Building the Research Program Framework

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KEY POINTS: BUILDING THE PROGRAM FRAMEWORK

- Build partnerships with community leaders or work with a well-connected community-based organization.
- Develop research program goals and evaluation metrics with program partners and use these to track progress.
- Determine what the program is trying to change, and identify ways to measure changes.
- Plan data collection strategies, paying careful attention to research requirements, participant privacy, timelines, and reporting needs.
- Define roles and responsibilities for all team members.
- Make a communications plan to share program information.

TOOLS, TEMPLATES, AND RESOURCES

- Community Demographics Template
- Community IRBs and Research Review Boards
- Understanding Community-Based Processes for Research Ethics Review: A National Study
- IRB Registration with OHRP Video
- Office for Human Research Protections (OHRP) IRB Registration Process
- Gathering and Displaying Program Data Information Sheet
- Communications Plan Template
- How to Set Up a New Gmail Account

Partnering With a Community

Understanding local dynamics can help build strong community relationships. Approach each community/community member respectfully, recognizing the research program is a guest in their space. When a program team engages thoughtfully, community members will feel valued and see how the research program's goals can benefit the community.

REAL-LIFE EXAMPLE

SYCT partnered with Pitt County, North Carolina, Hamilton County, Tennessee, and Merced County, California. Each community had distinct demographic characteristics. The programs focused on areas with low vaccination rates, high medically underserved populations, and high infection rates. By collaborating with these communities, these research programs served historically marginalized groups, addressing racial, linguistic, and socioeconomic barriers. The success of these programs was rooted in collaboration with community leaders and community members, and partnerships with organizations that had been established in previous research studies. While the research programs were designed to serve specific populations, the program teams were mindful to avoid alienating the rest of the community.

Consider the following questions when establishing a program within a community:

- How is community defined for the research program (e.g., by ZIP code, demographics)?
- Which communities have the greatest need?
- Who are the populations to be served by the research program?
- Are there limits on the geographical area or population size the research program can support?
- Are there existing relationships with potential partners?
- Do local public health entities support the research program?
- Are there connections to key community leaders?

- How can the research program gather input from community members?
- Do community organizations believe in the research program's mission?
- Are local political leaders invested in this cause?
- What networks (grassroots or health department–led) can help support the research program?
- What are the languages spoken in the community?
- Are there reliable local language resources to provide translation and interpreter services?
- What benchmarks might the research program use to measure impact?

The Community Demographics Template can help you consider, research, and describe the communities your program will serve.

Building a Team

Every public health research program will have a unique structure. This section suggests some of the key roles and responsibilities you may need for planning and running a research program. A program's structure can vary depending on its goals, size, budget, anchor partner model, or available staff.

Large, community-engaged research programs must perform certain functions. For these programs, the lead organization should have the fiscal experience to manage the project details according to the funding requirements. For national research programs running in multiple communities, there might be centralized support, with local teams handling specific tasks.

In smaller community-engaged research programs, one person might handle multiple roles. Clearly defining roles and responsibilities for all team members, including the anchor partner, is important regardless of the setup. Teams must also understand the program's timeline and follow any necessary protocols.

New programs can look across their partnerships to help fill program roles. In many cases, positions will have multiple responsibilities. A good starting point is to assess the program's needs, existing staff skills, and available human resources, and then hire for additional positions as funding is available.

REAL-LIFE EXAMPLE

In YMTT and YMCF, community organizations managed activities on the ground, while a central operations team based at an academic institution handled overall program organization. The operations team included staff responsible for both implementing and managing the program. Partner organizations supported the operations team by sharing updates on test distribution, effectiveness of communications strategies, and real-time feedback from community members. These organizations were part of broader networks, helping the program reach underserved areas. A consistent central operations team overseeing all program sites helped streamline processes and apply lessons learned from one location to the next in the nationwide rollout. This team monitored the program's timelines, activities, and budgets while handling administrative and regulatory tasks, allowing community organizations to focus on delivering the program effectively.

