

## **The Suitability of the Asynchronous Remote Communities (ARC) Method for Studying Stigmatized Populations**

**Juan F. Maestre** | [jmaestre@indiana.edu](mailto:jmaestre@indiana.edu) | Indiana University Bloomington

This extended abstract is based on a study conducted with people living with HIV (PLH) that focuses on adapting Human-computer Interaction (HCI) research methods to online settings.

Researchers have been conducting studies with PLH and their caregivers using methods for recruitment and data collection with the aid of both FtF (e.g., Derlega et al., 2003) and web-based instrumentation (e.g., Coursaris and Liu, 2009.) 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. As for data collection, traditional instruments have been used such as paper-based questionnaires (e.g., Derlega et al., 2003,) FtF interviews (e.g., Peterson, 2010) and FtF focus groups (e.g., Lester et al., 2010) as well as newer methods like web-based surveys (e.g., Carballo-Diéguez et al., 2006), automated data retrieval mechanisms (e.g., Coursaris and Liu, 2009;) and, in some cases, interviews conducted in online chat rooms (e.g., Rhodes et al., 2010.)

As a result of their work with both FtF and online instrumentation, researchers from the social fields have already pointed out the challenges of using FtF strategies for recruitment of PLH and data collection due to HIV-related stigma (Rhodes et al., 2003). Understandably, PLH may be cautious about disclosing their HIV status to others, as a breach of confidentiality may have serious implications in their personal and professional lives (e.g., affecting health insurance or getting fired from a job). Nonetheless, people living with a highly stigmatized condition such as HIV are 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 (Berger

et al., 2005; Rhodes et al., 2003). Consequently, researchers in the social sciences have turned to online platforms to reach, recruit, and gather data from this population.

In contrast, HCI researchers have relied mainly on FtF traditional methods for recruitment and data collection involving PLH such as focus groups (e.g., Ramanathan et al., 2013), questionnaires or interviews (e.g. Joshi et al., 2014), and participatory design workshops (e.g., Marcu et al., 2016.) 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. In order to address these limitations, our work builds on MacLeod et al.’s work by exploring the use of their Asynchronous Remote Community (ARC) method in order to conduct research with PLH as a means of overcoming barriers of recruitment and data collection. MacLeod et al. (2016) introduced the ARC method as a study that involves a group of participants in an online environment completing periodic activities both individually and as a group. Previous 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., Sweet, 2001) 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 that allow for data triangulation.

We have recently completed a study using the ARC method with PLH<sup>1</sup>. The method was deployed in a secret Facebook group during a period of 8 weeks. A total of 19 people (11 men, 7

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<sup>1</sup> For more details, see Maestre et al. (2018).

women, and 1 queer) with different sexual orientations (8 heterosexual, 8 homosexual, and 3 bisexual) were recruited from online HIV support groups whose administrators allowed us to recruit from<sup>2</sup>. Based on self-reported data, there were 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, and there was one participant from each Mexico, Kenya, South Africa and the UK.

Table 1 includes a list and description of all the weekly activities that participants had to complete during the study. Overall, the ARC method successfully engaged people living with HIV during the entire duration of the study in terms of sustained participation (Figure 1) and little delay in completion of activities (Figure 2). Additionally, the data collected from the different activities allows validation of findings through triangulation and consistency check procedures (Figure 3).

Doing research with PLH entailed many ethical considerations that had to be addressed in all stages of our study from IRB documentation preparation and recruitment to data collection, data analysis and storage. Participants gave their consent to be part of our study in order to help us understand better their needs and challenges. We had to make sure that their confidentiality was protected at all times to the best of our abilities, and that participants were aware of the possible risks of breach of confidentiality that were outside of our control like participants sharing information from the public activities with others, etc. We addressed these concerns by using clear consent documentation, a group code of conduct, as well as by restricting our interactions with the participants on social media outside of the scope of the study, and by allowing participants to share more sensitive data through anonymous surveys or via direct email

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<sup>2</sup> Four different Facebook HIV support groups allowed us to post a recruitment ad.

to the researcher. Accordingly, working with people who live with a stigmatized condition carried ethical concerns that had to be evaluated with the participants taking into account the direct benefits from the study and the risks associated with breach of confidentiality.

After this experience, we learned lessons related to recruitment, data collection, language and communication as well as multicultural interactions that could be of use to other researchers working with people who live with a highly stigmatized condition. Moreover, our study contributes to an ongoing discussion on how research with marginalized populations has failed to “do good” in direct and meaningful ways, but has mainly benefited the researchers’ academic agendas (Pal, 2017). Accordingly, we argue that through the application of the ARC method we could directly and immediately benefit our study participants. In fact, they asked us not to close the secret group as they have been actively using it for support exchange since the study ended. We are currently replicating the study with PLH recruited in person in a rural area in order to assess the generalizability of findings.

In conclusion, we argue that the ARC method could be indeed suitable for studying stigmatized individuals under an HCI lens while at the same time helping researchers address ethical concerns. Ultimately, we hope that this methodology not only helps researchers conduct studies with hard-to-reach populations, but that it also helps balance out the benefits derived from such endeavors between researchers and participants.



