Asynchronous Remote Communities (ARC) for Researching Distributed Populations

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ABSTRACT

Existing research methods are largely intended to be conducted co-located and synchronously with a study population, but this approach is not feasible with remote or distributed populations. We describe a needs assessment study we conducted on Facebook. We report on our use of adapted versions of commonly used HCI research methods and lessons learned from this approach.

CCS Concepts

•**Human-centered computing** → *Human computer interaction (HCI);*
•**Applied computing** → *Consumer health; Health informatics;*

Keywords

research methods; focus groups; remote populations; Facebook; rare diseases

1. INTRODUCTION

Human-centered research methods, including interviews, focus groups, diary/elicitation studies, design workshops, and role-playing are largely intended to be conducted co-located and synchronously with study populations to make significant contributions and impact the designs of future systems. Co-located studies are not always possible for group-based methods when participants have limited travel access or when social or political climates inhibit a potential participant's ability to assemble. In some cases, researchers may not have access to enough of them in their local areas. Finally, participants may not feel comfortable in a given setting, whether being physically present or allowing researchers into their environments.

We need ways of conducting group-based studies online to (1) ensure perspectives from underserved populations are considered when designing new systems, and (2) improve the scientific merit of our research (i.e. by expanding sample sizes to reach theoretical saturation or statistical power). This has been the motivation for previous discussion of remote interview techniques [14, 23], but there has been little discussion on remote group-based research techniques: What are the challenges of conducting group based research at a distance? How do the technologies we use to mediate this technique matter?

Here, we discuss the benefits and challenges of using Asynchronous Remote Communities (the ARC method) to conduct needs assessment studies, informed by our experience conducting a study similar to a web-based focus group, but with additional activities often used in design research (diaries, scenarios, personas, etc.). This study was conducted with people with rare diseases. Studying diseases that are extremely rare and impact a very small number of people makes local, in-person access to participants virtually impossible. We recruited nationwide and internationally to reach a reasonable number of participants and to ensure we covered a representative sample. Previous work [29] suggested leveraging platforms already in use by people with rare diseases, such as Facebook. Thus, we created a private Facebook group in which we conducted our study. Over the course of 22 weeks, participants completed a variety of activities to contribute to a deeper understanding of their needs and challenges.

In this paper [1], we reflect not on the results of the study, but rather on the methods we used to collect information about the needs of this distributed and remote population. Our main contributions are (1) a thorough description of our ARC method, and (2) a frank discussion of the lessons learned from this approach.

2. RELATED WORK

In this section, we discuss existing approaches to conducting HCI research remotely, and provide a brief overview of some commonly used research methods that have inspired or influenced our own methodological choices.

2.1 Remote HCI Research Methods

Some discussion has occurred on best practices for conducting research with participants remotely. In particular, researchers have proposed strategies for remotely conducting interviews, since these are deemed to be valuable but challenging methods [38]. Voida et al. [38] employed instant messaging as a tool for conducting interviews remotely, and note that attention expectations, timing, context, and persistence are all impacted as a result of the text-based method. Dimond et al. [14] extend this work to include email and phone as additional methods of qualitative data collection, noting that synchronous interviews (by phone) tended to produce much longer transcripts than semi-synchronous (instant message) or asynchronous (email) methods, but that they do not necessarily produce more unique ideas. Hillman et al. [23] provide an in depth

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[1] This paper is an expanded version of [28], and presents a more complete discussion of our experiences and lessons learned.

discussion of their approach to conducting interviews over video chat, and the challenges they faced.

Focus groups, although often used for needs assessments, have not seen the same level of discussion about their adaptability for remote populations. Researchers in social science and market research have suggested online ways of conducting these methods, either in a real-time virtual focus group with people participating simultaneously or asynchronously through online bulletin boards [35], or online communities [33]. These discussions do not necessarily take into account the specific goals of needs assessments in HCI, or the types of activities conducted in design research.

