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Recruiting Low Income and Racially/Ethnically Diverse Adolescents for Focus Groups

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Abstract

Purpose—Recruiting and enrolling low income, racially and ethnically diverse adolescents into research studies can be a challenge. This paper details our research team's methodology in the recruitment and enrollment of low income and racially/ethnically diverse adolescents in three cities as part of a broader study to understand adolescent perceptions of a health risks.

Methods—Our team used Florida's Medicaid and Children's Health Insurance Plan (CHIP) administrative databases to identify a sample of adolescents for focus group participation. Utilizing Geographic Information Systems software we generated maps of racial and ethnic group clusters in 3 cities and identified community centers within each cluster to hold the focus groups. We mailed initial focus group introduction letters, conducted follow-up phone calls for recruitment and further implemented techniques to optimize participant confidentiality and comfort.

Results—We enrolled 35 participants for 8 focus groups in 3 cities at a total cost of $264 per participant, including personnel, materials, travel, and incentives costs. As a result of our efforts, groups were fairly evenly distributed by both race and gender.

Conclusion—Administrative databases provide opportunities to identify and recruit low income and racially/ethnically diverse adolescents for focus groups that might not otherwise have the opportunity to participate in research studies. It is important that researchers ensure these populations are represented when conducting health assessment tool evaluations.

Keywords

Research Subject Recruitment; Minority Groups; Low Income Population; Adolescent; Focus Groups; Risk Assessment

INTRODUCTION

Recruiting and enrolling low income, racially and ethnically diverse adolescents into research studies can be a challenge. Barriers such as mistrust [1], constraints on time[2], and transportation[3] are well documented difficulties researchers face when recruiting a population like this. These barriers can be further complicated when research studies involve sensitive topics, such as, alcohol use, sexual activity, illicit drug use, and depression. Studies that have successfully recruited diverse, low income adolescents have obtained convenience samples of teens from agencies serving adolescents such as schools, health agencies, and community organizations[4–7]. This study describes a novel methodology in the identification, recruitment, and enrollment of low income and racially/ethnically diverse adolescents living in three cities as part of a focus group study to examine adolescent individual and contextual factors influencing participation in health risk assessments.

Focus groups are a widely recognized method of obtaining information about perspectives on health and health behavior [8]. They can be a particularly effective tool for capturing the beliefs and behaviors of adolescents, vulnerable or underrepresented groups[9]. The purpose of the current study was to conduct focus groups with adolescents to understand their perceptions of taking part in health risk assessments when they visit their primary care physician. The following sections will detail the major processes used to carry out the focus group research study with low-income and racial and ethnically diverse adolescents, which includes adolescent and focus groups site selection strategies, participant selection and recruitment, and focus group administration.

METHOD

Adolescent and Focus Group Site Identification Strategy

In order to identify low income and racially/ethnically diverse adolescents, we utilized spatial cluster sampling with Florida’s Medicaid and State Children’s Health Insurance Program (CHIP) databases. These databases are available within our research center as part of a state contract to house data and conduct quality assurance surveys. The adolescents participating in Medicaid and CHIP receive full or subsidized insurance coverage, and their families earn up to 200% of the Federal Poverty Level ($47,100 for a family of four in 2013). The state of Florida gave permission for our team to utilize the Medicaid and CHIP databases to identify and contact adolescents currently enrolled in the programs for our study. This study was also approved by the University of Florida, College of Medicine Institutional Review Board (project #H-172-2011 phase I; project #H-653-2011 phase II)

A spatial cluster sampling process was used to minimize issues related to the cost and availability of transportation to focus group sites, and to ensure that all participants recruited for the study could easily access focus groups sites. The process involved identifying and mapping areas within each city where clusters of racial/ethnic adolescents participating in Medicaid and CHIP live. First, the programming team identified all adolescents (ages 14–18 years) currently enrolled in Medicaid and CHIP in the three cities by conducting a search of the databases by city name and by ZIP code. The programming team generated a population database that included the race, gender, and address of the enrollees along with a unique identifier to facilitate mapping.

