
Conducting HCI Research with People Living with HIV Remotely: Lessons Learned and Best Practices

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Abstract

Conducting HCI research with people living with HIV in face-to-face settings can be challenging in terms of recruitment and data collection due to HIV-related stigma. In this case study, we share our experiences from conducting research remotely in two studies using the Asynchronous Remote Communities method with participants recruited from in-person and online support groups, respectively. Our findings and discussion around challenges, best practices, and lessons learned during the phases of recruitment and data collection expand and further support the suitability of the method to conduct research remotely with a highly stigmatized population.

Author Keywords

Asynchronous Remote Communities; HIV; stigmatized populations; social media; Facebook; research methods

CCS Concepts

•Human-centered computing → Web-based interaction; Empirical studies in HCI; User studies;

Introduction

Conducting HCI research with people living with HIV can be challenging due to the highly stigmatized nature of HIV [4]. On one hand, it may be difficult to recruit participants for research activities that necessitate face-to-face interac-

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W Activity

-
- 1 Introductions (A1)
 - 1 Baseline survey (A2)
 - 2 Problem ranking survey (A3)
 - 3 Photo elicitation (A4*)
 - 4 Technology use (A5*)
 - 5 Discussion of solutions (A6)
 - 6 App video & prototype (A7*)
 - 7 App survey (A8)
 - 8 Vignettes (A9*)
 - 8 Debrief survey (A10)
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Table 1: Weekly Activities.

W=Week. *Images of the prompt posts of these activities are located in the sidebars along this document. Artifacts and further description of the activities can be found in supplementary materials and in [5].

tion. Understandably, someone living with HIV may be wary about their privacy and confidentiality. On the other hand, if researchers do manage to recruit participants, it may be challenging to discuss sensitive topics related to HIV during a study as this may make participants feel uncomfortable or trigger a negative emotional response.

HCI research with people living with HIV has relied mainly on traditional methods for recruitment and data collection that require face-to-face interaction among participants and researchers (e.g., interviews). Although data collection has also been done with online surveys, HCI-based research methods like photo elicitation, user testing, and co-design have not commonly been adapted to online settings. In this sense, we evaluated the Asynchronous Remote Communities (ARC) method [3] to conduct HCI research with people living with HIV remotely [5]. The researchers found that the method was indeed suitable due to the high engagement and retention of participants as well as due to the possibility of deployment of data collection methods more relevant to HCI research, such as photo elicitation or focus groups. In this case study, we expand on this previous work by providing more detail regarding how the ARC method was used in the study mentioned above (study 1), as well as in a second study (study 2) which was conducted with participants recruited from a local support group. In the following sections, we describe the method and discuss the challenges, best practices, and lessons learned during the phases of recruitment and data collection.

Methodology

The ARC method, proposed by MacLeod et al. [3], allows researchers to collect data and engage with participants remotely via the deployment of weekly activities in an online group. These activities are varied, and were completed asynchronously. They ranged from online surveys to online

discussions and user testing. The ARC method has been used with populations facing in-person study constraints. For example, the ARC method has been used to work with people living with rare diseases who were geographically dispersed [3], or with mothers who could not attend studies due to their busy schedules and busy lifestyle [6]. More recently, HCI scholars have been using ARC in order to work with groups of people who are difficult to recruit due to their stigmatized identity (e.g., LGBTQ+ community) as well as those who have experienced a stigmatizing experience like miscarriage (e.g., [1]).

We used the ARC method to complete a needs assessment of people living with HIV in two different studies, each utilizing a separate secret Facebook group. For study 1 (S1), we recruited 19 participants (11 men, 7 women, and 1 queer) from Facebook support groups with different sexual orientations (8 heterosexual, 8 homosexual, and 3 bisexual), race/ethnicity (12 Caucasians, 4 Latinos, 2 Asians, and 1 African), and ages (18–60). Thirteen participants were from the US, two were from the Philippines, and there was one participant from each Mexico, Kenya, South Africa and the UK. For study 2 (S2), we recruited 8 participants (7 men, 1 woman) from an HIV support group located in a Midwest region of the USA. They had different sexual orientations (3 heterosexual, 3 gay, 2 bisexual), race/ethnicity (1 Black, 7 White), and ages (20–60). Both studies were conducted in English, lasted eight weeks each, and participants completed the activities listed in Table 1.

