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Short communication

Setting and motivation in the decision to participate: An approach to the engagement of diverse samples in mobile research

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ABSTRACT

Internet and mobile based research are powerful tools in the creation of large, cohort studies (eCohort). However, recent analysis indicates that an underrepresentation of minority and low income groups in these studies might exceed that found in traditional research [1–5]. In this report, we present findings from an experiment in research engagement using the Eureka Research Platform developed to enroll diverse populations in support of biomedical clinical research. This experiment involved the recruitment of African American and Latino participants in a smartphone based survey at a temporary, charitable, dental event sponsored, in part, by the research team, in order to explore the impact of setting and approach on recruitment outcomes. 211 participants enrolled including a significant representation of African Americans (51%) and Latinos (31%) and those with education levels at high school or less (37%). Interviews conducted after the study confirmed that our recruitment efforts within the context of a service event affected the decision to participate. While further research is necessary, this experiment holds promise for the engagement of underrepresented groups in research.

1. Background

Internet and mobile based research are powerful tools in the creation of large, cohort studies (eCohort). However, recent analysis indicates an underrepresentation of minority and low income groups in these studies [1–5]. There has been a number of factors suggested as a cause of underrepresentation including the existence of a “digital divide” [6–8] and, more strongly, an enduring mistrust of health research and researchers [3–5]. Contributing to this problem, internet based recruitment methods such as using email, texting, and social media seem to exacerbate the barriers of mistrust [5,9]. Community *engaged* approaches, built on interpersonal relationships, have been shown to ameliorate mistrust [10,11]. However, such approaches are somewhat ill suited to mobile based research which relies on samples larger than any one or set of bounded communities. Recruitment efforts implemented within the context of community events have also been shown to be valuable [12], especially when coupled with cultural competence [13]. However, the reasons why such recruitment is successful, beyond the convenience it might provide, are not well understood. Our team conducted an “experiment” to explore: (1) the feasibility of recruiting minority and low income participants into a mobile based survey using their own smart phones; and (2) the meaning of setting and approach in motivation for participation. Using an eCohort research platform, Eureka, created for the Health eHeart Study (formerly known as Health ePeople) at the University of California, San Francisco (UCSF), we set out to recruit in the unique setting of a temporary, charitable, dental clinic sponsored by the Maryland Center for Health Equity (M-CHE), along with community partners. After the event, we contacted a subset of survey participants (n = 24) and conducted semi-structured interviews to explore their perceptions, experience with recruitment and motivations for participation. All research activities were approved by the Institutional Review Board at University of Maryland, College Park IRB (#1079151).

2. Method

Health eHeart is an eCohort study that aims to recruit one million diverse participants and shows great promise for cardiovascular and other health outcomes [1,14–18]. It is also a study that has experienced challenges in the recruitment of minority participants. For example,

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African Americans comprise approximately 4% of the sample while making up 13.3% of the U.S. population and representing the group most at risk for coronary heart disease, heart failure and stroke [1,19,20].

In this study, the UCSF group joined with M-CHE for a pilot that took place at the 2017 Mid-Maryland Mission of Mercy dental clinic using the Eureka Research Platform, developed from the experience and technology of the Health eHeart Study. During the event, we enrolled participants who used their own smartphones in a mobile survey to elicit health information about co-morbidities, cardiometabolic risk factors and related health behaviors, in part to assess the needs of Mission of Mercy patients for future event planning.

2.1. Setting

Mission of Mercy dental clinics are charitable events that are volunteer run and provide professional dental services, including endodontics, restorations and oral surgery for patients on a first come, first served basis. Such dental events occur in states across the country [21–23]. Typically, a line of hopeful patients begins the evening before the clinic opens. Organizers admit as many patients as can be reasonably treated given resources available (i.e. volunteer dental professionals). Services are free and there are no insurance or income requirements. Patients move through a variety of stations including registration, medical assessment, dental triage, xray, treatment (endodontics, restorations, hygiene or oral surgery), post op (if necessary), pharmacy and check out. The 2017 Mid-Maryland Mission of Mercy event described here provided approximately 858 patients with nearly one million dollars worth of treatment and was hosted over two days on the University of Maryland campus and organized by M-CHE in collaboration with our long standing partners, Catholic Charities of the Archdiocese of Washington and the Maryland State Dental Association Foundation. This collaboration had also previously produced the 2014 Mid-Maryland Mission of Mercy event where over 1,000 patients received services [22,23].

