

## Short Communication

# Lessons learned from principal investigators on recruitment for community-based health behaviour studies during the COVID-19 pandemic

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**Received:** 06 April 2023

**Accepted:** 14 June 2023

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## ABSTRACT

Little is known about pandemic-related impacts on participant recruitment into community-based health studies during the COVID-19 pandemic. The aim of this report was to summarize lessons learned from principal investigators (PIs) of NIH-funded community-based health behavior studies that were scheduled to recruit during the COVID-19 pandemic. We report on findings from three open-ended questions that were part of a 50-question online survey conducted from December 2022 – January 2023, completed by 52 PIs. Four categories of lessons emerged to optimize recruitment into studies: formalize relationships with community partnerships; focus on study operations; recruitment is a science and an art; and reduce participant burden and increase participant benefit. Taken together, these recommendations will require longer and more complex recruitment plans. To implement these plans, researchers and funders will need to allocate more time, thoughtful attention, and financial resources to support formal community partnerships, additional staff time and training, real-time monitoring and refinement of multiple strategies throughout recruitment, and increased attention to participant benefit.

**Keywords:** Randomized trials, Community-based, Lessons, COVID-19, Physical activity, Nutrition, Recruitment

## INTRODUCTION

During the COVID-19 pandemic, participant recruitment into non-COVID-19-related health studies was negatively impacted, especially initially. Reasons included prioritization of COVID-19 research, redeployment of research staff, and the need for social distancing. However, there is evidence from cancer trials that enrollment in treatment-focused clinical trials rebounded swiftly in the first year of the COVID-19 pandemic, while enrollment in cancer control and prevention trials remained substantially lower even after a full year of the pandemic.<sup>1</sup>

Less well-understood is the impact of the pandemic on recruitment into community-based health behavior studies. These studies in general play a critical role in translating knowledge-based health messaging into meaningful behavior change and reduced risk of chronic illness. While these studies, like many others, experienced pauses during the pandemic, their importance only increased as evidence mounted about chronic disease as a risk factor for serious illness due to COVID-19. As many of the acute restrictions of the COVID-19 pandemic have lifted, this is a critical moment to reflect on what we have learned and what can help us evolve our best practices.

The aim of this report was to summarize lessons learned from principal investigators (PIs) of National Institutes of Health (NIH)-funded community-based health behavior studies that were scheduled to recruit during the COVID-19 pandemic – so that knowledge gained is disseminated and can inform the design and implementation of future studies.

## METHODS

We report on findings from an online survey conducted from December 2022 to January 2023. A detailed summary of methods is published elsewhere.<sup>2</sup> Briefly, 225 eligible PIs were identified from the NIH-funded database [reporter.nih.gov](https://reporter.nih.gov) for: interventions starting between 01 January 2018 and 31 December 2020, being a clinical trial or intervention, community-based, and targeting health behavior change in diet and physical activity. They were contacted via email a maximum of three times over three weeks to participate in an online survey; a \$50 Amazon gift card was offered for completion of the survey.

The overall study goal was to understand experiences and lessons learned about recruitment during the COVID-19 pandemic for studies that were proposed to NIH before the pandemic onset. The survey consisted of a mix of close-ended questions (n=32) and open-ended questions (n=18) and was intended to take 15-30 minutes to complete. The analysis for this report focused on three open-ended questions asked at the end of the survey: now we'd like you to imagine a new investigator comes to you for advice related to recruitment challenges in community settings: (1) What would you recommend they avoid?; (2) What would you recommend they should do?; and (3) What did you learn about recruitment during this time that you will apply to future studies and recruitment in community settings?

A preliminary review of the responses to these three questions revealed substantial overlap and reference to each other. While the first two questions did not specifically reference the pandemic, the entire survey was about experiences and lessons learned during this time period. A content analysis was done to identify “lessons learned” that emerged from the data and responses to all three questions were coded together by an experienced qualitative researcher using rapid assessment and then summarized into broader categories.

When frequency of a category or lesson is discussed, each investigator was counted only once (e.g., if they mentioned “benefits of social media” in all three responses, it was only counted once). The categories are reported in the order of their frequency and saliency across respondents (i.e., the first group was mentioned the most frequently while the last was less so). Each category incorporates distinct lessons with supporting quotes provided, again listed in order of most to least frequently mentioned.

Our study was deemed exempt by the Texas A&M University Institutional Review Board. Investigators agreed to participate in the survey by reading the study information sheet and proceeding with the survey.

## RESULTS

Of the 225 eligible NIH-funded interventions recruiting during the pandemic, 52 PIs responded to our survey and took an average of 32 minutes to complete the survey. Most investigators who responded were experienced: 78.8% had conducted 3 or more studies recruiting in community settings. Additional details regarding the studies included are reported elsewhere.<sup>2</sup> Briefly, the studies were from all across the United States, varied by length of time that participants were followed, participant time commitment in the study, and the intensity of data collection.