Example Key Roles and Responsibilities of the Program Team

- **Program Director:** oversees program direction, funding, and high-level decisions
- **Engagement Lead:** works directly with program partners
- **Operations Lead:** tracks program progress, procures needed supplies, manages budget
- **Communications Lead:** creates and implements strategic communications plan
- **Data Lead:** coordinates data collection and standards, evaluates data technology
- **Engagement Team:** orients program partners, leads outreach, collects feedback
- **Site Manager:** coordinates events and supports partners with technical assistance

Growing Partnerships

Building trust, transparency, and strong relationships with community leaders and members takes time and can be especially tough for research programs linked to government or academic institutions. Recognizing and addressing existing opinions, perceptions, and concerns builds trust and avoids potential problems. Whenever possible, lean on existing partnerships and networks. Research programs can also benefit from community engagement experts who know how to create and maintain genuine relationships with local groups.

Distrust in academia, research, and government often stems from past negative experiences with healthcare systems and ongoing discrimination of racial and ethnic minority groups. This distrust varies by race, ethnicity, and religion and can be worsened by misinformation about health topics.

Working with individuals and organizations that have earned the community's trust is essential to overcoming these barriers. A lack of established connections can limit a research program's effectiveness when new to a community. Partners act as gatekeepers to their community, providing access and insight. Local leaders familiar with the program's work can help navigate community specifics, reducing disruptions and improving the program's chances of success.

In a public health emergency, there may be no time to create authentic community engagement. Ideally, an existing community advisory board or network would help guide the program. Some communities will be better prepared than others, with networks that can quickly respond to crises. An anchor partner, or well-connected community-based organization with the proper infrastructure and established networks, can help start engagement efforts in these situations.

REAL-LIFE EXAMPLE

Community Campus Partnerships for Health (CCPH) led the community engagement efforts for the COVID test distribution research programs. As a liaison between the programs and the anchor partners, CCPH identified local partner groups and trained them on the program's goals. They managed financial responsibilities, ensuring rapid payments so partners could focus on distributing tests. CCPH also provided a community engagement expert who guided best practices, showing the program's commitment to including community perspectives. The engagement team worked closely with the anchor partners throughout the research programs, offering technical support and applying lessons learned to improve the process.

Compensation

All program partners should be fairly compensated for their time. To determine compensation, consider the number of hours worked, staff involvement level, length of participation, and local market rates. Gathering a focus group from across community partnerships can help create an engagement plan that outlines logistics, roles, and responsibilities, including compensation.

Local Health Departments

Local health departments often play a crucial role in public health research programs. When working with health departments, emphasize shared goals and how the program will benefit the community. Health departments have experience running such programs but often face resource and staff limitations. Offering compensation for their time or partnering with trusted community leaders to support community efforts can ease a health department's workload and ensure effective outreach.

Establishing Goals and Metrics

Setting clear goals and evaluation metrics can help track a research program's progress towards these goals, identify what works, and find areas for improvement. These goals and **metrics** should be developed as a team, and local voices and interests should be involved. As a group, ask, "What are the community's goals, and how do they align with this research program?" For example, how does the community hope to support children's current and future health, such as by teaching, practicing, and modeling healthy habits?

Each research program should define **metrics** (a way to evaluate progress toward goals). Some potential steps to defining and tracking metrics include:

- Building a timeline with clear deadlines to meet benchmarks or milestones to reach larger goals
- Tracking each step of the program using benchmarks. For example, did the program reach the 100 local families using 1-3 schools?
- Reviewing metrics periodically to ensure the program stays aligned with its goals and within budget. For example, when we added "Budgeting for meals" and we only planned for "Meal prep" this caused delays due to research and surveying families. Planning a post-closure project debrief to review the success of goals using metrics

Metrics generally fall into four main areas: program demographics, community engagement, operations, and communications. The table gives examples of metrics and measures for tracking progress in each area. Remember, these metrics should connect to the program's goals, created from community input.

