Considerations for Using the Asynchronous Remote Communities (ARC) Method in Health Informatics Research

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Abstract

The Asynchronous Remote Community (ARC) method draws from existing Human Computer Interaction (HCI) methods such as focus groups, interviews, diaries, and scenarios. It applies them to an online platform to take advantage of the unique properties of qualitative research conducted through online forums. Drawing on existing literature[1,2] and our experiences running an ARC study with individuals living with HIV, we provide a guide to the most important considerations in conducting an ARC study. This guide emphasizes (1) when and how to use ARC, (2) special considerations for specific populations, and (3) considerations when choosing activities. We end with a discussion of how to move forward to develop a toolkit to assist with future ARC research.

Introduction

The Asynchronous Remote Community (ARC) method of qualitative research involves a group of participants in an online environment completing periodic activities both individually and as a group. "Activity" is an intentionally broad term, and in practice comprises anything from surveys, to ice breakers, to online adaptations of existing HCI research methods, such as diaries or personas. The main advantage of ARC is that it overcomes barriers that make it difficult to conduct face to face (FtF) studies with certain populations. ARC was initially introduced by MacLeod et al.[1] to account for the geographic distribution of people with rare diseases. Prabhakar et al.[2] extended this to pregnant women and new mothers, who generally do not have enough free time to participate in FtF studies. In our research we further extend ARC to individuals living with HIV to account for difficulties with validity of data[3] and recruitment[4] when approaching a stigmatized group.

ARC's use of multiple activities allows researchers to triangulate results from multiple sources, accounting for factors that may confound the results. ARC also allows for the analysis of posts and comments in the Facebook group. This information allows researchers to measure engagement, and to better contextualize the data generated from activities.

This paper extends the work in MacLeod et al.[1] and Prabhakar et al.[2] alongside our own research experiences from studying individuals living with HIV to highlight the advantages and disadvantages of the ARC method. We also take an in-depth look at the process for designing and adapting the ARC activities based on the research questions and target population with a focus on adapting activities over time. This paper serves to better equip the research community to both replicate the ARC method and to draw comparisons between studies conducted using ARC.

Related Work

The first ARC study focused on patients with rare diseases[1]. The activities used in MacLeod et al.'s[1] study formed a foundation other researchers have built on in their own ARC studies. MacLeod et al.[1] presented a series of lessons along with their research, with the goal of aiding others in evaluating and using the ARC method. These lessons range from the advantages of having an existing rapport with participants before the study begins, to balancing ethics and practicality to help ensure participants are fully informed when providing consent. Ensuring *informed* consent is particularly challenging for remote research without a researcher physically present; this difficulty is exacerbated by the additional risk factors introduced on online platforms, especially for populations where privacy is key[5]. These lessons, among others, helped form the groundwork for our understanding of the properties of ARC.

The second ARC study included pregnant women and new mothers[2]. Prabhakar et al.[2] modified the original ARC activities to suit their population. They introduced additional lessons from their own experiences, primarily advice for balancing effort and usefulness when designing activities. They suggest using multiple ARC activities to triangulate conclusions, providing a more complete picture of participants' perspectives. They confirmed lessons learned in the rare disease study[1], and both studies suggest continuous posting correlates with participant engagement.

We expand on this pool of knowledge in our work with individuals living with HIV. We examined the suitability of ARC for populations facing stigma and found that people living with HIV were very receptive. This is in contrast to difficulties that many FtF studies have encountered when approaching individuals living with HIV. Accurate reporting has been a major concern in the past[3], but the data triangulation possible with ARC means that researchers can be far more confident in their results. Difficulties recruiting stigmatized populations can also be mitigated through online recruitment[4]. We also implemented a participatory design element and found that the familiarity between participants that ARC fosters helped to create an environment of active discussion. Lessons learned from past ARC studies along with our own experiences dictate the recommendations given throughout this paper.

Key Considerations

Here we present the most important considerations for the ARC method as a whole, population-specific considerations, and details of the activities that have been used in each of the three existing ARC studies.

Overall Characteristics

Some features of ARC have remained consistent in all iterations of the ARC method, regardless of population. These features are important to keep in mind when deciding whether the ARC method is ideal for a particular research project, as well as during the design process. One of the advantages of the ARC method is its modularity, as it can be modified to suit most target populations.We recommended that researchers intending to implement it read up on previous implementations to better understand how the process looks in practice.