We are including one previously published quantitative result from the survey to provide context for the sample and the qualitative findings reported here: almost half of the respondents (46%) said recruitment was “very difficult” now, compared to only 2% who said it was more difficult before the pandemic.<sup>2</sup> Across the responses to the three open-ended questions, 14 lessons and/or recommendations emerged that were grouped into four categories.

The first category was about formalizing community partnerships (Table 1). This category included lessons that were the most frequently expressed by respondents. Respondents recommended ensuring buy-in and ongoing support from partners, including partners in formative work, and paying local leaders or hiring directly from the community for recruitment.

The second category emerged from lessons around study operations and implementation. Respondents recommended budgeting more time and money to recruitment, investing in staff for recruitment and their training, traditional forms of recruitment still have value, mitigating risks of fraud due to online recruitment, and utilizing existing networks, registries, or cohorts (Table 2).

The third category was that recruitment is both a science and an art. Respondents urged future researchers to try several strategies at once, learning and investing in methods that worked, but to also be creative and flexible (Table 3).

The fourth category emerged from lessons related to participant burden and benefit (Table 4). Specifically, reducing participant burden related to data collected and increasing flexibility in what data is collected and how it is collected (e.g., remotely). Additionally, respondents urged researchers to increase participant compensation and focus on how the research benefits participants.

**Table 1: Category 1 - formalize community partnerships (n=30).**

Lesson	Exemplar quotes
<b>Invest in time with partners to ensure buy-in and ongoing support (n=28)</b>	“Build strong relationships with community partners, as their buy-in is essential for conducting community-based research. Celebrate milestones with community partners and maintain regular meetings to have consistent communication and adjust expectations as needed.”
	“Involve community partners in other aspects of the work (beyond recruitment). The importance of meaningful relationships with community partners and authentic engagement/participatory work.”
<b>Include partners from the beginning through formative work (n=14)</b>	“Reach out to community partners and leaders to assess what community members are currently comfortable with.”
	“Have a leadership team comprised of key community partners to advise the recruitment process.”
	“Start with community listening sessions.”
	“Build relationships with the community prior to starting recruitment (e.g., open house event, work with community leaders).”
<b>Pay partners and community leaders to participate in work and hire staff from communities (n=5)</b>	“Form a Community Advisory Board, follow their advice.”
	“Provide support and compensation to community partners who support with recruitment activities.”
	“Find a leader in the community who has ties to the target population. Work with them to facilitate recruitment. A community member who has clout is exponentially more valuable than social media.”
	“Build relationships with people who have established trust in the community you are recruiting from. Many prospective participants, especially in more rural areas, are suspicious of research purposes.”
	“Need recruiters in person that represent the communities you are recruiting.”

**Table 2: Category 2 - focus on study operations (n=23).**

Lesson	Exemplar quotes
<b>Budget more time and money (n=11)</b>	“Plan more time for the recruitment.”
	“I will also continue to prolong my recruitment periods.”
	“Budget extra time/effort for recruitment.”
<b>Increase staff time and training (n=7)</b>	“Hire a 100% designated recruiter.”
	“Budget more staff time and staff training.”
	“Educate your staff about minority recruitment and its importance.”
<b>Traditional forms of recruitment are still valuable (n=5)</b>	“Use multiple sources of recruitment and focus on word of mouth. During this study we learned by telling participants to tell their family members and friends about us, we were getting lots of inquiries.”
	“Encourage word of mouth recruitment.”
	“We felt that recruitment approaches that involved personal interactions were important, e.g., recruitment at community events or working with trusted community organizations, churches.”
<b>Mitigate fraud risks (n=3)</b>	“Do not post survey links openly on social media. Even when using (paid) social media advertising, we had issues with bots completing the survey. This required more data screening on our part.”
	“[Avoid] reliance on social media, as there is too much opportunity for attracting fake applicants, including from other countries.”
<b>Utilize existing cohorts, lists, registries, and networks (n=3)</b>	“Work with the subject database of other colleagues or the institution.”
	“Use the states’ resources (like the state cancer registry) to facilitate recruitment . . . Utilization of federal resources, like the VA [Veterans’ Administration] are also a good idea.”

**Table 3: Category 3 – recruitment is a science and an art (n=17).**

Lesson	Exemplar quotes
<b>Recruitment is a science: test several recruitment strategies (n=15)</b>	“Monitor success of recruitment activities by watching the numbers and listening to feedback [from] recruitment staff, clinic/partner staff, and participants.”
	“[Avoid] starting the study without piloting/testing different recruitment strategies in the local study community (many of the strategies that worked successfully in other communities did not work in [name of community]).”

Continued.

