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Recruitment and Retention Strategies for an Urban Adolescent Study: Lessons Learned from a Multi-Center Study of Community-Based Asthma Self-Management Intervention for Adolescents

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Abstract

Intervention studies with urban adolescents and families affected by asthma are critical to improving the disproportionate morbidity in this population. Community-based recruitment and retention strategies in a multi-site longitudinal project evaluating an asthma self-management intervention for adolescents are presented. Successful recruitment strategies depended on the geographic and cultural characteristics of each study site. Partnering with providers and groups known to the target population and in-person contact with target population were found effective. Flexibility accommodating modified and new approaches, securing multiple contacts and repeating mailings as well as capitalizing on the benefits of subject payment was critical to achieving long-term subject engagement of 85% in the study. Ongoing monitoring and adjustment of recruitment and retention strategies is recommended. Key words: Urban Recruitment; Retention; Adolescents; Community-based research; Strategies

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Introduction

Asthma is the most common pediatric chronic health condition, affecting nearly 10% of adolescents in the U.S. with disproportionate burden of morbidity for urban children (Akinbami, Simon, & Rossen, 2016; Center for Disease Control and Prevention [CDC], 2017). Asthma mortality is 7.6 times higher for urban African American children and adolescents than for White children and adolescents (Gergen & Togias, 2015). Furthermore, African American children suffer greater asthma-related morbidity with a 2.6 times higher rate of emergency department visits and 7.6 times higher asthma mortality rate compared to White children (Akinbami, Moorman, Simon, & Schoendorf, 2014). Research is needed that addresses the disproportionate burden of asthma experienced by minority adolescents living in urban communities.

Many studies have been conducted that address the burden of asthma in urban minority adolescents using multifaceted approaches. Exterminating pests, providing vacuum cleaners and education, and improving communication between providers and families have led to reduction in asthma morbidity (Karnick et al., 2007; Mitchell et al., 2012; Morgan et al., 2004). However, often the effects of asthma-focused interventions and programs targeting urban adolescent populations have been mixed or inconclusive, due in part to inadequate power (i.e., small sample size) to detect the effect of these interventions often associated with challenges in recruiting and retaining adolescent participants.

Challenges of securing and maintaining adequate power in studies with urban populations are multifaceted, such as lack of transportation, time constraints on availability for study activities, and frequent moves that make enrollment and completion of study activities difficult (Grunbaum, Labarthe, Ayars, Harrist, & Nichaman, 1996; UyBico, Pavel, & Gross, 2007). Further, negative perceptions about research participation and mistrust of the research community are pervasive among ethnic minority groups, which present challenges to recruiting and keeping participants engaged in a longitudinal study (George, Duran, & Norris, 2014). In addition, adolescents often lack interest in study participation, and even if they are interested, coordinating schedules with their parents for study consent/permission and follow-up visits can limit participation (Hartlieb et al., 2015; Hinojosa et al., 2014). Despite the challenges inherent to urban adolescent research, conducting quality research is critical to address health disparities in this vulnerable population. To facilitate research efforts targeting urban youth with asthma, more specific directions and practical guidance to successfully recruit and retain the target populations are imperative.

The purpose of this report is to briefly review the literature on recruitment and retention strategies used to conduct community-based studies in general and to discuss our experience of recruitment and retention while conducting a multi-site study evaluating a community-based intervention designed to improve asthma self-management in urban adolescents with asthma. Finally, based on the literature and our experience, we provide practical suggestions to enhance recruitment and retention success for studies with urban adolescents and their families.

Literature Review

Recruiting Children and Adolescents in Urban Settings

Conducting behavioral health research utilizing community-based recruitment has become more complex as school and clinics often require a lengthy process for access and recruitment from schools and clinics is not equally effective across study sites (Childhood Asthma Management Program Research, 1999; Schoenfeld et al., 2000). The Engagement, Verification, Maintenance and Confirmation (EVMC) Model (Scott, 2004) was highly successful in retention of adults and has a replicable protocol which has limited testing in adolescent populations. Successful strategies for retention and recruitment of children and families for behavioral health studies (Recruit, Engage and retAin Children of REACH strategies) were developed primarily out of studies in school settings and may not be as effective in non-school, community-based settings (Schoeppe, Oliver, Badland, Burke, & Duncan, 2014; Scott, 2004). In the following sections, we describe common recruitment settings and optimal strategies that have been utilized in community-based health studies and reported in the literature.