In the following section, we describe our experience recruiting and collecting data for both S1 and S2. Table 2 summarizes the best practices from our experience conducting HCI research remotely with people living with HIV.

Table 2: Best practices and lessons for conducting HCI research using the ARC method with people living with HIV.

Recruitment and Informed Consent	
1	Find and, if at all possible, volunteer at in-person and/or online support groups where gatekeepers, such as social workers, health care providers, senior members, or group administrators, work directly with the target population. <u>Note:</u> based on lesson #1 in [3]
2	Have all IRB-approved documentation ready. Gatekeepers will need to see it prior to starting recruitment.
3	Ask gatekeepers to confirm study participants that they have reviewed and approved study procedures during recruitment. <u>Note:</u> based on lesson #18 in [5].
4	Use language that is not stigmatizing or offensive. Advice from gatekeepers can help in this regard. <u>Note:</u> based on lesson #21 in [5].
5	Use personal Facebook accounts if recruiting online. <u>Note:</u> based on lesson #20 in [5].
6	Review informed consent document carefully with potential participants. In online settings, do this via private chat or email. <u>Note:</u> based on lesson #2 in [3].
7	Warn participants about researchers' lack of control of confidentiality of data shared within the group (especially if this study is conducted via social media, like Facebook).
Researcher-participant Interaction	
8	Allow participants to submit data via private channels like the lead researcher's email and/or private chat messages with members of the research team.
9	Use language that is not stigmatizing or offensive. Advice from gatekeepers can help in this regard. <u>Note:</u> based on lesson #21 in [5].
10	Use personal Facebook accounts while interacting with participants. <u>Note:</u> based on lesson #20 in [5].
11	Intervene when miscommunication takes place among participants. <u>Note:</u> based on lesson #22 in [5].
12	Set up notifications so that researchers know when participants post or comment in the group.
13	Answer questions in a timely manner and intervene in discussions where no comments are being generated by participants <u>Note:</u> based on lesson #22 in [5].
14	Monitor for sharing of identifiable information in posts and comments.
15	Provide a code of conduct at the beginning of the study. This code should be available to participants throughout the study.
Data Collection	
16	Create the same schedule for all activities (i.e., posting the prompt, sending reminders, expected activity completion). <u>Note:</u> based on lesson #19 in [5].
17	Set up group and private reminders to complete activities towards the end of the week (on Friday and Sunday). <u>Note:</u> based on lesson #19 in [5].
18	Create independent activities. No activity should be dependant on the completion of another one. <u>Note:</u> based on lesson #8 in [3].
19	Deploy surveys that collect general data from participants during the first weeks of the study to assure a higher rate of completion.
20	Allow participants to submit surveys anonymously (except for demographics).
21	Use elicitation artifacts to encourage participants to engage in discussion with others in the group and researchers.
22	Have questions ready to foster conversation among participants.
Data Preparation for Analysis	
23	Export text and images from posts to plain PDF files. Post, comments and replies should be tagged and coded using de-identified codes and be color coded. Codes should identify if data is part of a post, comment or reply to a comment. The codes should clearly identify the participants who created them. Reactions to posts, comments and replies should also be recorded.

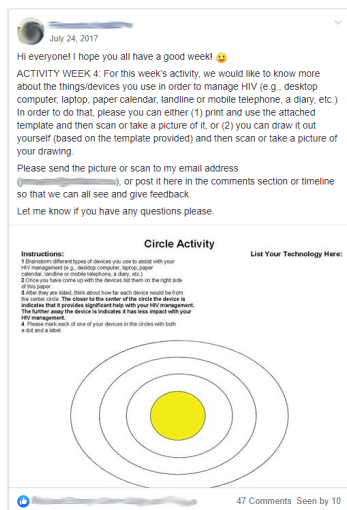


Figure 1: Prompt for A5 (technology use) in week 4. Participants were asked to download a template that consisted of concentric circles. Participants could draw or write the name of the different technologies that they use to manage HIV. The closer the technology is to the center of the circles, the more important it is for HIV management.