2.2 Overview of HCI Research Methods

Group-based methods add value by allowing researchers to obtain a range of viewpoints in less time. They may mitigate the shortcomings of one-on-one methods (i.e. if a participant is shy or a conversation is awkward) and can engender interaction between participants, enabling them to raise ideas they might not have thought of on their own [26]. Here we provide a brief overview of methods that informed or inspired our own methodological choices. Many of these are group-based methods, however we also leveraged some one-on-one methods and adapted them for a group setting.

Focus Groups have the benefit of reaching many perspectives at once and allowing participants to build on each other's contributions. However, participants may be unwilling to discuss sensitive topics in a group setting and talkative/opinionated participants may monopolize conversations [6]. These challenges are overcome by skillful facilitation and careful moderation; often a trained focus group moderator and an HCI researcher will work side by side [26].

Surveys are powerful tools for getting data from larger samples, and are often used to describe populations or explain behaviors [3]. They are often used alongside other HCI methods, as a way of validating findings across a larger population, confirming the results of qualitative analysis with the existing study population, or obtaining baseline information about an understudied population [16].

Diaries are useful when asking people to reflect on things that change over time, like mood or opinion [2]. They provide more accurate information, since people document things as they go, instead of having to remember past events [26]. There is room for a variety of media in diary studies, such as text, photos, audio, and video (e.g., [1, 5, 8, 12]) captured using a range of tools like paper, online forms, mobile phones, or cameras (e.g., [1, 12, 17, 32]).

Personas & Scenarios give designers a specific person or context to design for, without relying too much on an actual person's idea of how to address the problem. Cooper [13] argues that *"merely being the victim of a particular problem doesn't automatically bestow on one the power to see its solution."* These can be developed with participants to discover these use cases or personas [4], or can allow existing findings to be reframed in a way useful to design [39].

3. THE ARC METHOD

In this section, we provide an overview of our approach from recruitment and informed consent, to our procedure and analysis methods, and follow up after the study. [2]

3.1 Recruitment

We recruited adults with a rare disease from Facebook support groups, because Facebook is actively used by people with rare diseases as a way of connecting with each other (more than online platforms specifically for rare diseases [29]). We did not recruit from other sources because we did not want to create additional privacy risks by encouraging people to share their data on Facebook who were not already doing so.

3.2 Informed Consent

We used email or private messages to send our informed consent document to anyone expressing interest in the study. Potential participants were instructed to review the document, print it, sign it, scan/photograph the signature page, and return it to the research team by email or Facebook message. We required a physical signature, instead of a typed response or digital signature, to ensure participants took the informed consent process seriously, particularly in the absence of a physically present researcher to walk through the document. We also saw this task as a way of screening out participants who would be unable to complete activities during the study which required at least a moderate level of technological competency and access.

3.3 Participants

Participants ranged in age from 32–68 ($\mu = 48.9$, $\sigma = 14.4$). Eleven participants identified as female ($N = 13$). All participants were from the US, except one, who was from Australia. Two participants were employed full time, while the rest were either unemployed, receiving disability payments, or retired at the time of the study. They each received a $50 honorarium sent as a check by mail for their completion of the study, regardless of their level of activity.

3.4 Procedure

We created a private Facebook group for this study and invited people who had completed the informed consent process to join. We conducted the study over the course of 22 weeks, beginning with a 5 day period for introductions to help participants get to know each other and get comfortable in the group environment. We then introduced 11 activities (A1 – A11 in Table 1). Additionally, we sometimes posted research updates or other general discussion topics to the group and participants would independently start new conversation topics. At the request of one participant, we tagged activity posts (starting from A2) with [ACTIVITY] so that they could tell the difference between posts that were "official" research tasks and "less important" posts from researchers or other participants.

3.5 Analysis (of Research Method)

We used data from a variety of sources to evaluate the effectiveness of our approach. In particular, we were looking for useful and honest responses, participation over time by different people, and that the activities be comfortable for participants. We collected the comments and posts, as well as metadata such as timestamps, likes, and information about who had seen a comment or post. We also collected private Facebook messages and email threads we received from participants and survey responses from Typeform [3] (A11). For A9, participants could submit material by voicemail, text messages, or photo message - we collected these using Google Voice [4]. Finally, we summarized relevant discussions that took place in Facebook groups we had used for recruitment.

