

Defining Through Expansion: Conducting Asynchronous Remote Communities (ARC) Research with Stigmatized Groups

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ABSTRACT

Researchers in HCI have typically relied on face to face (FtF) methods for recruitment and data collection in their research with people living with HIV, whereas social scientists have adopted computer-mediated approaches to address concerns about data validity and access to this stigmatized population. In this paper, we use the asynchronous remote community (ARC) research method to leverage HCI instruments in an online format. ARC successfully engaged people living with HIV in terms of participation and retention by providing a safe space to discuss their experiences. By expanding on past ARC studies, we contribute to an ongoing conversation about defining ARC and working towards increased data validity – especially in stigmatized communities.

ACM Classification Keywords

H.5.3. Group and Organization Interfaces: Evaluation/methodology; H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

Author Keywords

Research methods; remote populations; HIV; stigma; Facebook.

INTRODUCTION

Researchers in the social sciences have been studying people living with HIV (hereafter called ‘PLH’) and their caregivers using methods that recruit participants and collect data with both face to face (FtF) (e.g., [14, 37]) and web-based instrumentation (e.g., [8, 34, 42]). For instance, study participants have been recruited via in-person outreach (going to places where PLH socialize) as well as via flyers, online posts, and e-mails. Regarding data collection, studies have used traditional instruments such as surveys (e.g., [14, 33]), FtF interviews (e.g., [23, 37]), and FtF focus groups (e.g., [40]) as well as online instruments such as web-based surveys (e.g., [4]), automated data retrieval mechanisms (e.g., [8]); and, in some cases, interviews conducted in online chat rooms (e.g., [45]).

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FtF recruitment and data collection are difficult because of the highly stigmatized nature of HIV [17, 43]. Understandably, PLH can be very cautious when it comes to revealing their HIV status to others, as a breach of confidentiality may have serious implications in their personal and professional lives. Consequently, researchers in the social sciences have often turned to online platforms to reach, recruit, and gather data from this population; individuals living with a stigmatized condition are already more likely to look for support, social connections, and health-related information on the Internet because of the perception that online platforms offer anonymity and privacy [2, 43]. In contrast, HCI research with PLH has relied mainly on FtF traditional methods for recruitment and data collection such as focus groups (e.g., [40]), questionnaires or interviews (e.g. [20]), and participatory design workshops (e.g., [29]). Although web-based data collection instruments—especially online surveys—have been widely used to collect data from these stigmatized groups, studies have neither been able to mitigate the problems of validating self-report data nor have they successfully adapted other data gathering instruments more attuned with HCI research methods, such as photo elicitation, focus groups and co-design to online settings.

To address these limitations, MacLeod et al. [27, 28] introduced the Asynchronous Remote Community (ARC) method, which can be likened to a web-based focus group. Past ARC studies have used a secret Facebook group to facilitate activities and discussions among participants to better understand their needs, towards designing innovative sociotechnical solutions. It is different from other types of web-based focus groups (e.g., [50]) in that it is conducted over a period of several weeks or even months and is augmented with adaptations of a variety of other HCI research methods to allow for data triangulation. MacLeod et al. [28] provided a “*detailed, in depth description of the ARC method such that other researchers may replicate, modify, and improve upon this method.*” They encouraged other HCI researchers to report on their own experiences with the method. Prabhakar et al. [38] subsequently applied the ARC method in a study with pregnant women and new mothers, validating some of the contributions of MacLeod et al.’s initial attempt, successfully improving upon some of the lessons learned, and introducing additional insights.

This paper builds on MacLeod et al.’s [28] and Prabhakar et al.’s [38] work by exploring the use of ARC for research with

PLH to overcome barriers to research with stigmatized groups. In this paper, we do not discuss the results of our study with PLH, but rather reflect on the method. We contribute to an ongoing conversation on the benefits, challenges and lessons of the ARC method in a range of situations where FtF research is challenging or even impossible. Additionally, we consider the process through which new research methods are developed, validated, and introduced to the CHI community. We review literature on the validity of other qualitative approaches and consider how new methods have been introduced in HCI. We do this in order to contribute with a formal definition of ARC as well as to create a guideline for its application.

RELATED WORK

The literature on stigma has shifted from the traditional definition of stigma as being a mark on someone of questionable moral status [18], to proposing a more complex view of stigma as a social construct based on human perceptions of differences (e.g., sexual orientation, health status, type of occupation, etc.), in a particular culture and time [32]. Regardless of the reason why an individual may be stigmatized, stigma has been linked to an array of negative outcomes such as discrimination, identity devaluation, prejudice, and deterioration of physical and psychological health [32]. Consequently, vast research on stigma has been focused on the identification of coping strategies that allow individuals to mitigate effects of stigma in their lives (e.g., [12, 31, 52, 53]). In particular, studies with stigmatized communities have identified people turning to the Internet to cope and compensate for a lack of access to information and the inability to form offline relationships with others who share the stigmatized condition (e.g., [12, 31]). The Internet has provided a means for them to disclose information regarding their stigmatized conditions more easily and experience the positive benefits of such self-disclosure, like decreased levels of stress and access to social support, without having to reveal their identities and feel embarrassment [39].

The Internet has also facilitated access to stigmatized communities for research purposes. Web-based recruitment and data collection instruments have reduced the limitations of traditional FtF methodologies in recruiting stigmatized or “hidden” populations, including data entry errors and social desirability biases in responses. Researchers in the social sciences have been able to access stigmatized populations like PLH from dispersed geographical areas and have them complete web-based surveys (e.g., [4, 41]), or be part of computer-mediated interviews in online chat rooms (e.g., [45]). Researchers have reported that data obtained via the Web are of better quality due to, for instance, the automatic detection of invalid data in the case of surveys as well as the disclosure of more information about sensitive topics – which has not been affected by interviewer bias – [16, 43]. For example, Rhodes et al. [44] found that participants recruited online were more willing to disclose current HIV status than participants recruited in FtF settings. Consequently, researchers usually turned to online communities such as blogs, forums (e.g., [8]), social media (e.g., [17]), and chat rooms (e.g., [43]) to recruit study participants and collect data via web-based instruments from stigmatized individuals who may otherwise be reluctant to

participate in FtF settings due to geographical location, embarrassment, or confidentiality concerns. Thus, the Internet has not only been beneficial for those who are impacted by stigmatized conditions like HIV, but it has also been helpful for researchers who study these populations.

