The Suitability of the ARC Method for Studying Stigmatized Populations

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ABSTRACT
The purpose of our research is to adapt human-computer interaction (HCI) research methods in an online support group in order to address limitations of recruitment and data collection in face-to-face (FtF) and online studies involving people living with a stigmatized condition (e.g., cancer, depression, obesity, HIV, etc.) The Asynchronous Remote Community (ARC) method was created for the purpose of studying people with rare diseases (MacLeod et al., 2016) and since then, it has also been used to study pregnant women and new mothers as well (Prabhakar et al., 2017). The purpose of this research is to determine the suitability of the ARC method to conduct HCI research with people who are not easy to recruit and interact with in FtF settings. In this sense, we are in the process of conducting an empirical study using the ARC method with people living with HIV. At the moment of writing of this document, the study is still ongoing and we are in the process of collecting and tabulating data. We look forward to discussing with other researchers interested in the topic on how to improve the application and use of this method as well as about the best strategies to analyze the collected data from both quantitative and qualitative approaches.

Author Keywords
HCI research and design methods, stigmatized communities, social support.

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

BACKGROUND/CONTEXT: THE ARC METHOD
The ARC method was developed by MacLeod et al., (2016) to study people living with rare diseases who are geographically distributed. Essentially, this method consists of recruiting participants from existing online communities and inviting them to a private virtual space so that they can interact with others who share the same situation or condition. In addition, participants have to complete weekly activities - both individually and as a group – which generate rich data for purposes of research. These activities are varied and are tailored to the population being studied. In the case of the study with people living with a rare disease, participants were recruited from existing Facebook support groups and were added to a separate secret Facebook group where the study was conducted. The activities that they had to complete included adaptions of traditional HCI research methods such as personas, diaries, photo elicitation and online surveys. As a result of this study, a number of lessons were learned regarding activity deployment as well as recruitment and engagement of participants.

Similarly, Prabhakar et al. (2017) used the ARC method to collect data from pregnant women and new mothers due to difficulties of meeting with them FtF due to time and mobility constraints. The activities deployed in this study were similar of those used in MacLeod et al. (2016), but were further improved and expanded taking into account the lessons and recommendation given by the rare disease study. As a result, new recommendations were given in terms of new activities (e.g., polls to gauge participant satisfaction with the study) and triangulation of data in order to confirm findings.

PRIOR WORK IN HIV RESEARCH AND RESEARCH GAP (TO BE CLOSED WITH THE ARC METHOD)
Researchers have been analysing social support exchange among people living with HIV and their caregivers in both offline (e.g., Peterson, 2010; Derlega et al., 2003) and online (e.g., Mo and Coulson, 2013; Coursaris and Liu, 2009; Reeves, 2000) settings. In both, social support has been found to have beneficial effects on physical and psychological health as it has been linked to decreased depression and positive adjustment to the chronic condition. In addition, HCI researchers have started to design and develop interactive applications for people living with HIV (e.g., Marcu et al., 2016). Yet, most of these studies have employed traditional data collection instruments such as surveys (e.g., Mo and Coulson, 2010; Derlega et al., 2003), interviews (e.g., Peterson, 2010), FtF focus groups (e.g., Marcu el al., 2016), and automated data collection mechanisms (e.g., Coursaris and Liu, 2009). Data collected with these instruments have been analysed with quantitative and qualitative approaches in order to understand better the needs and problems of this population so that researchers and stakeholders can propose and design ways to improve quality of life and overall well-being of those living with HIV.

Nonetheless, many of these studies point out the limitations that these instruments have in experimental

studies. For instance, recruitment of participants in FtF studies has proven to be difficult due to the highly stigmatized nature of HIV (Eveslage, 2015). Understandably, someone living with HIV has to be very cautious about revealing their identity and HIV status to strangers (even if they are researchers who have an IRB-approved protocol) as a breach of confidentiality may have serious and even deleterious implications in their personal and professional lives. Moreover, it may also be the case that participants who are willing to take part in FtF studies may be individuals who are already coping fairly well with their condition and who may not experience or feel the effects of stigma that much.

Consequently, the general population of people living with a stigmatized condition are more likely to look for support and health information in online platforms (e.g., Facebook support groups and online forums) due to the anonymity and relative privacy such environments provide (Berger et al., 2005). Indeed, recent research has relied on online platforms in order to reach, recruit and gather data from this type of populations. For example, Mo and Coulson (2013) recruited participants from HIV/AIDS-related online support groups and collected data with online surveys. Yet, while online surveys have been widely used in order to collect data from these populations, studies have not been able to successfully adapt other data gathering instruments more attuned with HCI research methods such as interviews, diaries, photo elicitation, focus groups, etc., to online settings in the study of people living with HIV. In particular, the adaption of focus groups is relevant and important, for the design and creation of new technologies can only be achieved via the active participation of patients and caregivers who inform and give shape to the final design outcome in a participatory fashion.

