

# REUSu17-Dunbar-Connelly

## [Extended Abstract]

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### ABSTRACT

The purpose of this research is to evaluate issues with current recruitment and data collection methods that are scene throughout face-to-face and online studies that evaluate support exchange among individuals living with HIV. These issues will be addressed through the adaptation of remote participatory design principles and the Asynchronous Remote Community (ARC) method. Our adaptations to the ARC method include online support group activities that promote user participation and provide intricate data [3]. We found that blabla. In conclusion blabla. This opens new doors to further explore bla and bla.

**Objective:** The purpose of this paper is to discover opportunities to improve social support exchange among people living with HIV via the use of technology.

**Methods:** We will be using an adaptation of the Asynchronous Remote Community (ARC) method with an online Facebook support group.

**Results:**

**Conclusion:**

**Discussions:**

### 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,  $\LaTeX$ , text tagging

## 1. INTRODUCTION

People living with HIV often feel withdrawn from others and, therefore, have difficulty getting the support they need [6]. Finding

participants for face-to-face studies has proven to be a major hurdle in past research because stigmatized individuals do not often want to expose the nature of their medical conditions in fear of social or professional backlash [10]. Some success has been had with anonymous surveys, but there are limitations to the richness of the data that can be gathered. It has been suggested that individuals living with stigmatized diseases are more responsive to online studies [1]. This fact has rarely been exploited for purposes other than wide survey distribution. There has been some success with online outreach (see related work), as patients feel their confidentiality is more protected, yet there has been very little actual technology designed as a result of this online research. In our research on patients with stigmatizing diseases, more specifically those living with HIV, we identify holes in support exchange that can be filled by technology. The Asynchronous Remote Community (ARC) method has been applied successfully in a study conducted with people living with rare diseases as well as a study with pregnant women. The first ARC study was successful in the collection of rich qualitative data [3]. MacLeod et al. note in their paper, however, that there are aspects of their methods that warrant further exploration. The second ARC paper made some modifications to the method, including splitting the population into multiple groups based on shared experiences, and the introduction of new activities [8]. The researchers provided evidence supporting many of the speculations from the original ARC paper, but many questions remain open, or warrant further confirmation. In particular, the second study did not attempt to incorporate some of the community building suggestions of the first. Walsh et al. demonstrate the advantages of participatory design in an online platform by using the process to iteratively develop an online design tool [11]. We adapt the ARC method, taking into account the lessons learned from previous studies, to be used on the population of individuals living with HIV and to incorporate elements of participatory design with the goal of designing technology to support our target population.

## 2. RELATED WORK

### 2.1 Recruitment and Data Collection Methods

#### *Face to Face Studies*

Participants for qualitative studies are often recruited through physically distributed materials [e.g. [8]], or contact with organizations (such as hospitals or support network in the case of people living with HIV) who then distribute the study information to potential participants [e.g. [7], [9]].

Face to face qualitative studies frequently employ surveys [e.g. [7]], interviews [e.g. [9], [7]], and focus groups [2] in order to ob-

tain their data. The advantage of surveys is that, after informed consent is obtained, they do not require input from the researcher. This means they can be distributed to a large number of participants, increasing the statistical significance of the data. Interviews require a lot of work on the part of the researcher, but can be used to gather rich data about experiences and opinions. The advantage of focus groups is that they encourage interactivity and generation of ideas.

Approaching HIV positive populations in person is difficult because the stigma makes much of the population wary of revealing their status to anyone [6][5][9]. 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. Peterson explains 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 [7]. This reinforces the necessity for recruitment that transcends demographic barriers.

### Online Studies

The most notable advantage of conducting research online is that more potential participants can be reached with recruitment material. Brenda Curtis notes this in her paper on the ethical challenges involved with reaching HIV positive patients online. She also explains that it is easier to reach a wider range of demographics than through traditional methods [1]. These advantages have led to face to face studies frequently recruiting through online means. Benjamin Eveslage demonstrates this 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 demonstrate the benefit of such an approach on a stigmatized group.

Online data collection methods are often similar to face to face approaches. Researchers frequently exploit the additional reach of online recruitment methods in order to more widely distribute traditional surveys [e.g. [4]].

## 2.2 The ARC Method

MacLeod et al., introduced the ARC method to facilitate conducting rich qualitative research on geographically distributed populations [3]. They conducted their research on patients living with 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 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 circumstances specific to the study [8]. Table 1 contains a list of the lessons and recommendations from previous iterations of the ARC method that we intend to build on.

## 3. METHODOLOGY

In this section we cover our process for gathering our data including recruitment, study activities, and entry and exit surveys.

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.
Rare Diseases	Recruitment	Try to recruit a homogeneous population.
Rare Diseases	Activity Design	Be mindful of the number of ways participants submit data.
New Mothers	Activity Design	Be mindful of the number of steps to complete an activity.
New Mothers	Activity Design	Consider participants' technology preferences.
New Mothers	Activity Design	Strike a balance between ease of use for participants and usefulness of data.
New Mothers	Activity Design	Adapt data capturing methods from focus groups to the ARC method.
New Mothers	Ethics	Intervene to help participants who are struggling outside of data collection.
New Mothers	Data Collection	Be proactive about designing methods to make data collection and overhead easier.

**Table 1: Recommendations**

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

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