In contrast, HCI research with PLH have relied more so on FtF traditional methods for recruitment and data collection such as focus groups (e.g., [40]), questionnaires and interviews (e.g. [20]), and participatory design workshops (e.g., [29]). For instance, Ramanathan et al. [40] recruited participants from AIDS service organizations and conducted FtF focus groups to assess features of a hypothetical mobile application in different scenarios. Joshi et al. [20] recruited participants from clinics with the help of doctors and collected data via FtF interviews to assess the usage of a mobile system based on voice alerts to help PLH adhere to medication and have access to relevant information regarding HIV. Marcu et al. [29] also recruited participants from clinics and collected data via participatory design workshops to design and develop a mobile application. Thus, although still scarce, HCI research has already reported benefits for PLH with issues related to medical adherence, social support and treatment management (e.g., [29, 40]). Yet, web-based recruitment techniques have the potential for researchers to reach “hidden” populations of stigmatized PLH, and, ultimately, expand the diversity of their participant pool. In addition, web-based instruments can return data that is less affected by self-reporting biases or researcher interactions with the stigmatized populations (as in [7, 19]). In this sense, it is important to explore online mechanisms that would allow HCI researchers to adapt data collection instruments –beyond the use of online surveys–to conduct research with stigmatized participants.

The ARC Method

MacLeod et al. [27, 28] introduced the Asynchronous Remote Community (ARC) method in their study of rare disease populations as a way of overcoming barriers to FtF group-based research. An ARC study involves a group of participants in an online environment (typically a private or secret Facebook group) completing periodic activities both individually and as a group. These activities can be anything from lightweight ice-breaker activities to psychometric exercises. Many of MacLeod et al.’s original set of activities were inspired by traditional HCI research methods (such as photo elicitation or personas), but adapted for groups in a web-based setting. The main advantage of ARC is that it overcomes barriers that make it difficult to conduct FtF studies on certain hard-to-reach populations. In addition, ARC was developed to account for people living with rare diseases who are geographically distributed. MacLeod et al. [27] provided lessons learned from their first attempt at conducting group-based research remotely. These lessons focus on informed consent and participatory engagement (refer to lessons #1 to #11 listed in Table 2).

Prabhakar et al. [38] leveraged the ARC method in their work with pregnant women and new mothers, who face time, mobility, and availability constraints that prevent them from participating in FtF studies. The researchers confirmed many lessons discussed in [27], and made modifications to the original ARC

activities to suit their population and specific research questions. They also contributed with new lessons that focus on finding a balance between effort and the usefulness of data when creating or selecting activities (refer to lessons #12 to #17 in Table 2). Additionally, the authors discussed the potential for using multiple ARC activities to triangulate conclusions to form a more complete picture.

Validity & New Methods Development in HCI

HCI researchers and designers regularly apply a range of methods to address different topics or questions [25]. When existing methods or practices are insufficient in some way or a new research opportunity is identified, they sometimes develop new methods or adapt existing methods for new contexts or settings [15]. Dickson and Stolterman [15] argue that new (design) methods are rarely developed in a user-centered way, nor are they tested or evaluated as such. In many cases these methods are used or tested only a small number of times [15,47–49] before being “*set aside as a point of analysis, discussion, and a starting point for future research*” [15]. One possible reason for this is that new methods may emerge out of a need for a new approach to a specific problem rather than a deliberate decision to create a new method that is useful to other HCI researchers and practitioners. Moreover, seeing the broader relevance of a new approach to different research questions can be challenging if the new approach is contextualized and discussed in relation to a specific problem. New methods and tools can appear context-dependent.

Discussions of validity of qualitative research are much more common in the social sciences where researchers have proposed ways of determining validity of research outcomes [10, 13, 30, 51]. Creswell and Miller [10] note that validity criteria might depend on “*the particular methodological design*” and “*the paradigmatic assumptions invoked by the research*”. Taxonomies of validity consider things like the rigor and sincerity of the work [51], making a substantive contribution to our understanding of social and cultural life [13], having potential for impact for its participants [13], and providing “*experience-near*” accounts that are fair to participants. It is thus important for qualitative researchers to articulate the grounds on which their validity claims rest.

These approaches to assessing validity can be valuable for examining qualitative research outcomes. However, there are other strategies researchers may use to improve the validity of their data throughout the research process. For example, triangulation involves using multiple sources of data to produce understanding; researchers often assume that this will result in some convergent meaning or “truth” [24] but this is increasingly controversial because “*it loses the context through which alternative meanings are derived, and [...] assumes some underlying reality to be converged upon.*” Instead, many researchers consider triangulation to be valuable in eliciting divergent accounts to produce an understanding that is “*rich, robust, comprehensive, and well-developed*” [46]. In particular, researchers use this triangulation to search for contradictions (consistency checking). Unlike in quantitative research, in qualitative research these outliers are critical to our understanding. They can tell us our initial interpretation or

themes may not be correct or there may be some mechanism in between that helps to reconcile these differences [6].

METHOD

To evaluate the ARC method in the study of PLH, it was necessary to take steps that would ensure an optimal deployment. After obtaining IRB approval, we began working with counselors and PLH. Next, we recruited participants from on-line Facebook HIV support groups and began using the ARC method to collect data. In the following sections, we explain each of these phases in more detail.

Pre-Study Target Population Research

The first author volunteered approximately 50 hours at a support center for PLH and conducted ethnographic research between the months of January and July of 2017. Although the ethnographic results are out of scope of this paper, this initial exploration informed our research team about the best ways to approach and communicate with the PLH community.