Thus, the goal of our study is to apply the ARC method in the study of people living with HIV. We expect that the ARC method will allow a better understanding of the needs of this population as well as aid in the co-design and co-creation of new technologies that would help people living with HIV and their caregivers manage the condition. Ultimately, our findings and lessons would allow HCI researchers to better study people who are living with stigmatized conditions. In this sense, our research question is:

R.Q.: Is the ARC method suitable to study people living with a stigmatized condition in the HCI field?

METHOD
The ARC method is being applied to understand better the needs and struggles of people living with HIV. The study was designed to be completed in eight weeks. Participants have to complete one activity per week. A total of 18 participants (12 men and six women) were recruited from support groups on Facebook for people living with HIV. An IRB-approved consent document was sent to all of them via either email or a private message. After participants sent a scan of the signed consent document, they were invited to a secret Facebook group and rules of conduct were posted and explained at first. Table 1 shows the list and a brief explanation of the weekly activities that participants have to complete.

Week 1 July 3 - 9	**Baseline survey and introductions.** Survey: demographic info, needs assessment, struggles, medical adherence, technology use, etc.
Week 2 July 10 - 16	**Problem ranking**. Participants rank a list of problems derived from the analysis of the baseline survey.
Week 3 July 17 - 23	**Photo elicitation.** Participants took at least three photos of things that are positive and negative regarding HIV management or living with HIV in general. They posted the photos (with explanations) in the group and participated in discussions with other participants.
Week 4 July 24 - 30	**Technology use.** Participants used a template with circles to determine the devices or things they use for HIV management. Those things located closer to the center of the nested circles were the most frequently used.
Week 5 July 31 – Aug 6	**Discussion about solutions.** Group discussion about things that they would like to have in order to manage HIV better.
Week 6 and 7 Aug 7 - 20	**Mobile application user testing.** A video of a mobile app to manage HIV would be presented to participants as well as a link to an interactive prototype. Participants would be asked to provide feedback and discuss about the design and features of the mobile application. In addition, participants would fill out a survey regarding the app.
Week 8 Aug 21 - 27	**Personas and debrief survey.** Participants would provide feedback about three personas that would be created by researchers based on the understanding of participants up to that point in the study. Participants would provide feedback. Finally, participants complete a debrief survey giving feedback about the study.

Table 1. Weekly Activities

CURRENT SITUATION
All but one participant have completed all activities thus far. At the moment of the writing of this document, they are working on the activity for week 7 (filling out the survey about the mobile application). The majority of them have shown a good level on engagement. We are in the process of preparing for study debrief as well as tabulating and preparing collected data for analysis. By the time the data analysis is completed, the goal is to compare the

quality of data with that obtained with traditional data collection approaches and also with participants recruited from offline settings such as clinics and centers for HIV management. We are in the process of recruiting participants from a clinic for patients living with HIV at the moment.

During the OzCHI 2017 consortium, we would like to present the richness of the collected data from our study and discuss methods of analysis and findings. In addition, we would like to discuss about the list of activities so that we can improve already existing activities as well as add new ones. In future research, we would like to create an interactive ARC toolkit based on the most effective activities that would allow participants to provide data to researchers in an even more engaging and interactive fashion. Other researchers could use this toolkit and adapt it to their research goals. Overall, we would like to discuss about the suitability of the ARC method for studying stigmatized communities in the HCI research field.

BIOS

PhD Student: Juan F. Maestre

Start date: September 2015. Expected date of completion: May 2019.

I am in the third year of the PhD program in Informatics (HCI design subtrack) at Indiana University Bloomington. My research revolves around human-computer interaction and computer-mediated social support in stigmatized communities. As a member of the LGBTQ+ community, I am particularly interested in how interactive technology can help those living with a stigmatized condition such as HIV. I will be presenting my research on video-based social support in OzCHI 2017.

PhD Supervisor: Patrick C. Shih

Dr. Patrick Shih is an Assistant Professor in the School of Informatics and Computing at Indiana University Bloomington. He directs the Societal Computing Lab (SoCo Lab). Dr. Shih's research focuses on the study of sociotechnical systems and mechanisms to enhance physical and mental wellbeing and to facilitate civic engagement and environmental stewardship. He utilizes mixed methods approaches to tackle research problems in online and geographic communities. Specifically, his current research focuses on leveraging the awareness of individual and community activities embedded in sensor technologies, smart devices, social media, and online forums in the design, prototyping, and deployment of novel personal informatics interfaces and civic engagement platforms.

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