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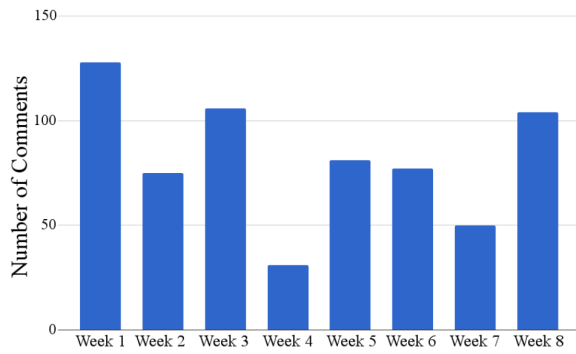
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## Appendix (Tables & Figures)

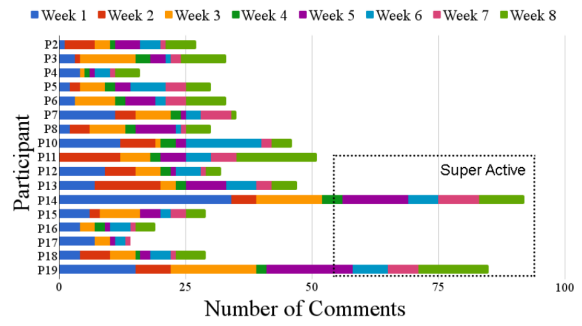
W	Activity	T	Data Type	C	P (%)	D ( $\sigma$ )
1	<b>A1: Introductions.</b> Participants introduced themselves to the group via separate posts.	Group	text/photos	94	17 (100%)	0.4 (1.5)
1	<b>A2: Baseline survey.</b> The items of the survey captured demographic information and needs assessment.	Survey	text	31	17 (100%)	1.5 (2)
2	<b>A3: Ranking of problems.</b> Participants were asked to rank a list of problems and challenges that PLH face on a daily basis.	Survey	Text	22	17 (100%)	0.6 (1.2)
3	<b>A4: Photo elicitation.</b> Participants were asked to upload to the group (or send via e-mail to the researchers) a minimum of three photographs that would show a positive and a negative aspect of living with HIV as well as one photograph that showed a thing or device that helped them manage HIV. Participants were asked to discuss and give feedback to each other's photos.	Group/e-mail	Photo	92	17 (100%)	4.1 (3.2)
4	<b>A5: Technology use.</b> Participants were asked to download a template which contained a set of concentric circles. Then, they were instructed to a list of devices or technology they use in order to manage HIV. After completing the list, they had to place each item of the list on the circles. The closer the items were located to the center of all the circles, the more helpful the item was for HIV management. Participants were asked to discuss and give feedback to each other's templates.	Group/e-mail	Scan/Photo	31	16 (94%)	4.1 (2.6)
5	<b>A6: Co-design of solutions.</b> 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. They were also asked to discuss, expand and give feedback to each other's submissions.	Group	Text / Photo	68	17 (100%)	2.3 (2.4)
6	<b>A7: Mobile application video &amp; prototype.</b> Participants were asked to watch a video and interact with TreatYoSelf which is a mobile application prototype developed by [31]. Participants were asked to discuss and give feedback about the video and prototype.	Group	Text	77	16 (94%)	3.3 (3.5)
7	<b>A8: Mobile application survey.</b> 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	<b>A9: Personas.</b> Participants were asked to provide comments about three personas which were presented to the group in separate posts. A persona description included a portrait photograph and a one-paragraph description of challenges and coping strategies that persona uses.	Group	Text	55	15 (88%)	1.7 (1.9)
8	<b>A10: Debrief survey.</b> 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.

Source: Maestre et al. (2018)



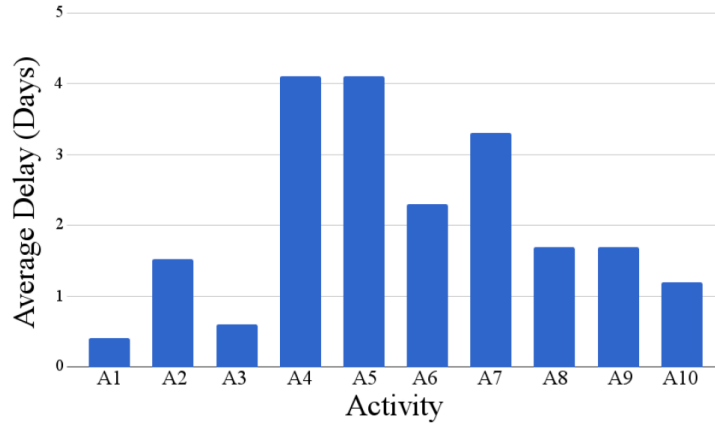
(a) Total Number of Comments per Week



(b) Total Number of Comments per Participant by Week

**Figure 1. Participant Engagement**

Source: Maestre et al. (2018)



**Figure 2. Delay in Completion of Activities**

Source: Maestre et al. (2018)