While the Florida Medicaid databases have very reliable race/ethnicity data, the CHIP data are less reliable. We found a significant amount of missing data on race/ethnicity because the state of Florida does not require that race/ethnicity data be captured during the enrollment process. As a result, we chose not to use race as a variable in our study among the CHIP population, instead, the focus groups we held with the CHIP adolescents were classified mixed race groups.

Once we obtained the population database, the addresses of the enrollees within the three cities were mapped and clusters of teens by race and ethnicity were identified using ARC GIS software[10]. The maps illustrating clusters of racial/ethnic enrollees were also used to identify proximal community centers within the areas with denser clustering to conduct focus groups. We found African American teen clusters in City 1, Latino clusters in City 2, and decided to conduct white focus groups in City 3. Additionally, City 2 had a cluster of CHIP recipients in a particular area of town which was selected for the CHIP focus groups. We allocated time and funds to conduct an additional 4–6 focus groups if the desired level of saturation was not achieved with the first 8 focus groups across the 3 sites.

Focus Group Sites Selection

Additional maps were created for all three cities which focused on illustrating areas with the greatest clustering of racial and ethnic enrollees. These maps were used to identify local community locations central to each of the cities' identified racial and ethnic clusters to hold the focus groups. Initially, public libraries were identified as focus groups sites because they are usually a familiar site within the community and the availability of wireless internet access. During the focus groups, teens were asked to review a secure, online health risk assessment (HRA) survey using the iPad mobile tablet and provide feedback which required a wireless connection. The research team learned after securing library sites that Florida law requires meetings held at public libraries to be made open to the public. The nature of the focus groups, however, requires restricted access to the general public to ensure confidentiality, therefore alternate community sites needed to be identified. Local community center settings were a good second choice, but many did not have wireless internet access. In order to hold the focus groups at the alternate community sites, mobile wireless internet units were purchased to create mobile wireless "hotspots." In City 1, two of the focus groups were conducted at a satellite campus of a university, four focus groups were conducted at a local community center in City 2, and two focus groups were conducted in a community room for a local apartment complex in City 3. All sites were provided free of charge with the exception of the community center which required a $200 deposit.

Participant Selection and Recruitment

Once the focus group sites were selected, the programming team provided us with the addresses and phone numbers of those teens living within a 2 square mile radius of the selected community focus groups sites in cites 1, 2, and 3. For the mixed race CHIP focus groups, we decided to utilize a 4 mile radius because there were not enough potential participants within a 2 mile radius near the designated community location. Adequate size for focus groups are generally thought to be between 4–12 participants[8,11] and we projected to have between 8 and 10 people per focus group which would provide a manageable number of people to engage in a group conversation without subjects feeling overwhelmed or singled out. We selected a random sample of 80 adolescents for each planned focus group within a 2- and 4-mile radius. After examining recruitment and enrollment rates using Medicaid and CHIP administrative databases in previous studies in our research center, we assumed that of the 80 families that received the packets, half of them (40) would have invalid or outdated contact information (based on administrative enrollment files), half of those would refuse (20 more) and half of those who accepted the invitation would attend the focus group (10 more) resulting in 10 people per focus group.

Recruitment packets were mailed to each of the 80 selected families for each of the 8 planned focus groups for a total of 640 packets. Each packet included a letter introducing the study and identifying the location, date and time of the focus group for which they were invited, 1 consent form (included consent and assent), an approval letter from the Contract Manager of the Medicaid and CHIP databases, and a self-addressed stamped envelope for them to return the consent form. In previous mailings done by the research team with this population, we found that mailing the packets first class (with hand stamping instead of metering) was preferable to a bulk mailing to have a greater chance of being opened. One week after the mailing, all 640 people were called to give them information about the study, answer questions and to invite them to the focus group. We called each person up to 3 times (excluding disconnected/non-working phone numbers). Subsequently, reminder calls were made the evening before the focus groups to participants who agreed to be in the study or who were undecided about participation.