Health clinics—On-site recruitment of participants during health care appointments is the most commonly used strategy to recruit ethnic minority populations into research (UyBico et al., 2007). Completing study activities during a scheduled office visit reduces subject burden and increases study participation (Goff et al., 2016; Smith et al., 2004). Identifying a project champion within a clinic to facilitate recruitment is also effective particularly when the screening process is streamlined (Childhood Asthma Management Program Research, 1999). Clinic staff are more likely to be known to and trusted by patients yielding greater success than unsolicited calls from persons unknown to participants (Hartlieb et al., 2015).

In order to use a clinical practice site, however, obtaining approval and support from clinic administrators, staff, and clinicians for needed time and resources is essential. In addition, patient volume for a specific diagnosis can influence achieving recruitment targets. Finding suitable space for confidential screening and enrollment for on-site recruitment can also present challenges (Yarcheski & Mahon, 2007). Despite the potential benefits of recruiting in health clinics, this approach alone has yielded mixed results in meeting enrollment targets for some eligibility criteria (Fitzgibbon, 1998; Kennedy et al., 2005; Martin, Olson, Mosnaim, Ortega, & Rothschild, 2012).

Community organizations—Recruitment success can be achieved working with community organizations and community leaders (Schoenfeld et al., 2000; Yancey, Ortega, & Kumanyika, 2006). Researchers seek to secure multiple sources of referrals and utilize multimodal approaches simultaneously—such as flyers and brochures; media announcements; and direct outreach by research staff at health fairs, schools, and churches—to promote the project (Sorkness, Ford, & Lemanske Jr, 2001). In a study of Puerto Rican children and parents for an asthma study (Martin et al., 2012), original community partners ended recruitment efforts due to their personnel and funding issues, leading the research team to form 40 new partnerships across varied groups and institutions in the community. The study highlights the need for a flexible, dynamic, and broad-based approach to securing

community partnerships instead of exclusively relying on one or two partnerships to support enrollment targets.

A common challenge associated with reaching out to multiple community-based locations is staffing and cost (Logsdon & Gohmann, 2008; Martin et al., 2012). Research staff need to visit identified sites and attend events with potential participants, which often take place in the evenings and on weekends. Once a potential participant is identified, additional staff time (that may include off-hours availability) and resources are needed to address specific barriers to participation (e.g., transportation, language, time constraints), particularly for under-resourced families living in large urban communities (Keyzer et al., 2005).

Schools—Schools are commonly used for recruiting large numbers of children or adolescents. Once potential schools have been targeted and key personnel identified, appropriate approval from the school or school system must be obtained for research staff to utilize classroom time, school facilities (e.g., cafeterias, libraries) or group activities for recruitment (Logsdon & Gohmann, 2008; Yarcheski & Mahon, 2007). For studies including parents and students, specific events with parents in attendance can be targeted (Villarruel, Jemmott, Jemmott, & Eakin, 2006). Securing support from school nurses, principals and health instructors is essential to recruiting the target group for a health intervention as well as facilitating study activities on-site (Melnik et al., 2007; Riesch, Tosi, & Thurston, 1999). Additional logistic complexities involved in school recruitment include individual school policies about research involvement and school calendars to coordinate the study timeline with routine or special school events (White, 2012).

Retention Strategies

Proactive procedures for retention such as developing a protocol for ongoing subject engagement; obtaining and verifying alternate contact information; and using telephone, mail, and home visits throughout the course of a study can facilitate uninterrupted contact and high retention rates (Scott, 2004). These strategies have been used successfully in urban and suburban middle and high school student populations (Diviak, Wahl, O’Keefe, Mermelstein, & Flay, 2006; Seibold-Simpson & Morrison-Beedy, 2010).

Establishing good rapport with subjects during the screening and consent process was found to be effective in building trust with participants and enhanced retention (Wallace, Berent & McCarthy, 2014). Research staff trained in culturally sensitive approaches to screening and obtaining consent can increase knowledge about the consent process and address distrust of participants to research activities (Corbie-Smith, Thomas, & St George, 2002; Susman, Dorn, & Fletcher, 1992). To promote long-term participation, the initial relationship can be strengthened by continued personal interest of staff through communications with participants using birthday cards, maintaining updated contact information during study contact points, and offering incentives (Ely & Coleman, 2007; Frank, Nader, Zive, Broyles, & Brennan, 2003; White, 2012).

Offering alternate modes of data collection such as mailings and online surveys improves retention by addressing time constraints and travel challenges faced by participants. (Booker, Harding, & Benzeval, 2011). Mailing surveys 2–3 times, sending several routine reminders

for survey completion (Eagen, 2002), and remaining flexible in meeting the scheduling restrictions of subjects (Motzer, Moseley, & Lewis, 1997) have been found to increase subject retention.