Two researchers reviewed all qualitative data and iterated on codes until converging on an inter-rater reliability (Cohen's Kappa) score of 0.78. We examined *conversational flow* (relevance of each comment to the main post or where two versions of similar conversations co-occurred in multiple threads), *comments about activities* (explicit

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[2] All of our study materials, including informed consent document, recruitment notice, activities, and follow up survey are available online, archived at http://www.webcitation.org/6fmeWoq7A.

[3] http://www.typeform.com/

[4] http://voice.google.com/

#	W	Name	D	G/R	T	M	Activity	C	N
A1	1	Diary	24h	recall	p's choice	text	Participants tracked interactions they had with other people about their disease. They documented who they talked to, how they communicated, what they discussed, and how they felt about it. (Inspired by [25])	10	9
A2	3	Circles	1x	generate	paper	draw	Participants used household objects to illustrate how comfortable they were sharing information with different people by drawing circles with themselves at the center and placing people at different distances from the center (Figure 1). (Inspired by [30, 22])	11	8
A3	3	Questions	1x	recall	group	text	Participants made a list of questions they wished their friends/family would ask them about their disease. (Inspired by [31])	31	9
A4	5	Problems	1x	recall	group	text	Participants ranked a list of problems, generated from posts and from [29], in order of how much each was a problem for them personally.	16	9
A5	8	Photo Elicitation	3 days	recall	mobile	photo	Participants were instructed to take photos representing two main themes from A4. They were asked to send them to the research team privately all at once. Then, we added them to the Facebook group and asked participants to comment. (Inspired by [27])	16	7
A6	8	Solutions	1x	generate	group	text	From the problems in A4, participants discussed strategies or solutions they had used to address these problems.	12	6
A7	15	Mad Lib	1x	generate	group	text	Participants were asked to create a mad lib, detailing the more humorous aspects of conversations they have surrounding their conditions. (Inspired by [4, 37])	17	6
A8	12	Movie Script	1x	generate	group	text	Participants wrote a script for a movie about their life, taking place between them and a friend or family member (keeping in mind the themes from A4 and A5). (Inspired by [11])	6	5
A9	15	Rant Line	3 days	recall	mobile	text, photo	We set up a "Rant Line", a Google Voice number that participants could call, text, or send photos to anytime they needed or wanted to rant about something. (Inspired by [20, 32])	25	4
A10	20	Personas	1x	generate	group	text	We created and posted two personas and asked participants to critique them and discuss how representative they were of their own lives. (Inspired by [13])	5	4
A11	21	Survey	1x	recall	website	text	Participants completed a survey to debrief their experiences in the study.	11	9

Table 1: Activities used in the study.
W=Week introduced in the study. D=Duration of activity. G/R=Whether the task involved recalling past experiences or generating new artifacts/opinions. T=Tool used to complete the activity. M=Media type. C=# of comments on this activity. P=# of unique participants that completed the activity.

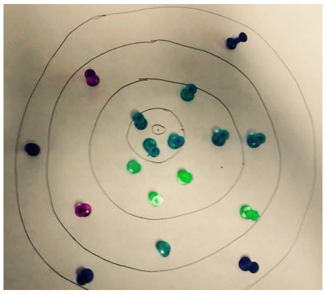

Figure 1: Sample of A2 (Circles Activity)

positive or negative feedback about an activity or comments contextualizing participation, such as apologizing for delayed responses or expressing confusion), and *life events influencing participation* (such as a relative passing away, being hospitalized, having a job interview). Throughout this paper, quotes used are copied exactly from text posted by participants and researchers and are reproduced exactly as written.

We used Tableau [5] to visualize the Facebook metadata and responses to the closed-ended survey questions, as well as simple analytics to compare what participants actually did and what they said they did during the study.