Focus Groups

Focus groups were conducted with a team that included a moderator, co-moderator, and coordinator. Focus group team members were members of the core research team which was spread across the three cities. The moderator was in charge of leading the conversation, keeping the flow of conversation going and emphasizing the questions on the semi structured interview schedule. The co-moderator took notes, kept time, and asked follow up questions when necessary. The coordinator sat outside the focus group room and managed people coming into the room and collected and checked all of the consent forms for accuracy, made sure that the iPads were connected to the mobile Wi-Fi units, managed the food that was delivered to the focus groups, and managed the $25 gift cards to be distributed to each participant at the end of the session. Each focus group leader went through a training session where the focus group schedule was reviewed and interviewing techniques were emphasized.

In order to facilitate the flow of conversation and encourage comfort and honesty in the focus groups, adolescents were stratified by gender, race, and ethnicity[11–13]. We race-matched the focus group leaders to the participants. The single exception was the African American male focus group where, due to circumstances outside of our control (moderator and alternate were unavailable), the focus group was led by a white/Caucasian moderator. We also matched by gender for the co-moderators to promote open conversation[14]. Additionally moderators were no more than 10–15 years older than the teens participating. For the focus groups containing Latino adolescents, the moderator was a Latino male who also spoke Spanish and Latina girls had a Latina moderator that was not fluent in Spanish. Once participants arrived and checked in with the coordinator outside the room, they were invited to complete a health risk assessment survey on the iPad. When this was complete, they handed over their iPad to the co-moderator and were invited to eat the food that was prepared for them by a local vendor. As all teens were finishing up their food, the focus group moderator began the session via a semi-structured interview schedule.

RESULTS

Participants

Figure 1 indicates that of the 640 participants randomly sampled from the Medicaid and CHIP administrative database, 47 mailed in signed consent forms and 35 participated in the focus groups. We identified 225 (35.1%) people with invalid phone numbers, 22 (3.4%) with both incorrect addresses and phone numbers, and 173 (27.0%) that did not answer the phone for a total of 420 (65.7%) people for which no contact was made. Of the other 220 individuals for which phone contact was made, 119 declined participation and 101 agreed during the phone call. Of the 101 that agreed, 47 signed and returned a consent form. The consent form was considered complete if the parent or guardian provided a signature for consent and the adolescent provided a signature of assent. For participants that were 18 years of age, they signed the consent form themselves. Of the 47 that signed a consent form, 35 showed up for one of the 8 focus groups. Our smallest group had 3 teens and our largest group had 7 teens. Table 1 shows the percent of teens that attended the focus groups divided by race and gender.

Personnel and Time

This project was one part of a larger ongoing project that had a large research team. In order to organize the eight focus groups several faculty and staff were involved in its main organization and facilitation as seen in Table 2. Once IRB approvals were secured it took our team took five weeks from the selection of the initial population sample by programmers to the completion of all 8 focus groups. One faculty member oversaw the focus group coordination, four project coordinators (two in City 1, one in City 2, one in City 3) secured the sites, created packets, and organized the mailing. The team also enlisted the help of research assistants, a GIS programmer, an administrative database programmer, several interns and volunteers. We estimate that we used 161 hours of time at a cost of $30/hour (average of faculty, project coordinator and student pay) for a total of $4830 in personnel costs plus $875 for incentive gift cards. The cost of shipping for this mailing, including printing and postage, totaled $1920 (about $3 per participant packet).This coupled with food

($1600) from local vendors to supply each focus group and mailing costs averages out to a cost of $264 per focus group participant.

DISCUSSION

This research details the costs and time estimated to perform a series of high quality focus groups in a difficult to reach population of adolescents. Our study team found benefits to the utilization of administrative databases for focus group research including the ability to: 1) identify and attempt recruitment of diverse populations, 2) create homogenous focus groups, and 3) find a neutral and easily accessible location for the focus group to optimize participation. Through the process of recruitment and enrollment, we experienced unanticipated logistical problems, all of which we were able to work out satisfactorily. To our knowledge this is the first study to fully detail the use of Medicaid and CHIP databases for recruitment to focus groups. A previous study assessing adolescent access and use of preventive services similarly used insurance administrative database, however it was only within one health plan with Managed Care Medicaid enrollees in one city[15]. Using a Medicaid and CHIP administrative database, we were able to quickly implement eight focus groups involving a total of 35 both low income and racially/ethnically diverse adolescent participants in three different cities with an average cost of $269 per participant in our study. This is within the range of cost from other studies in the literature on the recruitment of low income and minority populations[16–22]. Our study adds to the literature by detailing our experiences with the recruitment and enrollment of low income teens using insurance administrative health care databases and geocoding to regional, racial, ethnic and linguistic diversity.