Face-to-face contact for initial and subsequent data collection has yielded the highest retention rates (Mills, Pederson, Koval, Gushue, & Aubut, 2000; Novo, Hammarström, & Janlert, 1999). However, frequent in-person meetings and home visits can be impractical or cost prohibitive given finite study personnel time and resources.

Communicating with adolescents and families to schedule follow-up appointments is inevitable in longitudinal studies. Older adolescents are in a stage of transition from home to college or work. Many rely on cell phones for communication and have frequent changes in phone number, email, or mailing address, making long-term follow-up challenging, if not impossible. Multiple strategies including face-to-face initial encounters, collection of multiple contacts including peer contact information, and multiple reminder contacts using phone calls and mailings achieve higher retention rates for adolescents than mailings or phone calls alone (Boys et al., 2003; Meyers, Webb, Frantz, & Randall, 2003). Adolescents may be involved in many activities including school, sports, and work, leaving little time for or interest in research appointments. Coordinating parent and adolescent schedules for follow-up meetings improves with flexible scheduling in the evenings and on weekends, meeting in public places, and maintaining contact between study time points (Rait, Prochaska, & Rubinstein, 2015; South-Paul, 2014).

The following sections discuss the lessons learned concerning recruitment and retention as we conduct a relatively large urban multi-site study of adolescents with asthma.

Lessons Learned from the PLASMA study

Study Overview

The Peer-Led Asthma Self-Management for Adolescents (PLASMA) study is a multi-site randomized controlled trial targeting adolescents ages 13 – 20 years residing in 3 large cities in the U.S., including Buffalo NY, Baltimore MD, and Memphis TN, with particularly high rates of pediatric asthma and asthma-related morbidity. PLASMA is an intervention designed to improve adolescents' asthma self-management by using trained peer leaders who delivered the asthma education program to adolescents with asthma in a day-camp setting. We screened 508 teens, and 479 were found eligible for participation (see Table 1). Of those eligible, 78% (373) were successfully enrolled: 322 campers (12–17 years) and 51 peer leaders (16–20 years). After the asthma camp, adolescents received six bi-monthly phone contacts from their peer leaders or research staff depending on their assigned group. Participants provided data at enrollment, immediately following the intervention, and every 3 months for 15 months of follow-up.

Recruitment Strategies by Study Sites

The three study sites developed a recruitment strategy to reflect the unique characteristics of their region, culture, population, and available resources. Staff structured recruitment around a camp intervention date that was predetermined by the availability of a camp venue and the

number of participants needed to implement the intervention protocol. Recruitment duration for each site was 7 to 10 months, during which each site encountered expected and unexpected recruitment challenges in reaching the enrollment target. As a result, enrollment targets were not met in time, and two sites extended recruitment into three phases yielding three cohorts of participants. The Institutional Review Board (IRB) in each site played a critical role in recruitment and enrollment, as the study teams continually revised and added the potential recruitment venues and strategies, often necessitating protocol amendments or intermittent Health Insurance Portability and Accountability Act (HIPAA) waivers to add recruitment sites. Specific recruitment strategies we utilized are presented as follows. Table 2 lists details for each strategy.

Institution-wide promotion—The study sub centers were located within University-affiliated institutions, creating a starting point for “getting the word out” about the study. Throughout the recruitment phases, teams presented the project to colleagues, posted flyers, sent out emails, posted items in staff/institution newsletters, and collaborated with other projects to get assistance and tips on recruitment sources.

Study website-based recruitment—The coordinating center created a website for recruitment tailored for each location to solicit self- and clinician/community referrals. The website introduced the research project targeting adolescents, parents, and providers, and included web links to IRB-approved, site-specific consent documents, recruitment flyers, and brochures. During face-to-face recruitment, often just the adolescent or the parent was available; however, both were needed for screening and enrollment. In these instances, staff directed potential adolescent subjects to the website to share project information with their parents and to enter their contact information to indicate interest. This method was found to be highly successful in our study.

Clinic-based recruitment strategies—Direct access to a patient database for recruitment was not available to sites. So, each site focused on established relationships or connections across pediatric or family practices either affiliated or nonaffiliated with the participating university medical centers to identify a project champion. Local providers and practices were informed of the project through mailings, presentations, and phone calls. Many practices participated at various levels: some hung flyers, some sent letters, and others provided registries. Two practices partnered with the research team via practice champions who actively recruited participants.