ARC Deployment

The ARC method was deployed in a secret Facebook group in order to compare and validate findings with previous ARC studies that have used the same platform.

Recruitment and Informed Consent

In May and June of 2017, we searched for groups on Facebook with the keywords “HIV support”. To reach more people for recruitment purposes, several groups with more than 1K members were sent a “join group” request. The administrators of four different support groups contacted the first author and asked for IRB-approved documentation. It was important to make it clear in the informed consent documentation about the potential risks of breach of confidentiality due to permanency of data and poor confidentiality protections on a social media platform [11], and about possible actions that were outside of the researcher’s control like participants sharing data posted in the group elsewhere. After receiving authorization from the administrators, the first author was added as a member and proceeded to recruit participants via a post on the timeline of each group. Group members who were interested in the study commented on the post and were asked to send either an e-mail or private message (PM) to the first author. Once a participant contacted the first author, an IRB-approved consent document was sent to the participants. Questions regarding the consent form were addressed via chat on Facebook. After participants sent a scan of the signed consent document, they were invited to a secret Facebook group (named Chicken Soup Group) in order to be part of the study. Participants were compensated with \$50 paid via PayPal at the end of the study, regardless of their participation activity level.

Participants

We recruited a total of 19 people (11 men, 7 women, 1 queer) with different sexual orientations (8 heterosexual, 8 homosexual, 3 bisexual) for our study. For race and ethnicity, participants self-reported: 12 Caucasians, 4 Latinos, 2 Asians, and 1 African. Participants ranged in age from 18–60 and the number of years living with HIV ranged from 1–30 years. Thirteen participants were from the US, two were from the Philippines,

W	Activity	T	Data Type	C	P (%)	D (s)
1	A1: Introductions. Participants introduced themselves to the group via separate posts.	Group	Text/Photo	94	17 (100%)	0.4 (1.5)
1	A2: Baseline survey. The items of the survey captured demographic information and needs assessment.	Survey	Text	31	17 (100%)	1.5 (2)
2	A3: Ranking of problems. Participants were asked to rank a list of problems (based on A2) and challenges that PLH face on a daily basis.	Survey	Text	22	17 (100%)	0.6 (1.2)
3	A4: Photo elicitation. Participants were asked to upload to the group (or send via e-mail to the researchers) photographs that would show positive and negative aspects of living with HIV as well as devices that helped them manage HIV.	Group/e-mail	Photo	92	17 (100%)	4.1 (3.2)
4	A5: Technology use. Participants were asked to download a template which contained a set of concentric circles. They were instructed to a list of devices or technology they use in order to manage HIV. The closer the items were located to the center of all the circles, the more helpful the item was for HIV management.	Group/e-mail	Scan/Photo	31	16 (94%)	4.1 (2.6)
5	A6: Co-design of solutions. Participants were asked to comment and upload visual materials like photos or drawings about different things that they wish they had in order to help them manage better their lives around HIV.	Group	Text/Photo	68	17 (100%)	2.3 (2.4)
6	A7: Mobile application video & prototype. Participants were asked to watch a video and interact with TreatYoSelf which is a mobile application prototype developed by [29].	Group	Text	77	16 (94%)	3.3 (3.5)
7	A8: Mobile application survey. Participants filled out an online survey that captured more detailed feedback about their impressions regarding the design and features of the prototype used in A7.	Survey	Text	47	17 (100%)	1.7 (2.3)
8	A9: Personas. Participants were asked to provide comments about three personas which were presented to the group in separate posts.	Group	Text	55	15 (88%)	1.7 (1.9)
8	A10: Debrief survey. The items of the survey captured feedback about the study.	Survey	Text	21	15 (88%)	1.2 (1.4)

Table 1. Activities Used in Study. W=Week. T=Tool for collecting data. C=# of comments on this activity. P=# of participants who completed the activity. D=Average of days to respond to activity. Participants were asked to discuss, expand and give feedback to each other’s submissions and comments.

and there was one participant from each Mexico, Kenya, South Africa and the UK. Four participants were employed full time, while the rest were either self-employed, unemployed, or receiving disability payments. Five participants had a college degree and the rest had a high school degree. They all were able to write and speak English fluently. Their level of stigma regarding HIV ranged from moderate to high in a scale based on shame and discrimination enacted by others [1].

Activities

Table 1 describes the weekly activities participants were asked to complete. Almost all activities are adaptations of traditional HCI methods. All activities were independent based on MacLeod et al.’s recommendation [28] and also because we did not want participants to feel pressured that they had to complete an activity before continuing with another one. Some participants had busier weeks than others due to life and HIV-related issues that made them finish an activity with some delay. With dependent activities, participants who could not complete an activity on time, might have felt that they were lagging behind and that were not part of the activity the other participants were working on. Such situation could have affected their retention. The prompt of each weekly activity was pinned as an individual post at the top of the group wall each Monday morning. Participants were asked to complete the activity by the Sunday of that week at midnight before the publication of the next activity on Monday. Depending on the activity, participants were asked to complete it by writing a comment or by uploading a photo directly in the comments area of the post that contained the prompt of the activity. If the activity required scans or photos, then they could also complete the activity by sending their submissions via e-mail to the researchers. In the case of activities that involved surveys, we asked participants to type the word “done” in the

comment area of the activity post after they had successfully submitted the survey, so that we could keep track of activity completion, and also because we wanted other participants to be reminded of the activity via a notification (following lesson #7 from [27].) However, if participants did not complete the weekly activity by Friday, the protocol was to post a reminder on the group’s wall by Friday afternoon. For those participants who did not complete the activity by Sunday morning, a one-time PM reminding them of the activity was sent as well.