Accessing and including low income and racially/ethnically diverse adolescents into research can be a difficult task, with most focus group studies using convenience samples of adolescents who utilize agencies that provide services to adolescents. Due to the sensitive nature of the discussion in this study, we wanted the focus groups to be homogenous in both race/ethnicity and gender to promote the comfort of participants. The Medicaid and CHIP administrative data base allowed us to easily plan the focus groups and make sure that we had an adequate sample size of racially/ethnically diverse adolescents. Additionally, in conducting our focus groups we used moderators with the same race and gender to further facilitate the comfort of the adolescents. In order to optimize confidentiality and comfort we wanted to increase the chance that participants would not know each other thereby further making the utilization of the insurance administrative database optimal. Often adolescents who utilized an agency would regularly see and interact with each other would have pre-existing relationships/power dynamics that could affect a focus group. Furthermore, we did not want to approach adolescents who were accessing community center/program or clinics because we wanted to make sure that we discussed health risk assessments with a broad range of adolescents including those who may not regularly utilize those services. Despite not using an agency for recruitment we were able to find community settings near to where participants lived to facilitate access to the focus groups. This is particularly important as we sampled low income adolescents who may have limited transportation.

Our two primary logistical difficulties involved venue selection and consenting of parents and adolescents. Our initial focus group venues were public libraries; however, we discovered that by law they were not allowed to offer the type of privacy and confidentiality needed for such a research project. However, we were able to utilize a more detailed GIS map to find other accessible and more private venues. Another necessary but difficult task was having parents and adolescents sign our lengthy IRB required consent forms correctly. Our University's IRB required an 11 page consent form which entailed the need for multiple signatures and names to be placed on multiple locations throughout the document which varied depending on whether the child was the legal age of 18 years or not. Although we put fluorescent stickers on the consent forms in all the appropriate places, the majority of the ones returned to us were still improperly completed. We were able to resolve this by having the parents and teens re-sign when they came in to the focus groups and none were turned away due to difficulty with the consenting process. Another difficult task was the logistics of managing focus groups in three different cities all at least 2 hours away from one another by car. Our team planned for this and hired research staff in each of the cities who understood how to read GIS maps and were familiar with the city thereby able to select good community venues for holding focus groups.

Limitations of this study method include self-selection bias, small participation rate, and accessibility of the methods used. As in all research studies, the individuals who choose to participate may have strong opinions about the topic, or otherwise differ from those that could not be reached or those who declined to participate. However the methods we utilized aimed to optimize participant confidentiality and comfort and to allow participation of a diverse group of adolescents that may not utilize clinical care or community resources. Additionally, similar to the previous study that utilized an insurance administrative database, we had a large portion of our sample who could not be contacted or refused participation[15]. Another limitation is the generalizability of our process to the wider research community, especially those in institutions or departments with not as many resources. Overall the success of this phase of the project depended on a large, well staffed, and well funded research team working in coordination with multiple academic and clinical departments across three cities. Our team had access to faculty, programmers, coordinators, GIS mappers, research assistants, medical students, interns, volunteers, and most importantly administrative databases. Had our department not had these kinds of resources, this study simply would not be possible. This study demonstrates that it is possible to use Medicaid and Children's Health Insurance Plan (CHIP) administrative databases to identify and recruit low income, racially/ethnically diverse adolescents into 8 focus groups across 3 cities within a short amount of time.