Budget constraints or clinic-specific policies prevented the study teams from offering financial incentives to participating clinics or clinic staff for aiding recruitment. Instead, bartering services such as consulting on a grant review board or assisting with a local asthma initiative were provided to the clinic as a token of appreciation.

School-based recruitment strategies—School nurses who are usually familiar with students with asthma were approached through phone calls, email, school visits, and via school nurse managers. Responses from school nurses, managers, and city-wide administrators were mixed. Although some administrators offered good verbal endorsement of the project, this seldom translated into face-to-face time with individual school nurses.

Barriers across sites included difficulty in getting a response to outreach by study teams, competing priorities for consideration at the school personnel meetings, time constraints of school personnel, difficulty identifying persons with authority granting permission for access to students, and inability to navigate approval process for study access at each school.

We found the method of “cold calling” principals and nurses unsuccessful. Instead, we obtained reasonable success by capitalizing on previous relationships with school principals to distribute flyers to the general student population and obtained permission for study staff to recruit at multiple school-related events attended by parents. These activities were relatively successful, but gaining initial entry was time-consuming, as some schools required permission through the human subjects committee within school systems for any study activities.

Community-based recruitment—Study staff strategically sought out community groups involving adolescents or whose members were connected to adolescents for project endorsement and referrals. Referrals from individual groups were small but often led to additional recommendations requiring continual research staff effort and creativity to enlist additional recruitment locations. Engagement with a community wide asthma campaign and city wide library system in Memphis garnered the most success in promoting the project and recruiting over connections to smaller community groups and churches.

Having realized in-person contacts as the most effective strategy for recruitment, study staff targeted access to local events and venues with a likelihood of having adolescent/parent pairs in attendance for direct recruitment. Study staff had greatest success by directly approaching adolescents and parents/guardians with questions, such as “do you know someone with asthma?” Displaying recruitment materials for maximum visibility, placing free items such as hand sanitizer, t-shirts, candies, and information booklets on asthma were effective attention grabbing strategies at public events.

Retention Strategies

Some retention strategies were built into the study protocol, such as allowing participants who did not participate in the intervention to remain in the study, periodic follow-up contacts and distribution of subject payments at each time point with increased amounts for the study exit contact. To maximize engagement of enrolled subjects for the prolonged follow-up period of this study, we employed additional strategies, resulting in an average retention rate to date of 85% with follow up participation ranging from 60%–100%. See Table 3 for a list of specific strategies used to address common challenges to retention. Below is the list of the strategies by category.

Building and maintaining rapport—Initial engagement of adolescent participants to project staff and activities was identified as a critical first step. Enrollment was conducted in-person, which established initial trust and rapport with adolescents and parents. Thoughtful and respectful approach to the processes of informed consent and enrollment helped the staff build initial trusting relationships with participants. The relationships were further strengthened by maintaining respectful and regular contact with participants throughout the

project. During contacts, the individual needs of participants such as transportation, illness, or scheduling conflicts were continually identified and addressed.

Frequent personalized contacts—Many of our participants face competing priorities for their time such as social commitments, part-time jobs, or sports, so each team developed contact schedules and strategies for outreach utilizing multiple platforms including texting and social media to effectively engage their attention in the project. Each contact with participants was treated as an opportunity to individually connect with them. To maximize participation in the intervention, study staff contacted families by phone and mailings as a reminder and confirmation of attendance, which resulted overall in a 79% attendance rate. Besides sending personalized messages during regularly scheduled follow-up, study teams mailed personalized cards for life events such as birthdays, graduations, or death in the family. Survey data reflecting significant asthma distress (e.g., hospitalization or multiple ED visits) was flagged and responded to by the site PI who reviewed asthma care plans with families. Study newsletters were also used to share study-related information with participants and announce upcoming study activities.

Updated contact information—Keeping up-to-date contact information for all participants was prioritized since frequent moves, phone access, and phone number changes were regularly reported by our participants. To address these life situations, study staff collected information on both the adolescents and parents as well as up to three collateral contacts. Staff verified contact information during scheduled follow-up time points, bi-monthly calls, and distribution of subject payment. Staff monitored and contacted all participants whose mail was returned undeliverable and those who missed two consecutive follow-up time points. When the outreach failed, home visits to the last known address were conducted in teams of two, when feasible, and assessed for safety prior to exiting vehicles and left notes for the family if no one was home.