Findings and Discussion

Recruitment and Informed Consent

Prior to recruitment, it was necessary to have all the Institutional Review Board (IRB)-approved documents ready. In particular, the informed consent documentation required the inclusion of potential loss of confidentiality risks due to the study being conducted on a social media platform like Facebook. The consent document was also required to emphasize the lack of control researchers have on how participants disclose group information outside of the study group.

In S1, we contacted administrators of 16 closed HIV support groups on Facebook that had more than 1K members and that resulted from a search using the keyword phrase "HIV support"¹. Administrators of these groups acted as *gatekeepers* of these groups and were contacted via a private message explaining the nature of the study. IRB approval and consent form documents were attached to the message. Administrators from four groups replied back and asked for more information regarding the study. Their questions were mainly related to privacy and confidentiality of participants' identities. The administrators of the groups invited one of the researchers to be a member of their groups before proceeding to create recruitment posts within the group. Potential participants did not reply to the recruitment post at first. It was only after one of the group administrators vouched for our study by assuring that they had reviewed and approved the privacy/confidentiality documentation, that members of the group started to comment on the post and sent a private message indicating their interest to be part of the study. A private message with the consent form attached was sent to each of the interested

members. Further discussion and questions regarding the consent form were addressed via private messages. Out of 32 potential participants who contacted us, 19 completed enrollment for the study, they printed and signed the consent form document and either scanned or took a photo of it. The signed consent forms were sent to us via a private message or via email.

In S2, recruitment that involved signing a consent form with potential participants in a face-to-face setting entailed a slower and more difficult process. The first author built rapport and trust with the social worker staff at an HIV support center via volunteering and helping out at events and educational campaigns like the AIDS Walk for about six months prior to asking their help for recruitment. In this case, the social workers were the *gatekeepers* to the people living with HIV that they were providing support to. Once rapport was established with the social worker staff and IRB documentation was reviewed by them, they provided the first author with a list of 12 potential participants within the following two months. The first author reached out via a phone call to schedule a meeting at the HIV support center to discuss the study and go over the consent process. Eight participants responded to the call and scheduled a meeting. It took about two additional months to get the 8 participants enrolled for the study. Participants in both studies were compensated with \$50 (USD) paid via PayPal in S1, and in person in S2.

Data Collection

The ARC method proved to be effective at engaging and generating discussion among participants. In S1, participants found it easier to complete the activities as they seemed to have more experience using Facebook. Participants in S2, required researchers to provide more explana-

¹Closed groups on Facebook are searchable, but it is necessary to be accepted as a member of the group to have access to the posts within the group.

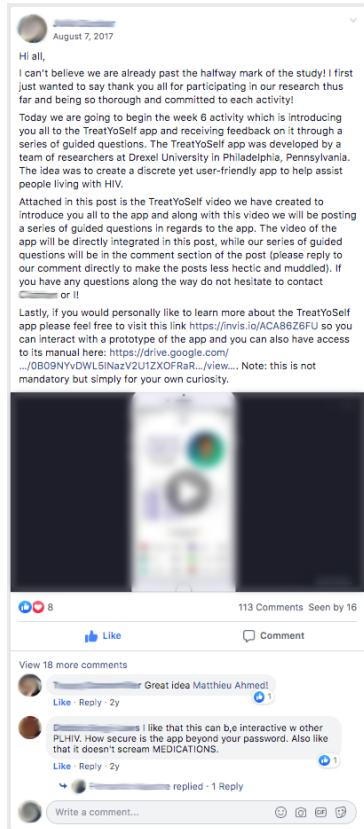


Figure 2: Prompt for A7 (app video & prototype) in week 6. Participants were asked to discuss features and user interface design of technology used for HIV management after watching a short video and interacting with an online interactive prototype.

tion about the activities via private messages². A possible reason for this may be that participants in S1 were already active members of support groups on Facebook; whereas, in the case of S2, half of the participants self-reported not being active users of social media. Yet, as seen in Table 3, there was a rather high activity completion rate in both studies with an overall delay average of 2.2 days to complete activities for both studies. In both studies, the activities that had the most delays were A4 (photo elicitation) and A5 (technology use) that require participants to prepare materials prior to submission (e.g., taking photos, printing, scanning).