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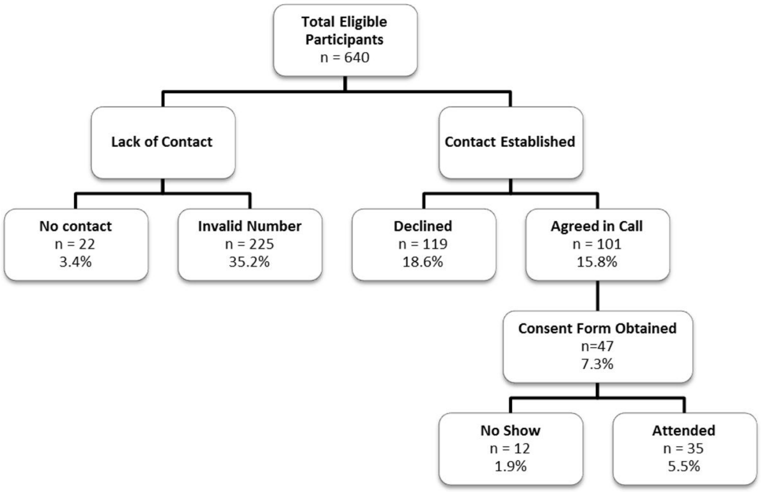

Figure 1.

Flow Diagram of Participant Recruitment

Table 1

Breakdown of participant by racial/ethnic group

Group	No Contact[*]	Invalid Phone Number[**]	Busy/Message Left	Declined	Agreed in Call but no Consent Returned	No Show[***]	Attended Focus Group
African-American							
Male	7.5%	36.3%	18.8%	15.0%	15.0%	2.5%	5.0%
Female	3.8%	37.5%	27.5%	16.3%	6.3%	3.8%	5.0%
Mixed Race							
Male	0.0%	26.3%	25.0%	30.0%	10.0%	0.0%	8.8%
Female	1.3%	23.8%	25.0%	26.3%	11.3%	5.0%	7.5%
Latino/a							
Male	2.5%	47.5%	26.3%	11.3%	5.0%	2.5%	5.0%
Female	7.5%	56.3%	21.3%	5.0%	6.3%	0.0%	3.8%
White							
Male	3.8%	27.5%	30.0%	26.2%	6.3%	1.3%	5.0%
Female	1.3%	26.3%	42.5%	18.8%	7.5%	0.0%	3.8%
Total	3.4%	35.2%	27.0%	18.6%	8.4%	1.9%	5.5%

N=80 for each group, N=640 combined

[*] No Contact: Mailing sent back and invalid phone number

[**] Invalid Phone Numbers include “Disconnected”, “Wrong Numbers”, “Numbers not in Service”

[***] Informed consent sent back signed but not present at focus group

Table 2

Breakdown of personnel and time spent

Team Member	Tasks	Time
Faculty Lead	Oversaw all aspects of focus group participant selection, recruitment, enrollment and management of focus groups	10 hours
Community Research Associates (City 1, 2 and 3) and Research Coordinator	Secured focus group site, Coordinated food, Recruitment Calls, Reminder Calls, Organized the mailing, Prepared 640 mailings, Managed 640 phone calls, Moderated focus group, Secured Informed Consents	75 hours
Research Coordinator	Moderated and Co-moderated focus group	
Health Risk Assessment Project Coordinator	Organized incentives, Moderated focus group, Co-moderated focus group, Recruitment Calls, Reminder Calls	15 hours
Research Assistant (3)	Moderated focus group, Co-moderated focus group, Labeled informed consents, Prepared 640 mailings, Secured Informed Consents	15 hours
Vendor in department	Co-moderated focus group	8 hours
M.D./Ph.D. Student	Moderated focus group; organized the focus group training for moderators, co-moderators, and organizers	8 hours
Intern and Volunteer	Recruitment Calls, Reminder Calls	20 hours
GIS Map Analyst	Identified 2–4 mile clusters of at least 80 participants in different areas of City 1, City 2, and City 3	10 hours
Programmers	Two different data draws; first identifying all adolescents (14–18) enrolled in Medicaid and CHIP; second, identifying the 640 teens to recruit	5 hours
Total		**161 hours**