Identifying and addressing transportation issues—Each community had differing public transportation infrastructure that needed to be factored into facilitating participation in study activities. Cost of transportation was included in subject payment for the camp intervention in Baltimore with access to public transportation and in Memphis where families needed to use private means. Buffalo provided free shuttle service to the camp location and offered travel reimbursement on an as-needed basis. To overcome transportation barriers for participants requesting in-person follow-up, home visits were conducted.

Diversifying follow-up assessment methods—To facilitate maximum participation, we offered three methods of survey completion: online, mail, and in-person (home, office, public setting, or phone). Participant preference was obtained for each study time point to accommodate changes in address and access to computers and transportation. After surveys were distributed, study staff followed up with participants by phone, text, mail, and email and sent out additional surveys as needed. No specific imposed limit to the number of contacts for follow-up or number of times surveys to be resent allowed study staff to individualize follow-up strategies for each participant.

Flexibility in timing of data collection—Study teams carefully assessed the window for each follow-up in light of school vacations, exam schedules, and holidays to maximize on availability of the adolescents and minimize anticipated barriers to participation. Survey distribution was adjusted by a few days before or after the scheduled three week data collection window to account for these anticipated conflicts. Assessment of unanticipated barriers was reviewed at team meetings, and additional adjustments were made as needed.

Effective use of study payment—Subject payment was offered in different forms and method of delivery across study sites. Buffalo and Baltimore used prepaid VISA cards and gift cards, respectively, for completed surveys by mail and online. These methods of payment were either mailed or provided on the spot for in-person completion. One research assistant in charge of payment maintained close communication with team members to facilitate rapid disbursement of payment. The Memphis site exclusively offered cash payment that was hand delivered to the home or at prescheduled times at four public libraries throughout the city. Although this approach was time consuming, it allowed for frequent face-to-face engagement with families yielding the highest completion rates of the project to date at over 90% for all cohorts.

Use of motivational incentives—Having noted a decline in participation at around 9 months post intervention at the Buffalo and Baltimore sites, study teams added motivational incentives (e.g., raffles, pizza parties) to subsequent time points (12- and 15-months contact) with IRB approval to provide greater novelty for continued participation. Participants were routinely notified of added incentives in a newsletter, postcard and letter invitations, during survey distribution, and follow-up phone calls. Also, capitalizing on the adolescents' expressed desire to see others who had attended camp, the study teams arranged a study party at the 12- and 15-month time points. The events, along with added motivational incentives, resulted in stabilizing and increasing participation across sites.

Discussion and Recommendations

In our multi-site project, we met our enrollment target in two of the three sites despite known difficulties associated with recruitment of urban adolescents and their parents. Each site's unique characteristics in demographics, geographic distribution of target population, and culture greatly influenced choice and success of recruitment and retention methods. The coordinating center worked closely with the study site staff who acted as community insiders to identify and pursue sources to access adolescents and their parents. Use of insiders has been recommended to facilitate successful community-based recruitment and was critical to the successful recruitment of urban adolescents for this study (Hinojosa et al., 2014; UyBico et al., 2007).

Deferring to the expertise of study personnel on the cultural context of their site was critical in the development of effective recruitment and retention strategies for our multisite project. In Memphis, connections to recruitment sources took time, as building trust and establishing credibility with community groups was part of the cultural norm for gaining access to the target population. Furthermore, to address the lack of reliable public transportation, the study team secured public sites for recruitment, enrollment, and follow-up of participants.

The Baltimore site, on the other hand, was able to center study activities in the immediate vicinity of the study office, as many in the target population lived in and had easy access to this central location. More poignantly, the Baltimore study team, in the wake of a racially charged social incident unfolding in the locale at the time of recruitment, carefully assessed its potential impact on local urban families in regard to feelings of distrust, vulnerability, and frustration and approached the families with sensitivity. Team members took this context into account when engaging potential subjects in screening, enrollment, and subsequent study activities.

Another critical factor to recruitment and retention of our community based subjects was the importance of linguistic and cultural competency. The knowledge and experience the research personnel had with the study population at each site helped staff to implement effective strategies building rapport during initial contact that strengthened with subsequent contact. Participants frequently commented that research team members were approachable and accommodating, suggesting they felt respected. The relationship created between subjects and research staff indicates that personnel had a level of cultural competence that helped sustain subject engagement and reduced potential barriers of distrust and cultural incongruence often experienced by minority participants (George et al., 2014).