W	A	C S1 (%) n=19	C S2 (%) n=8	D S1 (s)	D S2 (s)
1	A1	17 (100%)	6 (100%)	0.4 (1.5)	0.7 (0.8)
1	A2	17 (100%)	6 (100%)	1.5 (2)	0.4 (0.8)
2	A3	17 (100%)	6 (100%)	0.6 (1.2)	1.9 (2.7)
3	A4	17 (100%)	6 (100%)	4.1 (3.2)	4.1 (2.4)
4	A5	16 (94%)	6 (100%)	4.1 (2.6)	5 (1.8)
5	A6	17 (100%)	3 (50%)	2.3 (2.4)	2 (2.6)
6	A7	16 (94%)	4 (67%)	3.3 (3.5)	0.8 (1)
7	A8	17 (100%)	5 (83%)	1.7 (2.3)	2 (3.1)
8	A9	15 (88%)	5 (83%)	1.7 (1.9)	4.6 (4.6)
8	A10	15 (88%)	5 (83%)	1.2 (1.4)	0.4 (0.5)

Table 3: Activity Completion and Delay. W=Week. A=Activity. C S1=# of participants who completed the activity in S1. C S2=# of participants who completed the activity in S2. D S1=Average of days to complete the activity in S1. D S2=Average of days to complete the activity in S2. Two participants dropped out of S1 and S2, respectively.

²Examples of interactions between researchers and participants are included in supplementary materials.

A few participants in both studies preferred to submit certain activities via a private email as they did not want to share their submission with the other members of the group. This was particularly true for activities that involved self-disclosing sensitive information in the form of text and photos and especially in the case of participants living outside the U.S. Therefore, it was important to give the opportunity to submit information through more private communication channels.

Researcher-Participant Interaction

Prior to starting the studies, it was necessary to get familiarized with the language that participants speak regarding living with HIV to avoid using terms that could be offensive or that could further stigmatize the participants (e.g., infected, HIV positive). This familiarization with use of proper language was accomplished under the guidance of gatekeepers as well as of people living with HIV at the HIV support center.

It was also important to encourage and moderate participation in both studies. The first post in both studies consisted of a 'code of conduct' that listed the rules to be followed by everyone during the study. Such rules reminded participants to respect one another, to not invite others to the group, and to not share confidential information exchanged within the group. We also wanted the participants to perceive that we 'were there' for them should they have any questions. We tried to answer questions as quickly as possible so that participants' perception was that we were always connected and paying attention to what they were doing or saying in the group. It certainly helped that we set up our Facebook accounts to receive notifications regarding any interaction happening in the group so that we could moderate more effectively. We used our personal Facebook accounts to help build rapport and trust with administrators

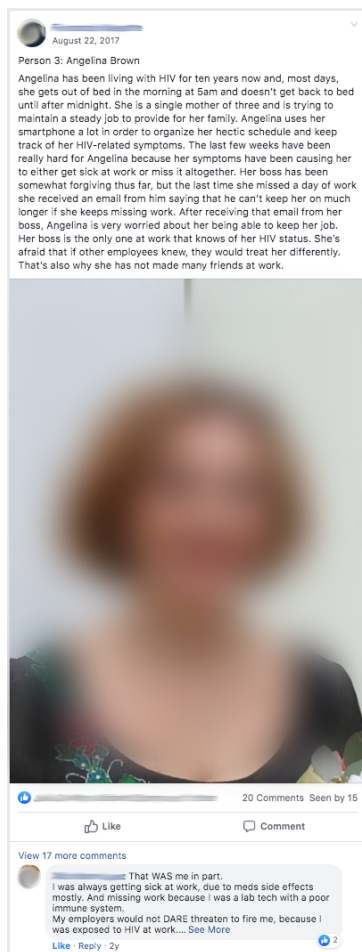


Figure 3: Prompt for A9 (vignettes) in week 8. The use of vignettes helped generate discussion around sensitive topics related to challenges of living with HIV and facing HIV-related stigma.

and participants, by giving them a better sense of our individual identities.