Example Metrics

Metric	Measure
Community Engagement	
Identify anchor partner	Estimated duration
Identification of program partners by lead partner	Estimated duration
Number of program partners	Manual count
Development of budget with anchor partner	Manual count of iterations
Grassroots community connections	Type and manual count
Face-to-face meetings with program partners	Manual count
Virtual meetings with program partners	Manual count
Conversations with community members	Manual count via lead organizer
Program events planned and implemented	Manual count
Community members who participated in program	Electronica data collection tool
Thank you notes sent to program partners	Manual count
Operations	
Timelines	Types of timelines generated
Participant incentives issued	Manual count
Informed consent forms completed (English and Spanish)	Manual count
Translations into other languages	Manual count
Iterations of program partner budget and final spend	Manual count and financial records
Planning meetings held with anchor partner	Manual count
Inquiries received about program	Manual count
Results-sharing opportunities (e.g., presentations, publications)	Manual count
Communications	
Website activity	Web analytics
Social media measures	Follows, likes, clicks
Newsletter or outbound emails	Analytics and email metrics
Local media	Demographic reach
Awareness of program among community members, including populations of interest	Survey (market research)
Source of program awareness (i.e., which channel), including among populations of interest	Survey (market research)

Understanding Research Requirements

Institutional Review Boards

The operations team must gather all necessary information to meet research requirements. This often includes institutional review board (IRB) review and compliance with **Health Insurance Portability and Accountability Act (HIPAA)** regulations. IRB approval is critical to protect participants' rights and welfare.

Understanding which activities require IRB review can be complicated, so partnering with an organization familiar with the IRB process may be helpful. When in doubt, consult the IRB directly. Even research that qualifies for an exemption must go through IRB review to receive an official exemption determination. Programs affiliated with academic or research institutions often have access to an IRB, but independent IRBs are also an option.

Programs that need IRB approval should account for review timelines when planning. Determine whether participants need to provide informed consent and, if so, establish a process to collect it. If a program has a tight timeline but still needs IRB review, submit the overall program design and make amendments later to include finalized participant-facing materials.

Other approvals, such as city permits or permission to host events at certain locations, may be necessary. Some venues may require liability insurance as part of their event approval process.

Community-Based IRBs

There is growing interest in community-based IRBs or research review committees. These are created and run by an organization or community group that is outside of, or works in partnership with, a traditional research institution, such as a university.

Community-based IRBs or review committees have been created by nonprofits, tribal communities or organizations, and other community groups. They began because some researchers and community members thought this type of IRB could understand the risks, benefits, and principles of community-engaged research better than institution-based IRBs.

Those planning to create and run a community-based IRB or research review committee will need:

- Funding to support operations
- Administrative processes, including those for member **recruitment** and retention, member onboarding and training, research proposal submissions, reviews, and decisions

To be a federally recognized and compliant IRB, obtaining a Federal Wide Assurance from the Office for Human Research Protections within the US Department of Health and Human Services is required. See the video describing the application process. Board membership and operational processes of the community-based IRB must meet the requirements of federal regulations known as 45 CFR 46.

REAL-LIFE EXAMPLE

The Rocky Mountain Tribal Leaders Council in Billings, Montana, created a community-based IRB to promote the sovereignty of Tribal Nations, build on the strengths and resiliency of Tribal populations, and protect the rights and welfare of research participants in the Billings area. The Rocky Mountain Tribal IRB works to eliminate exploitative research practices that would only benefit external groups and to protect individuals and Tribal populations involved in research. They achieve this by promoting and advancing the concerns of Tribal Nations in research projects, ensuring researchers engage ethically and collaboratively, and enabling Tribes to approve or reject research protocols and publications. These practices help the IRB maximize community benefits, ensure equity, require cultural competency, and protect cultural integrity.