ARC Platform. Once participants have been recruited, they are invited to a private online forum (traditionally a secret Facebook group). The forum should be private in order to protect participants' information and prevent outside interference during the study. Participants are asked to complete a series of activities, generally with wide completion windows to give participants of all different backgrounds the time to complete them. These activities are generally adaptations of traditional research methods (e.g., focus groups, surveys, co-design, etc.) While it is recommended that researchers include baseline and debriefing surveys, the overall content of these activities should be tailored to the population and research questions.

Sample Size. We can look to existing literature on focus groups, which share many similarities with ARC, to guide us in coming up with recommendations for sample size. While there is some disagreement, experts tend to put the range at somewhere between five and twelve participants[6]. Too many participants can ultimately dilute interactivity as a few individuals dominate a conversation, and if too few people are participating the value of the interaction goes down. The major difference between ARC and a traditional FtF focus group is that ARC can both support and requires a slightly larger sample. The extended duration and drop-off means that ARC cannot support a small sample, however Figure 1 shows the decline in interest over time.

We recommend an ARC study should have 10–20 participants. While it is far more feasible to conduct ARC with a large number of participants than a focus group, each additional participant adds more work for the researcher both during the study and in processing the data. Prabhakar et al.[2] showed the effectiveness of splitting their sample into several internally homogeneous groups, using the same activities in each subgroup.

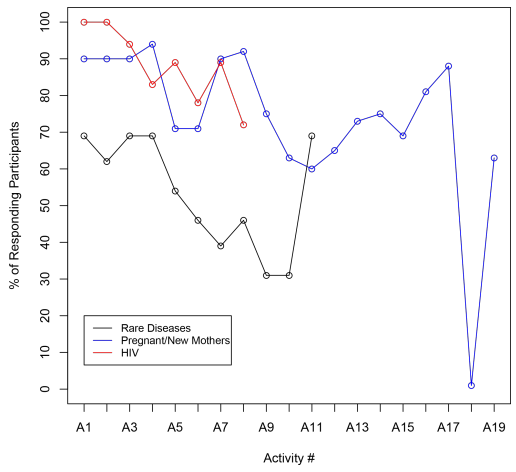

Figure 1: Response rate for each activity across the three studies. Note that these studies each took place over a different period of time with a different total number of activities. Some of these activities (but not all) were the same, but were presented to participants in different orders.

Volume of Data. The ARC method collects a lot more data compared to other methods of qualitative research. While this is an attractive feature of the ARC method, it also presents complications. Data from ARC can be in a variety of formats, and thus provides many angles from which to look at the trends in the study. This means that analysis will require more effort on the part of the researcher than other methods, especially if the activities implement a variety of medium for their responses. MacLeod et al.[1] note this and suggest paying attention to the inputs for each activity to avoid unnecessary challenges in analysis. It is difficult to automate pulling data from Facebook, and doing this manually is time consuming. Attempting ARC on platforms other than Facebook is a future research direction that may mitigate this. We recommend that if a research question can be answered satisfactorily using other methods of qualitative research, to consider those alternatives before resorting to ARC.

However, discussions directed by participants can also be useful. Thus, the ARC method is an excellent choice if research questions are exploratory enough that rich and varied qualitative data is helpful. If the research questions are more focused, there may be faster and less effort intensive ways of answering those questions. In other words, the less known about what the ultimate findings will be, the more appropriate ARC becomes.

Modularity. The ARC method generally takes quite a while to run (8–22 weeks). Thus, there is sufficient time to adjust the study as the research is ongoing. While researchers should have a detailed plan before starting the study, they should be prepared with backup activities if they learn that there are certain types of activities that their group is not receptive to or be prepared to introduce completely new activities if the results of a prior one need further clarification. In our initial draft of activities for the HIV study we had an ice breaker activity, but we removed it after learning that many participants were very motivated to participate in research. Since such an activity might come off as informal, we felt that it might annoy these more serious participants.

Population Considerations

All aspects of the design process for an ARC study should be informed by the unique features of the given population. Different demographics will be more responsive to different types of activities, the size of the sample will influence the dropout observed, and the unique situations of the individuals involved may raise additional concerns to which researchers will need to pay attention.

Location. Participants' locations helps determine many aspects of study design. It is recommended that, if researchers are not already aware of where the participants reside, for that information to be included in the entry survey. Geographical location can provide an element of familiarity, and can help to determine how larger samples should be split. It is important to take into account the time zones of participants when deciding when activities should start and end. Location may also influence what technology participants have access.