We conducted social network analysis to understand the strength of the relationships between participants and identify emerging subcommunities [21]. We counted interactions between participants (either a participant's comment in response to another's post/comment or a participant liking another's post/comment). These counts determined the weights of the edges connecting the participant nodes. We used Gephi [6] to calculate the modularity (used for detecting clusters or communities in networks) and to visualize these relationships.

3.6 Post-Study

At the end of the study, we left the Facebook group intact so participants could continue to connect with each other. We told them we would post updates about the research, but no further research would take place in the group. Finally, we informed participants that they could receive updates about the research by email if they opted to leave the group after the conclusion of the study. We continue to inform participants, as well as the Facebook groups we recruited from, about the status of our rare disease research.

We provided participants with a draft of this paper to ensure they were comfortable with the content. This mitigates misinterpreting or misrepresenting comments and ensures participants have final say over how their data is used. Rare disease communities present unique challenges from a privacy perspective because the diseases in question are extremely rare, thus it is easy to re-identify an individual using only a few pieces of demographic and contextual information. We provide only the minimum amount of information required to contextualize and understand our findings; we refer to participants with gender neutral pronouns and omit participant ID's (P1, P2, etc.) from quotes because of the privacy risk this presents in a rare disease population. We acknowledge that this may not be necessary in most other populations.

4. LIMITATIONS

Our lessons are influenced by our decision to conduct this study on Facebook. In a few activities, participants seemed to miss notifications or were not aware we had posted an activity. The mechanics of Facebook's algorithms are unclear, so we are not confident in our assessment of why this happens or how to prevent it. Additionally, "seen by" tracks whether someone has acknowledged a notification but not necessarily that they have actually read the post. We use counts of how many participants have "seen" a notification as an extra measure but acknowledge that this cannot be fully relied upon to determine whether someone has actually read the post.

Additionally, our lessons are derived from our work with a population with some unique characteristics. The topics discussed in

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[5] http://www.tableau.com/

[6] http://gephi.github.io/

the group were of critical importance to participants, and there are greater risks involved in studying this population than one might find in other contexts. We believe many of these lessons can be extended and applied in these other contexts as well.

5. STUDY EXPERIENCE

Here we report on participant engagement in the group and how they interacted with each other and researchers. Specifically, we discuss lessons learned through our recruitment and informed consent process, the types of activities we used and participant responses to them, engagement and activity levels throughout the study, and our own reflections on conducting this study. We conclude with a discussion of the researchers' perspectives on the experience.

5.1 Pre-Study Interactions

5.1.1 Recruitment

Most groups from which we recruited were groups we had been part of for over a year. We initially joined these groups to recruit for past research and found members of these communities to be enthusiastic about our presence and eager to be involved in research. The researcher was known to group members and had built rapport by sharing results of previous research and contributing to the community in other ways (e.g., by helping to access academic articles of interest located behind paywalls). In these groups, questions about the study were easily satisfied. If a group member had a question about the study a different group member (usually a participant from a previous study) would jump to the researcher's defense, vouching for the researcher's legitimacy and expressing gratitude for ensuring their condition was represented in research projects.

Although we followed recommended practices for recruiting from online communities [7], we encountered a few individuals with concerns, asking questions about the goals of the research. In groups where the researcher was new, there was a lot of discussion about credentials, IRB approval, study procedures, and benefits/risks of participation. Some group members were disappointed to learn that the research would not lead to outcomes directly used by physicians to improve the treatment of their health condition; they viewed our presence in the group as an attempt to profit without providing anything in return. HCI research can be viewed by group members as less of a priority than medical research and as taking too long to produce meaningful and directly applicable results.

> ***Lesson #1:*** We recommend taking the time to build a strong rapport with members of groups used for recruiting before, during, and after the study, following not only best practices for recruiting [7], but also good practices for maintaining those relationships at the conclusion of the study [36].