Data Analysis

All data (textual and visual) from surveys, posts, comments, PMs, and e-mails were collected, stored, and organized by activity. This data was analyzed with quantitative and qualitative perspectives by three researchers. To explore the suitability of ARC for PLH, we analyzed the number of comments per participant for each activity, the number of participants who completed each activity, as well as the delay in days that each participant took to complete each activity. In addition, two researchers iterated on codes until converging on an inter-rater agreement of 0.75 using Cohen’s kappa coefficient. We analyzed participants’ feedback (positive or negative), progress of completion (completion, delay, or excuse/reason for delays or for not completing), and clarification (seeking or provision) regarding the study and each of the activities. Finally, to start examining consistency with our findings across activities regarding how frequent problems (A3) were mentioned or appeared in each activity, we performed a triangulation of data across groups of activities that assessed challenges/needs (A2, A3, A4, A9), and existing HIV management strategies (A4, A5). Codes were created based on the problems from A3 and applied to each group by two researchers with Cohen’s kappa values of 0.74 and 0.71, respectively.

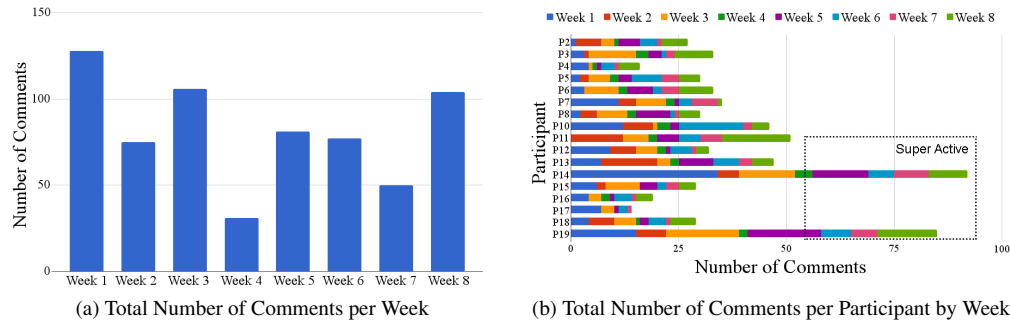


Figure 1. Participant Engagement

FINDINGS

In this section, we report results on participant engagement and activity preference in our study. We also provide an example of how a consistency check of data could be carried out via data triangulation across different activities.

Participant Engagement

Overall, participants were engaged and eager to collaborate during the entire study. Table 1 includes the total number of comments per activity, the number of participants who completed each activity as well as the average delay (in days) to complete each activity. All activities were completed by almost all participants (median = 17). The first four activities were completed by 17 participants and then the number fluctuated between 16 and 17 for the next four activities (two participants dropped out of the study after the first and third week due to time constraints); and near the end, 15 participants completed the last two activities. On average, participants generated a total of 82 ($s=31.3$) comments per week during the entire study (see Figure 1a) with each participant writing an average of five ($s=2.8$) comments weekly. Following MacLeod et al.'s [28] typification of participants based on their level of engagement: Super Active (SA), Active (A), Lurking (L), and Dropped Out (DO), we only found two SA participants (P14 and P19) with an average of 11 comments per week ($s=0.6$) (see Figure 1b). There were two DO participants (P1 and P9) and the rest of participants were considered Active as they produced an average of 3.7 ($s=1.5$) comments per week.

Activities that received the greatest number of comments from participants were those that required discussion or feedback (initial introductions (A1), photo elicitation (A4), discussion about solutions (A6), feedback about the mobile app video (A7), and personas (A9)). In contrast, activities that received the fewest comments were those that only involved online surveys (A2, A3, A8, A10). Participants in these activities were just required to type "done" in the comments area when the survey was submitted. It was interesting that the activity about technology discussion (A5) did not spur more comments from participants. Their filled out templates were uploaded to the group wall, but other participants did not provide much feedback about them. Overall, the metrics on engagement in this study surpassed those reported in previous studies using ARC [28, 38]. There are a number of different variables that may have contributed to this difference, including study length, number of participants, types of activities, and order of activi-

ties. There are very likely also differences in characteristics between the three types of participants such as level of experience using online support groups and need to self-disclose.

The average delay to complete an activity was two days ($s=1.32$). The activities that had the highest delay were those that required participants to generate or interact with materials (A4, A5, A7). Those activities that consisted of surveys were completed without much delay (see Figure 2). Although participants had an entire week to complete an activity, the majority of them warned the researchers about the expected delay via a comment or e-mail. There were three main types of reasons for why participants completed an activity past the weekly deadline. The first type involved day-to-day events taking place in their lives at that moment: "Heading out at moment but will complete today," or "Crazy work week will get it done before Sunday." The second type involved distressing problems that were not explicitly tied with health issues: "I'm having a disastrous week, some major personal problems going on right now. I will do my best to get it done for Sunday though." And the third type involved distressing situations related to health complications: "I had to see my Psychologist and Internist and treatment advocate and finish some blood work and STIs tests - which will take a lot of time. I'll get back to you on week #6 assignment." When a participant did not send any warning of a late submission, we followed the protocol to wait until Friday to post a reminder and then send a PM asking them politely if they had already completed the activity scheduled for that week. Sending an activity reminder via PM to participants was not very common - we sent a total of 15 reminders during the 8 weeks. After sending a PM, participants usually gave a reason for the delay and completed the activity within two days.