2.2. Recruitment approach

All English speaking patients at the 2017 event were eligible and made aware of the survey activity in several ways. Initially, each patient received an information card at patient registration which included information on how to enroll. Posters posted throughout the event included the same information. In addition, research staff approached patients as they waited between medical assessment and dental triage. Our staff were public health graduate students who received training on respectful engagement methods [5,24,25] in the week before the event. Several were also students in our MPH program in Health Equity. There were approximately five to eight research staff present at each four hour shift. While our team was recognized as part of the event, we also took steps to encourage identification of them as different from other types of volunteers. Research staff wore t-shirts that were of a different color (red) and used a prepared script that stressed that the survey was sponsored by the M-CHE and not the Mission of Mercy. The script also reinforced that dental treatment was in no way related to survey participation and that participation was entirely voluntary. Staff also informed patients of the research goal.

Interested participants were given instructions to text “MOM” to a number which prompted a text with a URL to join the study. Information about the study, consent form and surveys were all provided via smartphone. Following the electronic consent process, participants were prompted to complete a survey that was approximately 20 min in length. Face to face, individualized, personal technical assistance was provided on an “as-needed” basis and research staff were present to respond to questions about the study. Due to the limited scope and resources for this experiment, surveys were only provided in English. No incentive was provided. Some participants choose to immediately complete the survey while waiting for services. Others choose to wait (often due to pain). Research staff checked in with participants later on as they waited for services to inquire if they needed assistance or had any questions.

2.3. Follow-up telephone interviews & analysis

A subsample of initial survey participants were contacted by telephone and asked to participate in an interview. Interviews (n = 24) were conducted via telephone, lasted approximately 30 min and participants received a $25 gift card. Interviews included general questions about the event (ex: *What was your general impression of the dental event held at UMD in September? Did you receive the treatment you needed? What was your impression of the volunteers*?); as well as questions about their experience in the mobile study (ex: *At the event, you signed up to complete a survey on your phone. What was that experience like? Did you feel encouraged/welcomed or pushed to join the study? What were main reasons that you decided to join the study*?). Interviews were conducted by a trained data collector who did not participate in the original recruitment or any other part of the Mission of Mercy event. Interviews were audio recorded and transcribed verbatim.

We used NVivo 12 software to facilitate qualitative data management and analysis. The primary goal of our analysis was to reveal motivations for research participation. While we sought to answer this question, we also used an iterative, adapted grounded theory approach [26,27] to explore themes that might shed light on participant experience and the context of the recruitment event. Overall, interview transcripts were short and tightly focused.

3. Results

211 participants completed the online consent (approximately 25% of patients attending the event) over 2 days. The sample (63% women/36% men) was composed of a significant representation of African Americans (51%) and Latinos (31%) and those with education levels of high school diploma or less (37%). These proportions reflected or exceeded those of underrepresented minorities of patients attending the event (45% African American; 33% Latino). Of 232 patients queried regarding nonparticipation, the most common reasons were: 1) lack of a smart phone at the event (29%); 2) inability to complete the survey in English (25%); 3) preference for doing the survey at home or at a later date (21%); and 4) inability to receive texts or other carrier limitations (13%). Reasons given for nonparticipation given by the remaining 23% of patients queried included: difficulty navigating survey (5%); dead cell phone battery (4%); no interest (4%); no email address (4%); wifi difficulties (3%); too tired/not feeling well (2%); don't know how to use phone (1%).