In activities that involved interactive discussion, we intervened in cases when participants did not comment in active discussion threads for longer than two days, or when there was confusion about an activity, a post, or a comment. We also intervened when there was miscommunication among participants. This is something that happened in S1 in particular, as participants were from different countries and cultures. We also monitored the sharing of identifiable information among participants although this situation did not occur in either of the studies.

Activities

The prompt for an activity was posted at the top of the group timeline on each Monday morning. We asked participants to complete the activity by the end of the week on Sunday at midnight. This schedule allowed participants to complete an activity at any point during the week. It also gave a structure to the study so that they can integrate it into their weekly routine. The activities were independent from one another as we did not want participants to feel pressured to complete an activity prior to starting another one. This gave participants the flexibility to skip any activity if they did not have enough time during a busy week without impacting their ability to continually participate in the study. Four and three participants skipped at least one activity in S1 and S2, respectively. Participants could have been working on completing a delayed activity; but, generally, the delayed activity was completed within 2 or 3 days. Thus, completing the activity of a previous week, did not affect the completion of any subsequent weekly activity.

Across activities participants could provide information by three ways: (1) posting text or images directly on the timeline or via comments within a post, (2) filling out and submit-

ting a survey, or (3) sending activity deliverables directly via email or private message to the researchers. We posted a reminder on the group timeline on Friday if all participants had not completed an activity. For those who had not completed an activity by Sunday morning, we sent them a private message inquiring about reasons for the delay and whether the participant needed our assistance.

The format of the activities fell under the category of either an online survey (A2, A3, A8 and A10), or a group discussion (A1, A4-A7, A9). Online surveys were accessed via a link provided in the prompt of the activity on the group timeline. As seen in Table 3, surveys that were deployed during the first weeks in both studies S1 and S2 had a 100% completion rate whereas surveys posted at later points in the study had 88% in S1 (2 participants not submitting) and 83% in S2 (1 participant not submitting). In this sense, we suggest that if researchers need to collect important baseline data via survey instruments, do so during the first weeks of the study. In addition, participants should be able to submit survey information anonymously except for demographics (without providing names or any other identifiable information). Anonymity encouraged participants to further disclose and provide information about sensitive topics related to challenges of living with HIV and facing HIV-related stigma which also happens to people living with stigmatized chronic illnesses in online settings [2]. When participants completed a survey, they typed the word 'done' in the comments section of the activity post so we can track activity completion.

Discussion groups took place via posts and comments generated within the post containing the activity prompt. All discussion group activities, except for A6, required participants to use an artifact to elicit comments. Overall, participants in both studies generated more comments when participants

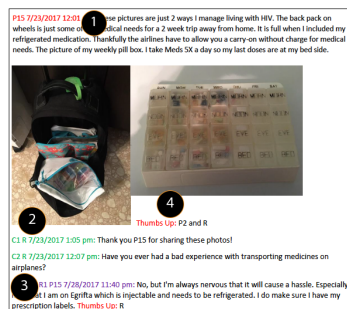


Figure 5: This is a sample of data exported from A4 (photo elicitation) in week 3. Different colors were used for tags identifying post, comments, and replies. All tags contained participant code, date, and time (1). Tags for comments and replies also included the code C or R[number of reply] at the beginning of the tag (2). Replies were indented below their parent comment (3). In addition, we recorded the reactions to each post, comment or reply (4).