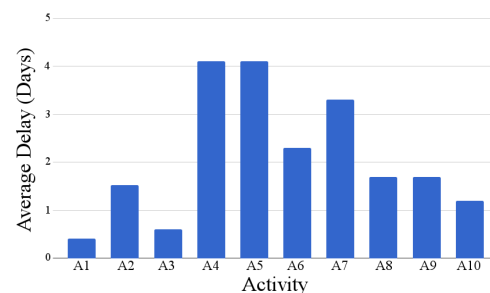


Figure 2. Delay in Completion of Activities

Activity Preferences

Overall, participants engaged with all activities and did not find them difficult. With a 4-point scale (1 = "Not at all", 4 = "Very much") in A10 measuring how much participants enjoyed (\bar{x}_i) each activity and how difficult (\bar{x}_d) participants thought each activity was to complete, the median for all activities was 4 and 1, respectively. Activities A1 (introductions) ($\bar{x}_i = 3.8$, $\bar{x}_d = 1.2$), A6 (co-design of solutions) ($\bar{x}_i = 3.8$, $\bar{x}_d = 1.2$), A7 (mobile app video) ($\bar{x}_i = 3.8$, $\bar{x}_d = 1.2$) and A9 (personas) ($\bar{x}_i = 3.9$, $\bar{x}_d = 1.2$) scored the highest in the enjoyment scale, and the lowest in the difficulty scale. Participants enjoyed activities that encouraged them to exchange ideas ("*[I] like discussing among people living with HIV because we can relate to each other*"-A6) and help each other ("*I felt my input could help and assure others*"-A9). Some participants also mentioned that they enjoyed activities that allowed them to learn from other people's experiences and ideas ("*It was a good exercise at looking at some people's issues and how needs and solutions can be very different*"-A6, A9) and relate to what they do in their lives ("*...because i do this daily with people that i counsel.*"-A9). Participants also described enjoying activities that allowed them to clarify what researchers in HCI are doing for PLH ("*it was interesting to see what you are working on*"-A7) and that clarified what a real outcome of a study like this would look like ("*This brought everything to light and made the study very real to me*"-A6).

Some participants reported having trouble with creative tasks (A3, A4, A5, A6) that required them to express/communicate ideas and interpret meaning in different ways ("*[I'm] not good at expressing myself in that way*"-A4, or "*I'm still having issues coming up with a good one*"-A4). They also had a hard time making decisions about ranking ("*[I] had a hard time deciding between a couple that were close in ranking. Changed a couple a few times before concluding*"-A3) or ordering similar things ("*[I] find it difficult to put the different things in order*"-A5).

Triangulation of Data

We started testing the analytical power of triangulation with data collected with ARC. Activities A2, A3, A4, and A9 all produced data on the challenges that participants faced. A4 and A5 both provided data on the strategies that participants used to manage their condition. In A6, A8, and A9 participants brought up solutions to problems. Including all of these activities in a single study allowed for richness and nuance that may not have been possible from conducting these activities individually. For triangulation regarding challenges, the sixteen problems in A3 were used as a code book for qualitative data analysis on responses in A2 as well as the text and images from A4. A9, along with the comments that participants left throughout the study were also used for interpretations of this data. Figure 3 shows the frequency that these themes came up in each activity. For A2 and A4 this is the number of unique participants who mentioned the given challenge. For A3 this is the number of participants who rated the challenge a three or higher in terms of relevance to them on a five point scale.

Side effects of medications was one of the most frequent problems that came up for all three activities, and therefore we

might confirm that this is a challenge/problem that is relevant to our population. Remembering appointments, on the other hand, was not uncommon to come up as an issue in A3, but was not mentioned once by participants in A2 or A4. One possible explanation for this is that it may not be something that the participants think about regularly, but when prompted specifically they perceived that it had an impact on their daily lives. It is also possible that the prompting in A3 led participants to overvalue the relevance of certain issues. A final example of the value of triangulation is stigma. On the graph stigma appears about middle of the road for all three activities, however a disproportionate number of comments in the study refer to stigma. "*After 10 years of service, I was fired due to having HIV. I had an attorney that wouldn't even shake my hand!*" (A9) is one of many examples. This discrepancy would certainly warrant further analysis of all the data. Yet, it could have gone undetected had the researchers relied on the data collected from one single activity.

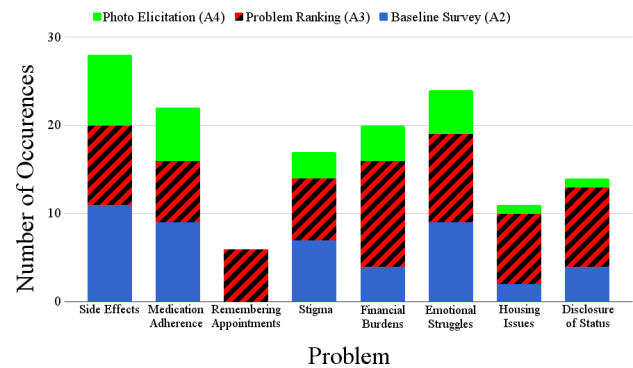


Figure 3. Triangulation

DISCUSSION

Determining the Success of the ARC Method for PLH

Overall, ARC proved successful for studying PLH. It facilitated recruitment and data collection. It registered a high response rate and little delay in completion of activities. It also sustained participant engagement throughout the study. This is evidenced by the high level of participation, retention of participants and the frequency of responses between participants' comments, as well as the generation of vivid discussions about topics outside of the activities. The ARC method immediately benefited PLH by creating a support space where participants could socialize and vent about their problems and seek support out of the context of a particular activity: "*Dear Chicken Soup folks, [h]ow do I tell my little sister that I now have HIV?*" as well as celebrate good news: "*After just 3 months on meds I am already undetectable!*" In fact, some participants asked us not to close the group after the study with messages like, "*Chicken soup must live on!*," or "*I found myself looking forward to the study week after week and feel like we built a family of support among the participants and study coordinators.*" Participants have kept using the group for support exchange even after the study ended. In this way, ARC allowed us to give something back to participants right away, which also helps address the issue of researchers or practitioners not always being able to directly benefit - or do good