3.1. Interviews

Twenty-four former participants (16 women/8 men) agreed to participate in telephone interviews after the event. Of the 24, 15 were African American and 3 Latino, constituting 75% of this small sample. The remaining six participants identified as White. Topics in the interview included: (1) perceptions of the Mission of Mercy event; (2) experiences with the study; and (3) reasons for agreeing to participate in the initial smartphone survey. Relevant themes are discussed below. Presented quotes from interviews were chosen as clear examples of a given theme and do not represent the totality of responses on a given theme.

Interviews were short and direct. Major themes about the event, in general, included: (1) gratitude for services provided; (2) respect and kindness afforded to patients by providers and volunteers; (3) surprise and concern about the number of people in need for dental services and wait times. Not all of these themes are relevant to the question of research recruitment.

Perceptions of the event, volunteers and study staff. Event staff were called “friendly,” “efficient,” “kind,” and “caring.” Many participants expressed feelings of deep gratitude for event and the volunteers that made it happen.

For example,

> “ …. you got to be righteous to do this to me, you know. It is not just because you … You are helping people, some of these people have $2,000 dollars' worth of work, $300 dollars' worth of work, $5,000 dollars' worth of work, a whole bunch of work … (African American, male participant)

This perception extended to our research staff who were identified by the interviewer specifically (i.e. “*what did you think about the volunteers who were helping with survey? They were the ones in the red shirts*.”), although several interview participants reported having difficulty remembering specifics in an event that included more than 2,000 patients and volunteers. For some, our research staff represented a “quick memory” and they responded with general statements such as, “I would say everyone was extremely friendly.”

Those that did remember reported sentiments such as the following,

> She was really nice. I believe she was wearing red. I think they all were, the ones that were doing that…She was very nice. I feel that everyone was very kind. (African American, female participant)

Participants also appreciated personal technical assistance. For example,

> Yes, she was helpful … But I don't remember her name anymore. Yeah. Very helpful … We talked about everything. (African American, female participant)

No participants reported any problems with research staff.

Reason for agreeing to participate. Participants were also asked, “*What were main reasons that you decided to join the study*?” The majority of responses (n = 12) expressed feelings of gratitude and connection with volunteers. For example,

> “... I thought, you know, I'll help you guys out by doing, like the survey thing because you guys are helping us out. We don't have insurance and stuff like that.” (African American, male participant)

And,

> “Because I was getting a service for free and like I said, it was the least I could do.” (Latino, female participant)

And,

> It's nice to have good people and, you know, you want to pay back. (African American, male participant)

An additional three participants reported that their reason for participation was influenced by the alignment of the research goal and their own beliefs. For example,

> I just thought something like this was really great so anything that I can do … (African American, female participant)

And,

> I just wanted to—I want my answers to make an impact, you know, on, generally on the, what you call it, the program. (African American, female participant)

The remaining responses reflected “the importance of research generally” (4) and “boredom” at the event (2).

Interview participants were specifically asked if they felt pressured to participate in the survey. Participants expressed feelings of being invited or encouraged rather than forced. For example,

> No. I was encouraged to do it. Like she was telling me all about the stuff. She was not like very forceful, whatever. She was just like if I have time I can do it. If not, it's okay. (White, female participant)

And,

> No, I didn't feel [I was] being pushed … I asked her a couple of questions about it and everything, you know? (African American, female participant)

Interview participants also reported that they were pleased with the flexibility and low burden of the research activity. For some, the survey was well suited to the flow of the event. For example,

> Well, one reason was, you know, the wait was a little long because of the large crowds and so I had, you know, I had the time and decided to do it. (African American, female participant)

And

> It wasn't a long study. It didn't take a lot; it wasn't supposed to take a lot of time to do it. So I just figured, since I will be sitting there waiting anyway, it will give me something to do. (African American, female participant)

Others appreciated the afforded flexibility of doing a survey on their own device.

> We were talked to by a couple of volunteers, [who told us] when we get a chance to just fill out the survey. But it wasn't nothing right then and there. (African American, female participant)

Future Research. All interview participants (24) reported that they would consider participating in future research with the study team.