Lesson	Exemplar quotes
	“Try a broad list of strategies, settings, and channels, and expand those that seem to yield the best results for your study's needs. Be flexible and keep a cycle of: try a setting/strategy; evaluate results; modify; repeat. Don't spend all of your time on any one strategy, but do learn how and where to focus your hours for the most productive results.”
<b>Recruitment is an art: be flexible and creative (n=5)</b>	“Be creative on subject recruitment. Don't rely on one or two sources.”
	“Be flexible with your approach, be mindful of the struggles everyone is dealing with, and keep your program officer in the loop.”
	“Be persistent and creative.”

**Table 4: Category 4 - reduce participant burden and increase participant benefit (n=15).**

Lesson	Exemplar quotes
<b>Ask less of participants and be flexible in what type of data you collect (n=8)</b>	“I'd suggest they avoid all/any questions or activities that participants will deem burdensome.”
	“[Avoid] requiring all activities be conducted in person.”
	“Have flexibility with the measures you collect from participants. Some may not be able to come in for in-person measures, but are religious in their efforts for survey completion and intervention adherence.”
<b>Utilize remote data collection (n=7)</b>	“Attempt to collect measures remotely. Remote data collection is developing very well, and many measures can be collected online via online surveys, video teleconference, and other services (like at home blood sample kits).”
	“Increase flexibility for data collection (in-person, phone, and online options).”
	“The importance of reducing barriers to participation (for example, allowing virtual survey data collection or interviews).”
<b>Increase participant compensation (n=3)</b>	“Increase incentives, especially data collection incentives.”
	“Add extra money on your budget for recruitment and incentives.”
<b>Focus on benefits for participation (n=3)</b>	“People like joining studies, but you need to make it flexible and enticing for them.”
	“The importance of always framing how your intervention will benefit those delivering it in addition to those receiving it.”

## DISCUSSION

Given the unique and exceptional challenges for health behavior study recruitment created by and surrounding the COVID-19 pandemic, we sought to capture the experiences and lessons learned by researchers of NIH-funded studies who were scheduled to recruit during this time period.

The first category of lessons learned related to formalizing community partnerships, with respondents urging fellow researchers to invest in time with partners to ensure buy-in and ongoing support; include partners from the beginning through formative work; and pay partners and community leaders to participate in work and hire staff from recruitment communities. These lessons are well-documented best practices in community-based research.<sup>3</sup> Our results suggest that these activities became critical to recruitment success during the pandemic, not just best practice.

The remaining three categories of lessons relate to new recommendations in community-based recruitment catalyzed by the pandemic experience. For example, the lessons summarized in the third category – recruitment

being a science and an art – suggest that the pandemic forced many researchers to expand their methods of recruitment and monitor their effectiveness in real time. They learned that this allowed them to be more adaptive and potentially more effective moving forward. The second category of lessons included how to operationalize a multipronged approach including: planning for recruitment to take longer and cost more and mitigating fraud risk associated with novel strategies (e.g., online recruitment). At the same time, PIs reported having less qualified and fewer staff on their teams available.

The final category of lessons learned was researchers need to make studies more worth participants' time by reducing participant burden, increasing compensation, and enhancing the appeal of participation. While pandemic restrictions and fear of contracting COVID likely played a large role in making study participation worth someone's time, other potential trends like increasing distrust in science/research or the proliferation of direct-to-consumer health programs may also contribute to current recruitment challenges. Future work should inquire directly from potential participants about their willingness to enroll in health behavior studies and what recruitment strategies and participant benefits would be most effective.

The findings of this study should be taken within the context of its strengths and limitations. The sample for this report is a geographically diverse group of community-based health behavior studies with experienced PIs. However, the findings are limited to community-based recruitment settings. It is also possible that respondents to our survey were more likely to struggle with recruitment than non-respondents.

## CONCLUSION

Events like the COVID-19 pandemic highlight the acute challenges of recruitment (e.g., loss of access to a recruitment setting) and the potentially more chronic challenges (e.g., perceived benefit of participating in research). While the acute challenges of the pandemic may have subsided, the lessons learned may be relevant moving forward as researchers have to respond to future social and environmental disruptions. Taken together, these recommendations will require longer and more complex recruitment plans. To implement these plans, researchers and funders will need to allocate more time, thoughtful attention, and financial resources to support formal community partnerships, additional staff time and training, real-time monitoring and refinement of multiple strategies throughout recruitment, and increased attention to participant benefit.

## ACKNOWLEDGEMENTS

The authors would like to thank the survey respondents.

*Funding: The study was funded by Texas A&M University and the National Cancer Institute [grant number R01CA230738]*

*Conflict of interest: None declared*

*Ethical approval: The study was approved by the Texas A&M University Institutional Review Board*

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**Cite this article as:** Fowler RAS, Demment M, Foltz SC, Graham ML, Maddock JE, Patterson MS. Lessons learned from principal investigators on recruitment for community-based health behaviour studies during the COVID-19 pandemic. *Int J Clin Trials* 2023;10(3):254-8.