L#	Lesson from MacLeod et al. [27] (1 - 11) and Prabhakar et al. [38] (12 - 17) and our work with PLH (18–22)	F	C
1	Building a strong rapport with members of groups used for recruiting before, during, and after the study.	Y	Y
2	Investigating alternative methods of consenting electronically. <u>Note</u> : in our study, all participants sent scans of their consent forms via e-mail after discussing about it with us via Facebook chat.	Y	Y
3	Encouraging participants to provide feedback and build on each other's creative contributions.	Y	Y
4	Encouraging participants to post directly to the group, even submissions still in progress. Seeing other participant's contributions can give inspiration to people. <u>Note</u> : our participants had the option to send their submissions via e-mail.	Partial	Y
5	Exercising caution when planning the study and selecting activities; conducting research asynchronously and online means researchers do not have the same chance to assess how a method is going as it is happening.	Y	Y
6	Taking time to understand potential participant's Facebook behavior to inform decisions about when and how often to post and the overall study duration. <u>Note</u> : we did not have access to all the participant's Facebook profiles. Duration of study and posting were dependent on number of activities, type of activity, and level of engagement.	N	N/A
7	Researchers should be prepared to adopt multiple approaches to ensure activities are seen by participants. <u>Note</u> : We pinned activities to the top of the timeline and asked participants to post comments regarding activity completion.	Y	Y
8	Discouraging activities that build on one another where sequence is important.	Y	Y
9	Providing opportunities for socialization between participants that are separate from formal study activities.	Y	Y
10	Giving careful consideration to the makeup of the group when recruiting, targeting either a highly homogeneous population or targeting several homogeneous groups. <u>Note</u> : Although participants were recruited from similar online support groups, they are multicultural.	Partial	Partial
11	Being mindful of the number of input mechanisms. Each additional input mechanism introduces additional overhead.	Y	Y
12	Being mindful of the number of steps needed to complete an activity when selecting activities for the ARC method.	Y	Y
13	Consideration of participant's technology preferences, while developing activities. <u>Note</u> : During recruitment, potential participants were asked to have a digital camera and access to a computer/smartphone with Internet.	N	N/A
14	Find balance between the ease of use and the usefulness of the data collection activities while engaging participants.	Y	Y
15	Adapt commonly used data capturing mechanisms used in FtF focus groups to use in online, asynchronous research methods.	Y	Y
16	Careful consideration of activity selection. When possible, we must provide meaningful and helpful interventions.	Y	Y
17	Researchers should be proactive about using strategies to make data collection and organization easier.	Y	Y
18	Make support group administrators understand, approve, and be part of the study so that they can vouch for the intention, safety, and potential benefits of the study.	New	N/A
19	Post activities and reminders on the same days every week.	New	N/A
20	Researchers should use their personal accounts when studying stigmatized populations with the ARC method on a social media platform like Facebook. Protect participants' identities by warning them about confidentiality risks and setting boundaries in the sharing of information.	New	N/A
21	Learn about the type of language to use when communicating with the stigmatized before using ARC.	New	N/A
22	Be prepared to clarify miscommunication and answer questions as soon as possible to avoid unnecessary distractions and misunderstandings among participants.	New	N/A

Table 2. Confirmation of lessons from previous ARC studies. F=Lesson followed. C=Lesson confirmed.

to - the groups being studied, which is a topic that has been brought to our attention by Pal [35, 36] with his CHI4Good or Good4CHI discussion on how research with marginalized populations has failed to 'do good' in direct and meaningful ways, but has mainly benefited the researchers' and designers' agendas. In the following paragraphs, we reflect on the use of ARC for studying PLH and introduce new lessons that we learned in the process.

Recruitment

During our initial ethnographic exploration, information regarding PLH was mostly collected from counselors rather than from PLH themselves. FtF data collection and recruitment of PLH proved to be difficult and time consuming task due to time, transportation and privacy constraints. In contrast, the ARC method allowed researchers to recruit participants more easily in a matter of days. However, participants did not comment or react to the recruitment ad until an administrator vouched for the researchers' identities and intentions. Thus, it was crucial to have approval and support from group administrators. Group administrators clarifying aspects of the study made members of the group feel comfortable about contacting researchers and asking further questions about the study such as confidentiality issues and about what was expected of them

during the study. This, in turn, helped build rapport and trust among participants and researchers.

Lesson #18¹: We suggest making support group administrators understand, approve, and be part of the study so that they can vouch for the intention, safety, and potential benefits of the study.

Data Collection

The ARC method allowed us to make use of data collection methods with established histories in HCI research, such as: surveys, photo elicitation, co-design, focus groups, and personas. As a result, we were able to collect vast quantities of various kinds of textual and visual data for purposes of important triangulation of data in subsequent analysis. Participants engaged in vivid discussion around the design and feature improvement for HIV management technology: "... [this] feature would be REALLY helpful to some people who aren't willing to disclose their information..." (A7), and proposed design ideas by uploading images that they created to the comments area of an activity post: "I did it on my computer instead for a

¹We continue with the numbering of lessons from MacLeod et al.'s [27] and Prabhakar et al.'s [38] studies. Refer to Table 2 for a list of lessons from these studies.

clearer image. Maybe something like this? With the rectangles representing different facets of the app?" (A6). They also engaged in interesting discussions filled with honest feedback about existing technology: "I like the bar graph for taking meds.," or "Don't think it brings anything new to the table..." (A7). Additionally, the activity-based study structure allowed participants to understand expectations and to integrate it into their daily schedules. They knew that activity prompts were going to be posted with the same format at the beginning of the week and submissions were expected to be completed by Sunday. However, on a few occasions, the deployment of activities caused trouble for participants when trying to find an activity: "Where is link to app we are to view please? Saw it yesterday/ early this a.m., but don't see it now." In fact, a few participants mentioned that "Sometimes activities got lost in posts in the page. It was not till last week's when I saw it as pinned post." We had to help participants locate the prompt of the activity, which was always pinned at the top of the group wall, by writing comments or sending them a PM. In addition, we found that sending a reminder at the end of the week and a PM over the weekend motivated participants to complete activities on time.

Lesson #19: We suggest posting activities and reminders on the same days every week. This structured design allows participants to better organize their schedules around the study.