Recruitment of our urban adolescents is time-consuming and often necessitates many more recruitment venues than anticipated, requiring perseverance and flexibility. An implemented strategy needs to be evaluated within a couple of weeks for success and modified as needed. Across our study sites, strategies yielded variable success, requiring each team to be open-minded and create an individualized, unique strategy for recruitment. We held regularly scheduled meetings with each site and with all sites to assist in monitoring progress and evaluating strategies to maximize effectiveness.

Our attempts at recruiting champions within clinics and schools were difficult due to the time constraints of these personnel. Targeting groups of school nurses and counselors as well as upper administrators as recommended by South-Paul et al. (2014) as a strategy was somewhat successful but by no means adequate. As reported elsewhere, we found that access to schools requires time (White, 2012) and that previous professional connections to school principals and administrators were key to gaining access. We recommend that key personnel within the target organization be approached during less busy periods and followed up periodically. We found that an informal recruitment method, “word of mouth,” was as effective as referrals from schools or clinics. Thus, strategically capitalizing on the social networks of enrolled subjects and study staff is also an important approach to subject recruitment in urban settings.

We used multiple strategies simultaneously to maximize retention of our urban adolescent participants. We found that routinely updating address changes or contact numbers through ongoing and often in-person contact with the subjects and collateral contacts, as well as conducting home visits to locate missing participants is critical to maintaining engagement. We also did not impose a limit to the number or type of contacts made by study personnel to pursue participants for follow-up data collection, as multiple contacts have been found to be effective in decreasing subject attrition in longitudinal studies with adolescents (Cotter,

Burke, Stouthamer-Loeber, & Loeber, 2005; Flores et al., 2017; Yeterian, Dow, & Kelly, 2012). However, care must be taken in attempting frequent contacts, as it can raise a concern of invasion of privacy or coercion. Although some subjects did lose interest in the project, from our experience, lack of subject response to contact was often due to changes in access to phones or computers, fluctuations in available phone minutes due to monthly limits of plans, or changes in mailing address. In many cases, we found that texting the participants and parents was often more effective in making contact than was phone calling or mailings. Families reported enjoying the personalized contact and flexibility of study staff. Many of our participants responded to our outreach, further underscoring the importance of frequent, personalized contact in study retention.

In addition, we found that offering choices of survey method (online, mailing, or in-person), flexibility in follow-up time frames, and varying the types and amount of subject payment could improve retention. The literature has also shown that offering choices of data collection method can increase participation in data collection in adolescents and adults (Schoeppe et al., 2014; Scott, 2004), although different data collection methods could potentially introduce bias (Brenner, 1985). Flexibility in data collection methods is particularly important for urban populations, as it can readily accommodate their changing circumstances around access to computers, transportation, or residence. We found that an in-person follow-up method was effective, although time-consuming, in building and strengthening personal engagement and increasing participant satisfaction, as it allowed for immediate subject payment. Nonetheless, mailing or electronic data collection methods offered to busy adolescents maximum flexibility regarding when and where to complete the data. As such, availability of multiple data collection methods can be carefully planned to maximize the opportunities that each method affords to enhance subject retention.

Flexible scheduling for follow-up data within the reasonable timeline is not often recognized as a retention strategy. However, we found it critical to proactively address time-bound barriers to follow-up time points (e.g., exam weeks, vacations, and holidays) by adjusting survey scheduling. Relaxing rigidity around timing of data collection windows to some extent can accommodate last-minute completers and provide study staff with additional time for rescheduling of cancelled appointments for busy families. As Booker et al. (2011) suggested, we found that sending repeated mailings (up to 3 times) of questionnaires instead of reminder letters was effective in increasing completion rates. Multiple mailings was particularly helpful for the adolescents in whom survey completion is often overlooked due to other competing priorities such as completing school work, working a part-time job, playing sports, or spending time with friends. In our participants, second and third mailings may also have been effective, as adolescents tend to respond better when surveys are scheduled close to the due date (Yeterian et al., 2012).

In our project, each site adopted different types of subject payments. Store gift cards can be readily mailed to participants, eliminating the need to schedule in-person distribution. However, if the accepting store is not conveniently located, participants might not be motivated by this type of payment. We also mailed prepaid bank cards that can be used as a debit card or cash, allowing for flexibility of use and more safety against the risk of loss or theft. However, it required at least 2–3 business days to be activated by the issuing bank,

rendering this waiting time less attractive to some participants. One of our sites used cash payment exclusively. Although cash offers the greatest attraction and ease of use, disbursement cannot be safely or conveniently done by mail. Study staff need to deliver cash payments in-person, adding more complexity to the study protocol and costs associated with staff time and travel. In the Baltimore site at the 12- and 15-month follow-up times, however, participants or their parents were willing to come to the study office to collect their cash payments. Overall, we found cash payments to be the most popular among our teen participants and effective in maintaining high participant engagement and retention, suggesting the value of this type of payment in projects with high-risk populations whose sustained involvement in the study is particularly difficult to attain.