Because ARC is an online platform, it has made the consideration of where participants are geographically located considerably less of a burden. Instead geographical locations seem to not matter at all and if anything have strengthened the research as a whole. Prabhakar et al.[2] saw this as a benefit such that their participants were able to work around their hectic schedules and in our study it helped emphasize anonymity while also providing us with a diverse population set from all over the world.

Time Constraints. Participants' time constraints should also be considered. Sometimes there will be constraints that are specific to the entirety of a population, as in Prabhakar et al.[2] where the participants in the new mothers group were expected to only have small chunks of time where they were available on any given day. There will also be individual time constraints based on the lives of the participants. It is important to try to get a feel for this when determining activity length, so it may be a good idea to ask participants about their availability in the entry survey.

Stigma. It is important to be aware when a population is affected by stigma. Stigma can affect how easy it is to get participants, as well as inform the sort of activities to which participants might be responsive. It is also important to watch for situations where participants could face issues in real life if their participation in the study were discovered. This is an additional personal risk to participants of which they should be informed. With highly stigmatized groups, such as individuals living with HIV, these concerns should be on the forefront of researcher's minds. In our study, recruiting participants proved to be a major challenge because of this stigma. Recruiting from stigmatized groups has frequently been a roadblock to past research. The solution to this problem, both in our experience and in existing liter-

ature[4], has been to come to the population as an insider in some way. Essentially, MacLeod et al.'s[1] recommendation to build rapport with the target population is especially important in the case of individuals living with HIV, and the approach needs to be considered carefully in order to foster trust. This is likely to be useful when approaching other populations that are slow to trust due to stigma.

Privacy. The biggest risk to participants in an online study is the possibility of their information being leaked. Even if researchers are diligent, the websites used can record information about the participants[5]. This makes informed consent especially important. Participants must also be made aware that, while the researchers are able to moderate activity within the group, they have no control over what participants choose to share outside of it. MacLeod et al.[1]

Activities	Description	Studies	G/R	Pros	Cons
Introductions	Participants post to the group introducing themselves.	R,P,H	R	Group cohesiveness	Minimal Data Generation
Diary	Participants write down details about a specific type of event as it occurs.	R	R	Not dependant on memory	High effort (participants)
Circles	Participants place objects in concentric circles to denote relevance to their lives.	R,P,H	G	Unique angle	Material Requirements
Questions	Participants come up with questions that they wish people would ask them.	R	R	Unique angle	
Problems	Participants rank problems based on how much they effect their lives.	R,H	R	Gets straight to the issue	Negativity
Photo Elicitation	Participants present photos representing certain themes and the rationale.	R,H	R	Unique angle	High effort (participants and analysis)
Open Ended Questions	Participants post replies to a prompt given by the researchers.	R,P	G/R	Participant enjoyment	Data filtering, extraction
Solutions	Participants discuss solutions to problems synthesized from literature & activity responses.	R	G	Highly constructive	Data filtering, extraction
Mad Lib	Participants create mad libs based on humorous aspects of their situations.	R	G	Creative, fun	Confusing
Movie Script	Participants write scenes for a movie about their lives.	R	G	Clear picture of participants	High effort, confusing
Rant Line	Researchers set up a number for participants to call and text when they need to rant.	R	R	Coping mechanism	High effort (researchers & participants), low usefulness
Personas	Researchers synthesize personas in the population, participants critique them.	R,H	G	Confirms & corrects assumptions	High effort setup
Poll	Participants are polled about their preferences with regards to ARC activity designs.	P	R	Helps improve ARC	
Surveys	Participants respond to a series of questions given by the researchers.	P	R	Low effort, anonymous	Not interactive
Validated Instruments	Surveys on which there is existing literature.	P	R	Can compare with other studies	
Advice Columnist	Participants act as an advice columnist giving advice to a fictional character.	P	G	Cathartic	High effort researchers
Ask Me Anything	Participants post questions and receive feedback from other participants.	P	G	Highly interactive	
Search History	Participants provide their recent search history to the researchers.	P	R		High effort participants, invasive
Participatory Design	Participants discuss design solutions that could solve their problems.	H	G	(incomplete)	(incomplete)
App Testing	Participants test and give feedback on an app prototype.	H	G	(incomplete)	(incomplete)

Table 1: Description, pros and cons of activities employed across three different studies that used the ARC method to collect data. **Studies (R,P,H):** R=Rare Disease Study[1] P=Pregnant/New Mother Study[2]. H=HIV study. **Generative/Recall (G/R):** G=Activity generated new information in a unique or different way. R=Activity involved recall or descriptions of past events.

chose to recruit only from individuals already in Facebook groups related to their condition, so as to not expose any of their participants to privacy risks different from ones to which they were already exposed. It is important to inform participants of the risks that they're engaging in and the policies of any third party websites regarding the accessibility of their data[5]. For populations where leaked data could create personal risk, researchers could consider hosting their own forum to aid in controlling the possible sources of a privacy leak.