Moderating the Study

- **Identity of researchers and participants' confidentiality.** From our initial approach to PLH and counselors, we learned that it was important for the researchers to use their real/personal Facebook accounts when interacting with participants. Using their real accounts when joining the Chicken Soup group built a more authentic, trusting relationship with participants. Using special Facebook accounts set up for research purposes could have sent the wrong message. It may have communicated that researchers were uninterested in friending participants due to their condition or that researchers were unwilling to disclose personal information while at the same time expecting participants to disclose theirs. Participants were not required to send a friend request to any of the researchers in order to be part of the study, and they all acknowledged and gave consent to the confidentiality risks of participating in a study of this nature on Facebook. Participants did send friend requests to one another, but privacy mattered to them. Some preferred to keep the research study separate from their personal lives: "Hey everyone your all awesome people but could you refrain from sending me message requests and friend request. I only add and speak to people I personally know. Thank you." Others were interested in establishing the boundaries and identity of the group "Are all the members of Chicken Soup group people living with HIV? Including [name of researcher] and [name of researcher]?...Just confirming the circle." Only a few sent friend requests to the researchers voluntarily. We added them to a different list in order to control the extent to which participants could interact with us on Facebook. We could imagine scenarios in which a researcher posts something that could go against participants principles or values, which might affect their perceptions

of the study in general. Moreover, unrestricted interaction could also put their privacy at risk [54]. In addition, at the beginning of the study, a set of group rules were listed in a post to warn participants against inviting other people to the group or sharing information generated in the group outside of the study.

Lesson #20: We suggest researchers use their personal accounts when studying stigmatized populations with the ARC method on a social media platform like Facebook. At the same time, it is also important to take steps to protect participants' identities by warning them about confidentiality risks and setting boundaries in the sharing of information.

- **Language and communication.** We learned from counselors that language in e-mails, PMs, posts or comments can impact participants' trust and engagement with the group: "our language can contribute to stigma... Try[ing] not to use the word infected, and try[ing] to remove those words from our language is super helpful." Posting an insensitive comment or erroneous information may signal that the researchers lack knowledge about the condition and/or do not really care about the well being of those living with the stigmatized condition, which would be detrimental for a study.

Lesson #21: We suggest researchers learn more about the type of language to use when communicating with the stigmatized before using ARC in their studies.

- **Multicultural interaction.** Working with participants from different nationalities and cultural backgrounds can lead to miscommunication. For example, after a participant posted "[I] I have lost my beloved grandma whom have used her photo in week3, I need your prayers and kind support at this trying moment in life," participants replied with comments of condolence right away. But then a day later, the same participant told the group that he did not need messages of condolence anymore because he had been given inaccurate information: "Ok the person who gave the [i/n]fo gave [it] wrong she [is] a co-wife to my granny." Participants got confused. Some participants kept writing messages of condolences and asking questions. Researchers had to intervene in order to clarify the situation for everybody and avoid misunderstandings among participants. In addition, the interactions between participants and researchers differed across participants from different cultures. For instance, participants from the US rarely contacted researchers using PMs whereas it was a much more common thing to do for participants of other nationalities. Three researchers were constantly monitoring and moderating the group so to be able to encourage participants to build on each other's contributions. We also answered questions quickly letting participants know that we were ready to help them as soon as possible.

Lesson #22: Miscommunication may be unavoidable when people from different countries participate together. Researchers should be prepared to clarify miscommunication and answer questions as soon as possible to avoid unnecessary distractions and misunderstandings among participants.

		Remote ← - - - - -	- - - - - Collocated
Asynchronous	Community	Online communities or forums	Installations, in situ deployments
	Individual	Surveys, remote deployments, photo elicitation, message exchanges, diary study, etc.	Installations, in situ deployments
Synchronous	Community	Remote focus groups, netnography, group chats	In-person focus groups, ethnography, observations
	Individual	Remote interviews	In-person interviews

Figure 4. Examples of Research Methods in HCI. ARC requires, at minimum, an asynchronous, remote, community (solid red outline). ARC may also draw from synchronous or individual methods (dashed red outline).

Towards a Formal Definition of ARC

Researchers in the HCI community sometimes describe themselves (in their publications) as having been “inspired by” a particular method or having borrowed parts of it without strictly adhering to the complete set of norms or rules of the method. In some cases, this is a way to signal to the audience that the authors should not be held accountable to those norms and rules or that a set of rules do not exist. This distancing from rules has the benefit of allowing for adaptations or tailoring of methods to new research questions, populations, or practical constraints. Thus, researchers can iterate on our approaches towards conducting better research overall. The evolving interpretation of rules also allows for conversations to take place around different applications or interpretations of methods; it may be that not every method has one single, agreed upon definition. The downfall here is that it is challenging to evaluate the validity or rigor of these adaptations; if the norms or rules of the original method do not apply, which norms or rules do? This flexibility can just as easily become an excuse if the method is poorly understood or executed.

From our work here with PLH, we have replicated the ARC method, building on the reflections and lessons of MacLeod et al. [27, 28] and Prabhakar et al. [38]. In Table 2, we report whether we followed and confirmed each of the lessons from the two previous ARC studies. Accordingly, all the lessons that were followed were confirmed in our study. Furthermore, in this paper we add our own reflections and contribute with five new lessons (#18 - #22) that derive from our experience conducting this study with PLH. Thus, with every iteration of the method we, as a community, gain additional insight into best practices or strategies for effective application of this method, which could be instructive to future researchers.