5.1.2 Informed Consent

We distributed 53 consent documents and 14 were returned. Many people who did not return the informed consent document (as well as some that did) struggled with the process of completing this document via printing, signing, and digitally sending it to the research team, despite not having communicated any concerns about the study itself to the research team. Some of these difficulties were technical (*"I might need to do a screen shot if I can't get the scanner to work, but is [tomorrow] okay?"*) and some were physical (*"I will have to wait for my dad to get off of work so he can print is and scan it for me. Sorry for the inconvenience, but if you can bare with me, I am in! I need something to do and I want to help...can I just email you that I give you my permission?"*). We were able to enroll an appropriate number of participants to ensure there were enough people to actively engage in discussions without being so large that participants could not reasonably get to know each other. However, we recognize that requiring a physical signature may have limited participants by physical and technological ability.

For in-person studies, participants are not always interested in taking time to read the informed consent sheet, and would be happy to sign without reading. As ethical researchers, it is our responsibility to talk through the information with participants to ensure they have understood what they are consenting to. When conducting studies remotely, we do not have the same opportunity to make in-the-moment assessments of how much attention the participant has given to the document and how much s/he understood, but this does not make *informed* consent any less critical [9].

> ***Lesson #2:*** We recommend investigating alternative methods of consenting electronically. One idea would be to seek consent via Facebook chat, mimicking how a researcher might walk through a paper consent form with a participant in person, pausing after each section for questions. Alternatively, require participants to pass a short quiz on the highlights of the consent document. Participants who do not pass the quiz should be contacted by a researcher to discuss the contents of the document and ensure their understanding.

5.2 Activities

5.2.1 Categories of Activities

We categorized activities by duration, (completed in one sitting or over the course of several hours/days (Table 1)). There was more engagement in activities that took place over time ($\mu = 17$ comments/posts) than for one-time activities ($\mu = 15.6$ comments/posts). Comments on one-time activities were often confined to a single thread, whereas discussions on longer term activities took place over several threads, with participants adding their own new material as they came up with it. In both cases, participants continued to respond to each other even after the activity had ended.

We also categorized activities by whether they required *recalling* personal information or *generating* new material (Table 1). We saw more comments when participants recalled information ($\mu = 18.2$ comments/posts) than when they had to be creative ($\mu = 10.2$ comments/posts). When asked to recall information, they distributed their responses over several comments, and built off each others' experiences. There was very little of this when activities were generative; they typically only posted the results of their efforts and did not discuss each others' contributions. One participant found this discouraging and stated (in reference to A8), *"Iwanted to know what others thought of my script and was a bit hurt when I didn't get any feedback"*. In A5, part of the activity was to comment and discuss each others' submissions, which did led to more feedback.

> ***Lesson #3:*** We recommend encouraging participants to build on each other's creative contributions. This can be challenging on Facebook if participants are not observing each other as the work is being created, and may need to be encouraged explicitly.

5.2.2 Activity Preferences

Participants eagerly volunteered feedback about each activity, both throughout the study and in the debrief survey (A11). They looked favorably on most activities; almost all activities had a median rating of 6 on a 7-point scale (1 = "*Hated it*!", 7 = "*Loved it*!").

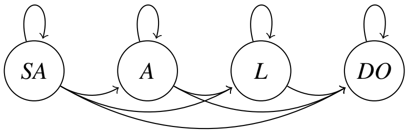

Figure 2: Transitions through different participation levels..

Participants really enjoyed the creative aspect of certain activities (*"It was fun to be able to engage my creative side" (A2)*).

A1 (*median* = 5, *modes* = 4,5,6) and A8 (*median* = 5, *mode* = 5) were not as popular. Some participants described being confused by the creative activities: *"I just couldn't understand what was wanted, despite the examples"*. They also seemed uninspired sometimes: *"I really don't understand what to do here, [Researcher's Name]. I'm big on taking photos but I don't get how I can take a photo of someone not caring or understanding" (A5)*. We posted abstract examples (as in Figure 1) or sample responses from other domains (as in the diabetes mad lib) to help provide a sense of what a response could be without leading too much. We also provided clarification and answered a number of questions. Especially for A5 and A7, these examples and clarifications were insufficient, as there was still a lot of questions. Instead, participants seemed to do better when they were following the lead of a fellow participant; in the case of A7, once one or two participants had posted mad libs, many others followed. In A5, participants submitted photos to the researcher rather than to the group, so participants did not get to see each other's contributions until much later.