Activity Selection

An important part of preparing for ARC is choosing activities for the study. These activities will determine the type of data gathered. Participant engagement will be a major factor in whether the study will succeed or fail. Table 1 contains a list of previously implemented ARC activities along with their advantages and disadvantages. See MacLeod et al.[7] and Prabhakar et al.[2] for more information on the implementation of each of these activities. The studies section (R,P,H) refers to whether an activity appeared in each of the three studies. R refers to MacLeod et al.'s[1] work with people with rare diseases, P refers to Prabhakar et al.'s[2] work with pregnant women and new mothers, and H refers to our work with people living with HIV. The G/R column refers to whether the response was generative or recall; MacLeod et al.[1] define recall activities as activities where the participants must report existing information, and generative activities as any that require participants to come up with ideas or be creative. Note that in Prabhakar et al.'s[2] work, the researchers instead define activities as reflective, reporting, or creative. Creative maps to generative, and reflective and reporting add more nuance to recall. Reflective is essentially 'conceptual recall', where participants are asked to share ideas or feelings. Reporting is 'factual recall', where participants are asked to share concrete information. We use generative and recall here for simplicity.

Purpose of Activity. Researchers should always pay close attention to what they gain from using a specific activity over another. Researchers should consider what they intend to gather from a given activity, and how useful that will be compared to other options.

Effort to Complete. The more effort an activity requires on the part of participants, the less likely they will complete it. This was displayed most evidently in the new mothers study, where only about 13% of participants completed the Google Voice activity (as opposed to 88% the week before and 63% the week after) and later voiced complaints about the effort required to complete it. In general, if there is a way to get the same or similar results with less effort, then consider that option instead.

Effort to Analyze. Researchers can also control the volume of data through activity selection. MacLeod et al.[1] encouraged researchers to be careful about the number of different input methods that are included between activities in an ARC study. The more input methods there are, the more effort the data will be to analyze.

Balancing Usefulness and Effort. Prabhakar et al.[2] discussed the importance of balance between usefulness and effort. Researchers should look at the purpose of a given activity along with the effort that participants will need to put into completing it, and the effort on the part of the researcher to analyze the data. These pieces together will help to inform whether the benefits of an activity are worth the challenges of including it. We recommend researchers create a list of potentially useful activities to compare the advantages and disadvantages of each.

Material Requirements. Consider what materials participants need to complete a given activity (e.g., a camera, a smartphone, pen and paper, etc.) The more specific the requirements, the more likely that certain participants will be unable to complete the activity. In Prabhakar et al.'s study[2], participation in one group dropped from 95% to 50% for the circles activity before rising again, likely because of the specific requirements for completing the activity. The authors suggested tailoring activities based on what participants are able to complete. Building on this lesson, our research modifies activities to have multiple options for completion to cater to the abilities of different participants.

Activity Triangulation. Prabhakar et al.[2] suggested activity triangulation as an alternative to sequential activities. The rationale for including sequential activities is that they can provide more detailed answers to a specific question, allowing researchers to confirm or further narrow down the possible interpretations of their results. Prabhakar et al.[2] point out that including multiple activities that frame similar problems differently and require different input methods allows researchers to generate this nuanced data without forcing participants to complete activities sequentially.

Activity Order. Researchers should pay careful attention to when an activity will take place. Activities situated earlier in the study are likely to be completed by more people (see Figure 1), so researchers should consider placing their most important activities earlier in the study.

Conclusion and Future Work

The ARC method is still new to the field and the community is actively iterating on the method to improve our understanding and ability to use it. Most importantly, we encourage researchers to use the method for themselves so that we can understand trends and develop consistent metrics of evaluation between iterations of the method. Researchers should also make modifications to ARC and report on how those modifications improved or hindered their studies.

There is also a need to design infrastructure to support the ARC method. Cross-platform applications that allow participants to more easily complete activities that are commonly implemented in ARC studies could increase participation in ARC studies. Customized forums could avoid some of the privacy issues associated with Facebook, and include interactive features that help to engage participants or are suited to ARC in other ways.

This guide should be a piece of a growing toolkit for the ARC method. We encourage researchers to consider how they can apply ARC to their interests, and share any modifications and tools that they generate with the community for further evaluation.

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