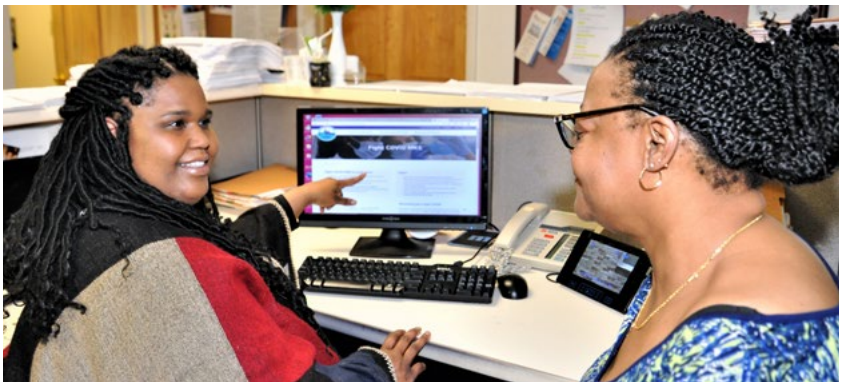
Determining Data Needs

Data can help determine if programs meet their goals, who they impacted (and how), and reveal insights into community heath, behaviors and attitudes that are related to ongoing community needs. Some public health research programs rely on publicly available data for evaluation, while others collect data directly to meet their goals. Data collection methods vary and may include interviews, questionnaires, surveys, and smart devices. Each program will have unique data collection, storage, and reporting requirements.

Programs collecting participant data or health information must follow strict regulations like HIPAA and 21 CFR Part 11. Programs collecting **personally identifiable information** (PII) or **protected health information** (PHI) must meet security and privacy standards, with severe penalties for noncompliance. Partnering with an experienced academic or **clinical research** organization can help the program develop compliant data systems.

Data Collection and Reporting Systems

After defining data needs, evaluate data collection systems. Often data can be automatically transferred from a data collection tool to an Excel file to support data analysis and reporting. Partnering with local, academic, or clinical organizations can also help to determine the best technology solutions. Programs should ensure the technology has the right system, integration, applications, confidentiality needs, security, and data reporting capabilities to meet their goals. While every program differs, developing, pilot testing (e.g., testing out planned data collection methods on a small group of people to identify and correct errors and pitfalls), and implementing a data collection system can take time and resources. Systems may vary significantly in cost, so budget should be factored into decisions.



When planning data collection and reporting, consider the following logistics questions:

Who	What	When	How

• Who will collect and enter data?
  ◦ For example, a program partner or clinician may interview participants and enter information on their behalf, or participants may receive a survey to complete on their own.
• Who will the data be shared with, and for what purpose?
	• What data will be collected and from whom?
	  ◦ Which data are necessary versus optional?
	  ◦ Is informed consent required?
	  ◦ Will the data collected be PII or PHI?
	• What regulations apply?
	• What are the privacy concerns?
	• What is the budget and timeline for creating data collection and reporting systems?
		• When and how often will data be collected?
		• When will reporting systems need to be ready and when are reports required?
			• How will the data be collected? (e.g. electronically, on paper, by phone)
			  ◦ Will data collection include multiple languages?
			• How will the program address issues with technology or connectivity?
			• How will data be stored and for how long?

The Gathering and Displaying Program Data Information Sheet highlights two data collection tools and two platforms that can be used to display data.

Using Surveys

Surveys are a common tool for evaluating public health research programs and understanding participant demographics. When designing a survey, consider:

- Are the questions relevant to achieving the program's goals?
- Who is answering the survey?
- Do the questions help me to measure program impact or what I hope the program will change for participants?
- Could questions be misunderstood?
- How will the collected data be used?
- Will the data help achieve the program's goals?
- Are the "Yes"/"No" questions specific enough to avoid "maybe" responses which lead to incorrect data?

REAL-LIFE EXAMPLE

During the YMTT program, participants completed optional surveys about their demographics, health, social interactions, and behaviors affecting COVID transmission. Surveys were given regularly (e.g., baseline, week 4) or at a particular time (i.e., use of a home test). The surveys were sent via text message or email, with an option to respond by phone for those without internet access. Participants provided informed consent (or assent for minors) through the program's app, website, or by phone. Though only a few participants responded by phone, this option ensured low-income and older community members were included.

Surveys should only ask for essential information. The data collected in surveys can inform future public health research programs by assessing whether a program's goals have been met. Many vetted survey tools are available to simplify data collection and support **program evaluation**. These include free services like Survey Monkey and Poll Everywhere, to professional services such as Qualtrics or REDCap. Partners should review what survey tools may be available within their partnership network and select the best survey tool based on factors including cost, reliability, and usability.