Part of what makes ARC an appealing option for researchers conducting studies with hard-to-reach populations is its flexibility. ARC was proposed by MacLeod et al. [28] as being suitable for groups that have “limited travel access”, when “social, political, or economic climates inhibit a potential participant’s ability to assemble”, when “researchers may not have access to enough participants locally” or when “participants may not feel comfortable in a physical study setting.” These kinds of potentially sensitive situations require great

care in ensuring activities are appropriate for participants and the study is well designed. Flexibility in applying ARC in different ways can help support this, and not every lesson from our work and from the previous ARC studies [28, 38] will be relevant to every population. And yet, there is still value in considering what *actually* is ARC? Which parts of this method are flexible? At what point does it become a different method entirely? We begin most simply by considering the three dimensions in the method’s title (asynchronous, remote, and communities) and their antonyms (synchronous, collocated, individual). Figure 4 provides examples of methods fitting the intersection of these categories. We constrain ourselves to only methods where a researcher is actively involved throughout the study and data is collected in response to some prompt or task given by the researcher. We exclude methods that analyze existing data (e.g., analyzing pre-existing social media posts). Realistically, many HCI research studies will move between these boundaries or use multiple methods (e.g., having participants take photos as an asynchronous, remote, individual activity, but meeting with them in a collocated setting for a follow up interview).

From this framework we argue that, at a minimum, “the ARC method” requires an asynchronous remote community, but also has the potential to include elements of synchronous and/or individual research (outlined in red in Figure 4). For example, all three ARC studies made use of surveys as part of the study and participants completed these independently. Prabhakar et al. [38] also introduced a synchronous component when they conducted remote interviews with the participants in their ARC study. Although we are not aware of an ARC study that has made use of any synchronous, remote, community methods, it is not difficult to imagine a case where a researcher might include a synchronous, group-based activity. This framework contributes to a definition of ARC as a method or approach to conducting research. However, it does not prescribe:

- *Choice of platform.* ARC has historically been conducted inside of secret Facebook groups. Researchers might decide on a different platform, possibly for reasons of data ownership, privacy, or anonymity. There may also be features of these other platforms that appeal to researchers (perhaps

features that simplify the analysis or allow for different kinds of activities to be included).

- *Activities and their frequency.* Researchers might choose different kinds of activities depending on which stage of the design process they are in, their population's access to different resources, the research questions they have in mind, etc. They may choose to incorporate elements of individual and/or of synchronous research.
- *Study length and sample size.* These parameters depend on the goals of the study, activity type, and the population being studied. Ultimately, researchers might want to collect enough data in order to reach study goals and choose a sample that is representative of the population.
- *Participant groupings and group size.* MacLeod et al. [28] encouraged to set groups up somewhat homogeneously, although they describe in a later publication [26] the value participants got from participating in a heterogeneous group. Prabhakar et al. [38] facilitated three separate ARC groups simultaneously, for different kinds of participants. Our study here (with PLH) was more international than the other two studies, but was still conducted entirely in English; future ARC studies might decide to make use of the automatic translation available on platforms like Facebook to further emphasize this type of diversity.

Of course, with the flexibility to make these choices comes a responsibility to do so in a way that is suitable for the participants or study population. A more public facing group might be appropriate for groups who strongly seek advocacy or transparency, but would not have been appropriate for our work with a stigmatized group. Using smart phones to take pictures to share with the group can lead to rich data within the group, but might not work well for people without access to that technology. Heterogeneous groups can lead to richer insights and help participants get to know someone they might not meet otherwise, but they could also lead to disagreements over differences. ***We strongly recommend that researchers spend time getting to know their study population before attempting an ARC study.*** This might take the form of a pre-study using more traditional methods like interviews, observations. It might also involve working with a community partner or someone who is familiar with the study population. The bottom line is that researchers should be familiar with the population so they can make appropriate decisions about the elements on which ARC is flexible.

Making Space to Reflect on Methods at CHI

Research methods seems to be a relevant topic of study to HCI researchers [3, 9, 15, 21, 22] and yet there seem to be relatively few papers published at CHI examining research methods directly or reflect in substantive ways on methods as tools for studying other phenomena. This dearth might be the result of a lack of page space or a perceived lack of value in reflecting explicitly on methods. Is there value in devoting more page space to a substantive discussion of methods? Are current HCI research methods somehow inadequate in supporting the search for answers to interesting and important research questions? We have devoted this paper to discussing the ARC

method and its value for studying PLH. Our ambition is to show the value of engaging in a more substantive examination of a research method. We believe our examination reveals opportunities to revise or expand on lessons learned in [27]. It reveals the fluidity with which the ARC method can be adapted to study different user groups. It can be used to study populations with rare diseases [28], pregnant women and new mothers [38], and people living with HIV. This is an important affirmation of the potential problem-independence of the method, and more broadly, it is an affirmation that HCI researchers need not reinvent the methodological wheel when they face new research problems. Research methods are an important part of HCI design work. We suggest, re-purposing an argument from Carroll and Rosson [5], that if we make our use of research methods more “*explicit[, then] we will better be able to manage and learn*” from each others’ experiences and build a richer understanding of method development and use, which is important for conducting more effective, web-based group inquiry.

LIMITATIONS AND FUTURE WORK

All participants in our study had access to technology to complete activities that required taking photos, uploading images, or interacting with a prototype. Future iterations of this study should extend this research by exploring how to apply the ARC method with participants who have less access to such technology. Our findings also warrant research on the design and development of interactive activities that could capture data in more efficient and engaging ways.

CONCLUSION

We started this paper by exploring how computer-mediated interventions have helped researchers study PLH in the social sciences. To contribute to the conversation on how HCI researchers could conduct studies with stigmatized populations, we analyzed the suitability of the ARC method for research with PLH in an online platform. We also offered a glimpse of the analytic power that ARC offers via data triangulation in order to validate findings. To summarize, the main contributions of our paper are: (1) the provision of five new lessons on how to apply the ARC method in HCI research via the application of the method to a highly stigmatized and isolated population, (2) the confirmation of lessons learned from previous ARC research, (3) the introduction of a formal definition of the ARC method, a list of minimum requirements for its application, and ways to determine its success, and (4) a contribution to the ongoing CHI4Good or Good4CHI discussion. To conclude, we argue that the ARC method is indeed suitable for studying stigmatized individuals under an HCI lens. We hope that this method not only helps the CHI community conduct studies with hard-to-reach – or atypical – populations, but that it also helps balance out the benefits derived from such endeavors between researchers and participants.

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