensures that researchers incorporate their perspectives into the manuscript and also **builds up youth's experience and capacity in academic settings**.





Identify who needs to be involved and at what stages to ensure meaningful youth participation.

Consider holding meetings with youth consultants or community advisory boards to understand whether youth are interested and how to engage them in the writing process.



What are the criteria for authorship? How will you factor in different levels of experience, interests or capacity for writing?

Are there sub-analyses that youth could lead under the mentorship of more seasoned researchers?



What will the writing process look like? How often will co-authors meet to review writing?

How will writing be divided among co-authors? How often will co-authors meet to review writing? What support might youth need through the process?



Should a parallel document be created that summarizes findings for lay audiences?

Consider asking youth to take the lead on adapting research jargon into plain language for sharing findings to broader audiences.

For additional resources on co-authorship and crediting youth, visit:

- [Authorship determination scorecard](#)
- [General guidelines for authorship](#)
- [Authorship practices for community-engaged research](#)

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Learn More

To learn more about the Institute on Digital Health and Innovation, visit: <https://idhi.fsu.edu>

For more about the Adolescent Medicine Trials Network for HIV Interventions: linktr.ee/atnresearch

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