4. Discussion

Our findings regarding the feasibility of mobile based research with typically underserved groups is somewhat mixed but instructive. We were able to enroll 211 patients using their own devices. However, we also found technical barriers to participation as 40% of our sample of non-participants reported either lack of a smart phone at the event, wifi difficulties or other barriers due to carrier limitations. The reasons for not having a smartphone at the event were diverse. Some reported not feeling safe having a phone in a crowded public event. One group of men reported that they were not allowed to have phones due their placement in a group home. Overall, like others have suggested, we do not find support for the existence of an insurmountable digital divide [3–5,28]. Provision of phones for use in research presumably would have helped. We also found that providing one-on-one technical support helped some participants with phones work through barriers. This is also in line with the findings of others [9]. Similarly, the translation of the survey into Spanish could have also increased engagement as 25% of non-participants reported language as a barrier.

Qualitative interviews indicate that those who participated did not feel pressured or especially burdened by the survey. Both these factors promoted engagement. Setting and research goal were also important. As a service event, the Mission of Mercy attracted potential participants who were united by common experience and who found themselves with considerable “downtime” while they waited for treatment. Setting and research goal also contributed to participants beliefs about the motivation and values of the people behind the research who they saw as “*helping*,” “*good*” and, even, “*righteous*.” In this sense, setting may have created a type of personal connection reinforced by the alignment of participant and research goals [29–31]. While participants may have appreciated that research staff were well trained and culturally competent, they saw their participation as a way to contribute to an event that they both supported and benefitted from. As we know from the social sciences, shared values, mutual goals and reciprocity are each significant components of human relationships and trust building [24,32,33].

It is important to note that our involvement in the 2017 Mission of Mercy was motivated by more than our interest in research recruitment.

Our overarching motivation was to provide service to those suffering from a serious health inequity in alignment with our organizational commitment to health equity and social justice. While participants could not be expected to know this, the event was the result of years of collaboration with our partners who trusted us enough to support our "experiment." In this sense, recruitment did benefit from a long term and genuine relationship. As such, our findings do not suggest that simply locating recruitment in charitable spaces is either ethical or effective. We do, however, recognize that conflation of the event with the research on the part of participants could because for concern. This requires further exploration. Certainly, we hope that readers see our work as fitting within the great body of research that supports the value of *authentic* relationships [5,34,35]. Moreover, we would encourage a nuanced and thorough discussion of reciprocity in research engagement. While recruitment in the context of service provision could easily be coercive, we must also recognize that reciprocity is the basis for ethical community engagement as well [36–38]. Certainly, we would argue for a thorough examination of the ethics of research recruitment that overlooks the health needs of vulnerable populations. Health equity research in particular, might consider the value of, as Maiter et al. [38] suggests, "going beyond the requirement to do no harm," to respond to the very real limitations of health and health care for the populations we hope to engage.

5. Conclusion

Our experiment resulted in enrollment informed by patient perceptions of our research team as "on their side" as evidenced by patient responses in subsequent telephone interviews. Other factors that contributed were culturally competent, face–to-face recruitment, technical support and location at an event that provided appropriate time for study registration, completion of the informed consent process and data collection. We also find indications that provision of smart phones or tablets as well as Spanish language translation may have circumvented barriers of access. Overall, further exploration is necessary to determine if recruitment coupled with service in the community could be an effective as well as ethical strategy to navigate mistrust and engage underrepresented groups in research and how this might be best operationalized [39,40]. This could have far reaching implications for large studies where the engagement of underrepresented groups is necessary but long term interpersonal relationships are impractical.

5.1. Limitations

This study was limited in a number of ways. Initially, due to limited resources we were only able to provide the survey in English. Additionally, this was a test focused on recruitment rather than retention, which limits itss applicability to eCohort research. Finally, there are limitations associated with our inability to include non-participants in our interviews which, had it been possible, would have resulted in a richer and more complete understanding of the decision to participate in the study.

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