

REUSu17-Dunbar-Connelly

[Extended Abstract]

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ABSTRACT

Categories and Subject Descriptors

H.4 [Information Systems Applications]: Miscellaneous; D.2.8 [Software Engineering]: Metrics—*complexity measures, performance measures*

General Terms

Theory

Keywords

ACM proceedings, L^AT_EX, text tagging

1. INTRODUCTION

1.1 Problem

Patients of stigmatized diseases often feel withdrawn from others and, therefore, have difficulty getting the support they need.

1.2 Obstacle

It is difficult for researchers to determine how best to reach stigmatized groups with support because it is hard to find willing participants. The participants that researchers have access to tend to be more closed off and difficult to extract data out of.

1.3 Technology Hole

There has been some success with online outreach [point reader towards related work], as patients feel their anonymity is more protected, yet there has been very little actual technology designed as a result of this online research.

1.4 Solution

In our research of patients with stigmatizing diseases more specifically those with HIV we will be determining holes within support networks that can be filled by technology.

1.5 Contribution aka Results

The Asynchronous Remote Community (ARC) method is a method of qualitative study that has seen success with patient populations of rare disease patients and pregnant mothers. This study [rare disease] has seen blabla success and we will build off of this and blabla. The study of [pregnant mothers] has also seen success with blabla and we will be furthering this by blabla. Lastly, the study of [need to pick a 3rd one] illustrates blabla and we will be using blabla but expanding upon blabla.

2. RELATED WORK

2.1 Approaching Stigmatized Populations

2.1.1 Face to Face

Summary of methods of recruitment and data collection methods.

Approaching HIV positive populations in person can be difficult because the stigma makes much of the population wary of revealing their status to anyone [5][4][8]. Patricia Reeves notes that her data may be skewed by the fact that the only people likely to volunteer for an interview come from a certain socioeconomic background. Jennifer Peterson notes that there are large subsections of the HIV positive community that are understudied and do not have access to the same resources as the more visible sections [6]. This reinforces the necessity for recruitment that transcends demographic barriers.

2.1.2 Computer-mediated

Summary of methods of recruitment and data collection methods.

In her paper on the ethical challenges involved with reaching HIV positive patients online, Brenda Curtis notes how online approaches mitigate many of the issues that researchers encounter face to face [1]. According to Curtis, researchers are able to find participants across all demographics, and it's easier for recruitment materials to reach a greater number of participants than more traditional methods (fliers, newspaper ads, etc...). Benjamin Eveslage demonstrates this advantage in his paper on reaching sexual minorities for interview in Ghana [2] by searching Facebook for 'men interested in men', joining Facebook groups for gay men, and adding friends of those encountered by the other two methods, Eveslage managed to recruit 64 members of sexual minorities (compared to the 49 that he managed to recruit through traditional methods) for interviews, observation, and focus groups in a country where homosexuality is criminalized. While his research did not specifically target HIV positive individuals, it did

Study	Challenge	Lessons Learned
Rare Diseases	Participation	Build a relationship with the participants.
Rare Diseases	Ethics	Explore alternate methods of receiving informed consent.
Rare Diseases	Participation	Encourage participants to build on each others' work.
Rare Diseases	Participation	Encourage participants to post their work to the group.
Rare Diseases	Activity Design	Consider activities carefully before implementing them.
Rare Diseases	Participation	Examine behavior of participants to inform study design.
Rare Diseases	Participation	Use multiple avenues to inform participants of activities.
Rare Diseases	Activity Design	Keep activities from relying on chronological participation.
Rare Diseases	Participation	Provide opportunities for participants to socialize.

Table 1: Recommendations

demonstrate the benefit of such an approach on a stigmatized group.

2.2 ARC Method

MacLeod et al., introduced the ARC method to facilitate conducting rich qualitative research on geographically distributed populations [3]. They conducted their research patients of rare diseases by inviting them to join an online community and asking them to participate in a series of activities from which data were gathered. In addition to their findings, the authors also listed the challenges they encountered and encouraged other researchers to replicate and modify their work. Prabhakar et al., adapted this approach to the population of pregnant mothers, showing the value in iterating on and tailoring the method based on past challenges and the target population [7]. Table 1 contains a list of the lessons and recommendations from previous iterations of the ARC method that we intend to build on.

3. METHODS

In this section we cover our process for gathering our data including recruitment, study activities, and entry and exit surveys. We will also discuss the changes that had to be made to previous iterations of the ARC method in order to protect and cater to an HIV positive population.

3.1 Recruitment

For our study, we recruited all of our participants through Positive Link (a care coordination organization in Indiana → will most likely specify hospital → for HIV patients). We asked Positive Link to give [ask Fernando about the specifics of recruitment].

3.2 Participants

[Demographic information goes here]

3.3 Outline of HCI Research Methods

Interviews

Face-to-face interviews that will be held with either one subject or a few subjects (2-3 subjects). Interviews will consist of question and answer sessions that will be recorded either with audio or visual with audio and later will be transcribed.

Online Surveys

Standard rating surveys that will ask HIV patients different questions ranging from social implications, treatments, and more. A debrief survey about the FB group activities.

ARC

Will be used with FB group, but don't know the specifics yet.

Forum Data Analysis

Discuss algorithm and data collection here.

FB Group Activities

Beginning Questionnaire

Questionnaire to gather demographic data and information about HVI patients.

Introductions

Introduction template made to beginning Facebook conversations.

Ice Breakers

Activities and questions introduced to the Facebook group to elicit initial conversations.

Ranking of Problems

Game or activity for group users to rank their problems in order of importance.

Photo elicitation

Participants choose 2 problems and take photos of them and post them to the Facebook group.

Circles

Draw a set of circles and put types of technology. The distance to the center would represent how important that type of technology is for the participant.

TreatYoSelf

App provided by Drexel University [go into further detail] A medical adherence evaluation.

Solutions

After being introduced to the Drexel app Facebook group users come up with their own solution ideas and discuss their solutions.

Analysis

Qualitative Analysis

Data from our research will be used to help understand more thoroughly the major themes that the data presents. [Talk about Algorithm designed here for forum data][This is many different things]

4. RESULTS AND DISCUSSIONS

5. REFERENCES

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