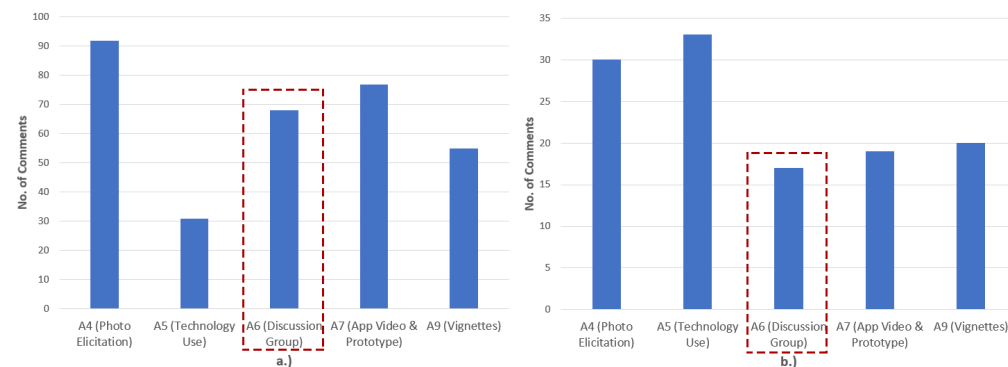


Figure 4: No. of comments in discussion-based activities in S1 (a) and S2 (b). No artifact was used in A6 (highlighted).

used artifacts around which they could provide thoughts, observations, or ideas. As seen in figure 4, in S1, A4 (photo elicitation) was the activity that generated the most participation with 92 comments followed by A7 (app video & prototype) with 77 comments.

In S2, however, A5 (technology use) and A4 (photo elicitation) generated the most participation with 33 and 30 comments, respectively. It was interesting to find that A6 (discussion of solutions), which did not require participants to use a particular artifact, generated more comments than other activities that used artifacts like A5 (technology use) and A9 (vignettes) in S1. However, all activities that made use of an artifact elicited more comments than A6 (discussion of solutions) in S2. The reason for this could also have been that participants in S1 were more likely to be already active users of social media and thus may not need elicitation artifacts to participate in a discussion thread. Regardless, for all the discussion-based activities, it was useful to have questions prepared in order to moderate the discussion. We also tagged 'silent' participants in comments to

encourage them to participate by asking them if they had any questions of if they wanted to add any thoughts. However, this was only for discussions that did not cover sensitive topics such as giving feedback about a technology feature.

Preparing the Data for Analysis

All text and images were exported manually (copying and pasting) onto plain separate PDF documents for each activity³. All data were positioned in the same order that they appeared on the group timeline and de-identified by replacing usernames with participants codes. In addition, all data within the posts, comments and replies were stripped of any identifiable information such as names or email addresses. Different colors were used in order to differentiate posts, comments, and replies. Tags for posts contained participant code, date and time (Fig. 5,(1)). Tags for comments and replies included the code C (comment) or R (reply) plus

³PDFs were used to preserve the structure and order of contents at the moment of importing data into an analysis software like Dedoose.

the number of comment/reply in the thread at the beginning of the tag (Fig. 5,(2)). The replies were indented below their corresponding comment (Fig. 5,(3)). Additionally, we recorded the reactions from participants for each post, comment, and reply (Fig. 5,(4)). Lastly, all the PDFs were imported to a research analysis software (i.e., Dedoose) for subsequent coding and analysis.

Conclusion and Future Work

This case study shows that it is feasible to conduct HCI research remotely with a highly stigmatized population using the ARC method. Moreover, by combining different in-person and online recruitment strategies and by following the best practices and lessons discussed in this document, researchers can collect rich data from a wider and more diverse participant pool. Thus, we exhort researchers and practitioners to continue exploring the use of the ARC method when face-to-face interactions are constrained with stigmatized and non-stigmatized populations. Moving forward, we hope to design more engaging activities that could be deployed in ARC-assisted studies that can make use of imaginative and interactive artifacts to help researchers create rapport and elicit deeper and more insightful discussions among participants.

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