Creating a Communications Plan, Messages, and Materials

Creating awareness for a public health research program can encourage community participation and help meet program goals. The first step is raising awareness about the program within the populations served. Next, the **campaign** works to inspire participation.

Creating a Communications Plan

A communications plan outlines essentials such as intended audiences, goals, key messages, **communication channels**, campaign tone, and methods to measure success. Communication strategies should reflect the community's unique characteristics. Therefore, create your communications plan, similar to your other program components, together with community members. Consider these questions together with community members when developing a communications plan:

- Who is the main audience? In other words, who does the program most want to reach, and how will you reach them?
- What are the key messages?
- When, where, and how often will you communicate?
- What actions should community members take?
- How should community members feel when they think about the program?
- What defines success for the program?
- How will you help create an identity for the program through logos or branding?

REAL-LIFE EXAMPLE

The YMH COVID test distribution program created marketing campaigns to raise awareness of COVID test availability, support test distribution at community events, and encourage frequent test use. Program partners requested information on an overview of research principles and how to create email accounts to help community members without an email address who wanted to join. The program created on-demand materials to meet community needs.

While the communications plan serves as a guide, there is no "one size fits all" approach. You can add to or modify the questions of your communication plan or modify your responses/answers if you find your key messages are not understood or if you are not effectively reaching your main audience. Repeat this process until you start to see traction in your program. Local partners are invaluable, offering insights into the community's history and present needs, preferred communications channels, and which groups are most important to reach. They also help customize the plan to address translation needs and cultural sensitivities. Understanding the languages spoken in the communities served can guide material production and minimize waste.

Use the Communications Plan Template to organize essential information for your program's public communications.

Developing Messages and Materials

Before creating and distributing materials, it may be wise to create a brand identity for your program. This can help build recognition in the communities served. A brand might include a program name, logo, color scheme, and tone of voice.

Once a high-level plan is in place, it is time to start drafting key messages. These messages will be the foundation for all program materials, ensuring consistency across platforms, including websites, printed materials, and social media. Feedback from community members and program partners is crucial to make sure messages are accurate and relevant.

After refining the key messages, begin developing or collecting specific materials to support these messages. Examples of materials include informational brochures, frequently asked questions, websites, advertisements, or any combination of print and digital materials. Before sending out the final materials, allow program partners to review and make changes. Ensure that all materials follow health literacy guidelines and consider cultural and linguistic sensitivities.

REAL-LIFE EXAMPLE

The YES program included Spanish-speaking populations in Miami, Florida and Durham, North Carolina. The name of the program, branding, color scheme, recruitment flyers, and other study materials were co-designed with partners in Durham and Miami, and also reflected local Spanish translation to ensure they were culturally tailored to the primary population. To avoid mistranslations, each item was reviewed by a local Spanish speaker for insight and guidance on appropriate translations. This was especially relevant for the Spanish language due to the many countries and dialects. Engaging local partners allowed for tailoring and trust-building.

Selecting Communication Channels and Metrics

Selecting the right channels to promote your program will depend on budget and how your audience can best be reached. Partners can also help identify missing channels and guide the communications strategy. Some communication channels may include: .

- Local media such as radio, TV, or newspapers
- A program website to create a public space for your program's information
- Social media
- Direct mail to participants or those interested in the community
- Digital advertising such as search engines, web banners, or other online advertising
- Signage such as billboards or other paid community awareness
- Free materials that may be left in public spaces such as libraries, health clinics, or government offices

Before launching a marketing campaign, identify metrics that will measure its effectiveness. You can use Google Analytics, built-in social media analytics, or other 3rd party tools. Standard communications metrics include the number of website visitors, newsletter subscribers, social media likes or clicks, and event attendees.

Note: Similar tools were described under "**Data Visualization**"

One method to optimize materials is A/B testing, where two variations are tested to see which performs better. For example, program leaders could distribute two flyer designs with the same information and track which one receives a better response. This data-driven approach helps improve campaign success by allowing program leaders to use the materials that work best.