In order to boost subject attrition toward the end of the project, we slightly increased subject payment for the final assessment point, added random awards (e.g., raffle) at the last two time points, and concluded with a participant reunion (e.g., project party). The combination of approaches was effective in improving participation, as subject payment alone is insufficient to increase retention (Frank et al., 2003; Wallace, 2014).

Table 4 summarizes our recommendations for recruitment and retention of urban adolescents in community based health research studies.

Conclusion

Conducting a longitudinal study with adolescents and their parents in urban settings calls for dedicated staff who is knowledgeable about the community, unafraid of reaching out to a multitude of local sources for support, and open-minded to exploring new approaches and strategies to boost recruitment and retention. Recruitment usually takes longer and requires more resources than initially anticipated. Continuous monitoring of recruitment progress and periodic assessment of recruitment venues and strategies for viability and response are critical. The project's capacity to respond to the periodic evaluation in a timely fashion by adjusting and revising strategies is of paramount importance in increasing the chance of success. It is also essential for the project to plan ahead for unanticipated expense and time needed for implementing new recruitment approaches to achieve targeted enrollment. Building and maintaining trusting relationships with participants is vital to securing their long-term commitment to the project. In addition, successful retention strategies include making frequent, personalized contacts via in-person encounters or phone calls or texting, offering multiple options for data completion at each assessment point, repeating mailings and text or phone reminders, accommodating school or life events in determining data collection timing, and maximizing the benefit of incentives offered to subjects. The effective strategies with urban participants outlined in this paper suggest that cultural competence, including knowledge about communities, respectful engagement, and a willingness to accommodate strategies to the life circumstances of the targeted families reduces barriers to participation. These three tenets are integral to successful recruitment and retention of diverse populations with varied health conditions across the spectrum of clinical research.

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Table 1

Number of participants referred or enrolled through each recruitment source

Sources	Total Referred n (%)	Total Enrolled n (%)
Word-of-mouth	104 (20%)	76 (20%)
Clinician referrals	94 (18%)	72 (19%)
School referrals	72 (14%)	51 (14%)
School events	59 (12%)	41 (11%)
ED/clinic direct recruitment	36 (7%)	34 (9%)
Study flyer	40 (8%)	32 (8.5%)
Community/group events	44 (9%)	32 (8.5%)
Clinical practice patient registries	34 (7%)	18 (5%)
Previous study contact database	20 (4%)	14 (4%)
Self-referral through the study website	3 (.06%)	2 (.05%)
Newspaper ad	1 (.02%)	1 (.03%)
Radio	1 (.02%)	0 (0%)
Total	508	373

Table 2

Community-based recruitment challenges and strategies to overcome them

Challenges	Strategies
Getting the word out to adolescents with asthma and their parents	<ul style="list-style-type: none"> Flyers should be designed for readability and attention-grabbing for teens Post and distribute flyers in high-traffic areas Design website for access to project information on multiple platforms Partner with community-wide campaigns on project health issue Use word-of-mouth referrals from study staff and subjects
Personnel at clinics and schools have limited time and resources to recruit	<ul style="list-style-type: none"> Set up study website for ease of referral and streamline process Use multiple methods of outreach (phone, email, mail, meetings) Partner with personnel with similar health interests and large target population Recruit study champions from schools or clinics Offer incentive or service to personnel for screened subjects Request small number of referrals per provider Follow up frequently with personnel Secure permission to recruit at the clinic or school events (lunch, nurses office, health fairs, college fairs, back to school event)
HIPAA restricts access to patient records	<ul style="list-style-type: none"> Utilize practice partners of the university affiliated with the investigators Utilize existing professional or personal connections within clinics Contact subjects from previous studies who had agreed to be contacted for future research projects
Clinic recruitment has many no shows and gaps in appointments	<ul style="list-style-type: none"> Obtain appointment times for patients meeting eligibility criteria Partner with other recruiters to screen for project target population Focus on sites with a large potential subject pool such as Emergency Departments
Schools require administrative approval for research activities	<ul style="list-style-type: none"> Familiarize yourself with school and district policy Be prepared to file IRB-related paperwork Capitalize on previous relationships with school principals, administrators, and nurse managers for access Plan in advance of school year start date to access key meetings and gate keepers
Small number of referrals per community group	<ul style="list-style-type: none"> Plan to contact and present to multiple groups with a target population or those who serve the target population (e.g., youth pastors) Identify study staff with flexibility to work off-hours to conduct outreach Recruit project promoter within a group (library, YMCA) Utilize knowledge of community insiders to identify sites Ongoing evaluation and adjustment of recruitment sites
Parent permission is required to enroll underage participants	<ul style="list-style-type: none"> Design a website with parent portal to access project information Target events in which parents and teens attend together Focus on parent engagement in project via highlighting benefits participation, providing small gifts Follow up with parent or teen shortly after first contact via phone/text

Table 3

Challenges to retention and strategies to address them

Challenges	Strategies
Frequent changes in contact information, address, and access to phone	<ul style="list-style-type: none"> • Identify and manage high-risk participants who moved two or more times one year prior to enrollment • Obtain multiple phone numbers at enrollment including friends • Avoid delay in contact after screening and/or enrollment • Update contact information regularly with parent and teen • Request participant preference for contact during each study communication • Utilize multiple communication methods (e.g., mail, phone, texting, email and social media) • Conduct home visits to locate participants with none-working contact numbers. • Set up a protocol to track participants who are not responding or have returned mail for individualized follow-up
Limited access to transportation, phone/and or computer and stable housing	<ul style="list-style-type: none"> • Offer multiple modes of data completion via mail, online, or in-person • Inquire about survey completion method preference at each time point to accommodate changes • Conduct home visits, use study office or public space for in-person study activities • Provide transportation or reimburse for travel expenses
Competing priorities for time such as school, work, family commitments, social time	<ul style="list-style-type: none"> • Be flexible with data collection window after assessing for avoidable conflicts such as school recessions, exams and holidays • Send out multiple reminders via mail, phone, text, social media prior to time point • Team up with parent/responsible adult to assist teen in completing study activities • Provide evening and weekend hours for study activities • Do not limit number of follow-up calls or distribution of surveys to participants for data completion • Extend data collection by a few days to accommodate last-minute completers • Evaluate study staff feedback and participant response to study activities for any changes in procedure to reduce participant burden
Loss of interest in study follow up	<ul style="list-style-type: none"> • Establish personal connection between study staff and participant during enrollment • Provide ongoing personalized contact during regular study activities (calls, mailings) • Send out personalized cards for individual life events such as birthdays, graduations, loss of family member, illness • Engage parent/responsible adult in encouraging participation • Distribute project newsletter with project updates and upcoming events • Send out greeting cards or letters to participants who missed consecutive time points • Offer an opportunity to re-engage in the project such as participant reunion events • Increase study payment and add motivational incentives toward end of project such as raffle prizes (e.g., gift baskets, gift cards) or pizza party

Table 4**Recommendations for recruiting and retaining urban adolescents****Recruitment recommendations:**

- Use community insiders to identify recruitment sites
- Identify cultural context of study site for developing recruitment and retention strategies
 - Defer to expertise of study personnel for local cultural norms
 - Be aware of recent community and national events impacting target population
 - Address access barriers to study office location by participants
- Monitor and evaluate success of recruitment strategy on a regular basis
 - Identify multiple recruitment sites on an ongoing basis
 - Drop non-viable sites as needed and add new ones
 - Devote adequate study personnel time for recruitment (i.e., nights, weekends)
 - Stay open-minded to unique, individualized strategies
- School and clinic site access is best achieved by:
 - Use of previous connections
 - Targeting key personnel during less busy periods
 - Adequate time for lengthy process of approval and coordination of study activities
- Strategically capitalize on social networks of enrolled subjects and study staff
- Partner with community wide initiatives related to study health issue

Retention recommendations:

- Maintain frequent contact with adolescent participants and their caregivers
 - Update participant phone number, alternate phone numbers, email address and home address regularly
 - Identify participant preferred method of contact (phone, text, email, mail) at each contact and study time point
 - Conduct home visits as needed to re-establish contact
 - Mail out personal cards such as birthday and get well cards
- Offer choice of survey completion method (e.g., online, mail, in person) at each data collection time point
- Repeat mailings of questionnaires up to 3 times or more
- Send reminders via preferred contact method multiple times
- Adjust survey scheduling by proactively addressing time bound barriers (i.e., school vacations, holidays, exam schedules)
- Cash incentive payments for study activities are preferable
- Increase incentive payment and add novel incentives at final assessment time points