> ***Lesson #4:*** We recommend having participants post directly to the group, even submissions still in progress. Seeing other participant's contributions can give inspiration to people who are hesitant to contribute creatively.

Participants discussed how activities made them feel. After completing A1, one participant remarked, *"Never spoke to a soul in person...Right now being homebound because of the illness, my life is pathetically limited."* Survey responses (A11) confirmed this sentiment: *"I am homebound and have very few interactions with others. The activity pointed that out to me yet again."* and *"Just hit home how often I have to talk to the doctors and how often I don't talk to other people in a day."* and *"kind of overwhelms or can depress me as I rarely see actual people."*. This activity drew attention to negative aspects of life that were uncomfortable to reflect on.

> ***Lesson #5:*** We advise exercising caution when 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. By the time researchers are aware of discomfort, it may be too late to adjust the method.

5.3 Overall Engagement

5.3.1 Levels of Engagement

We observed four different levels of engagement which we labeled Super Active (SA), Active (A), Lurking (L), and Dropped Out (DO) (Figure 2). Super Active meant commenting, liking, and posting frequently. Active participation meant contributing steadily, but not to the same volume as Super Active participants. Participants in a state of Active participation contributed mostly by commenting rather than liking posts; they responded to posts by researchers but were less likely to initiate new discussions or engage in conversations with each other. Lurking meant seeing posts but not engaging with them in any way. Finally, Dropped Out meant the participant had actually left the group. Participants transitioned between these states. No participant became more active; some participants maintained a steady level of activity, while others became less active over the course of the study (examples provided in Figure 3).

5.3.2 Engagement Over Time

We observed a burst of activity in the first 3 weeks as participants got to know each other. There were an average of 16.1 comments per day during the first 3 weeks (σ=14.0) but only 1.3 comments per day for the remainder of the study (σ=3.4). Participants posted a lot on Saturdays and slowly decreased throughout the week until Friday (even though many participants were unemployed).

> ***Lesson #6:*** We recommend taking time to understand potential participants' Facebook behaviour to inform decisions about when and how often to post, as well as the overall study duration.

Participants typically responded within 24 hours of an activity being posted (Figure 4), unless the activity took place over several days (e.g. A9). When participants did not respond within 24 hours, this was a sign that something was wrong; sometimes they missed notifications about new activities (*"sorry I didn't see this pop up!"*), had to take a break from the study (*"I'm just back in [city] today after 10 days in [another city] I am catching up."*), or forgot to do an activity they had seen (*"I completely forgot about the rant line. But I sure could have used it this morning."*). We tried four approaches to encouraging participation:

1. **Reminding participants of activities.** When posting a new activity, we reminded participants about the last activity. We saw a brief increase in responses after reminders.
2. **Pinning the current activity.** For the second part of A5 (sharing photos with the group and asking participants to comment), participants could not find the photos within the group. We pinned the album to the top of the group, and communicated this to participants. Pinning was an ineffective strategy because participants were still confused.
3. **Tagging participants in posts.** After seeing a reminder, some participants asked for clarification on which activity the reminder referred to. We tagged participants who expressed confusion in the comment section of the relevant post. This was more effective than pinning posts to the top of the group because participants could easily click the notification.
4. **Commenting on posts.** For activities where participants were uncharacteristically quiet, we commented on the post to provide clarification (in case of confusion) and to increase the likelihood the post would show up in their newsfeed (in case they had missed a notification). This strategy was effective; there was an increase in participation following the comment.

Despite these attempts to encourage participation, participants still mentioned in A11 that they were unaware of activities. It is challenging to work within the restrictions of Facebook to ensure posts are brought to a participant's attention.

> ***Lesson #7:*** Researchers should be prepared to adopt multiple approaches to ensure activities are seen.

We observed that several people revisited posts long after they had been posted initially or would do several activities at once (Figure

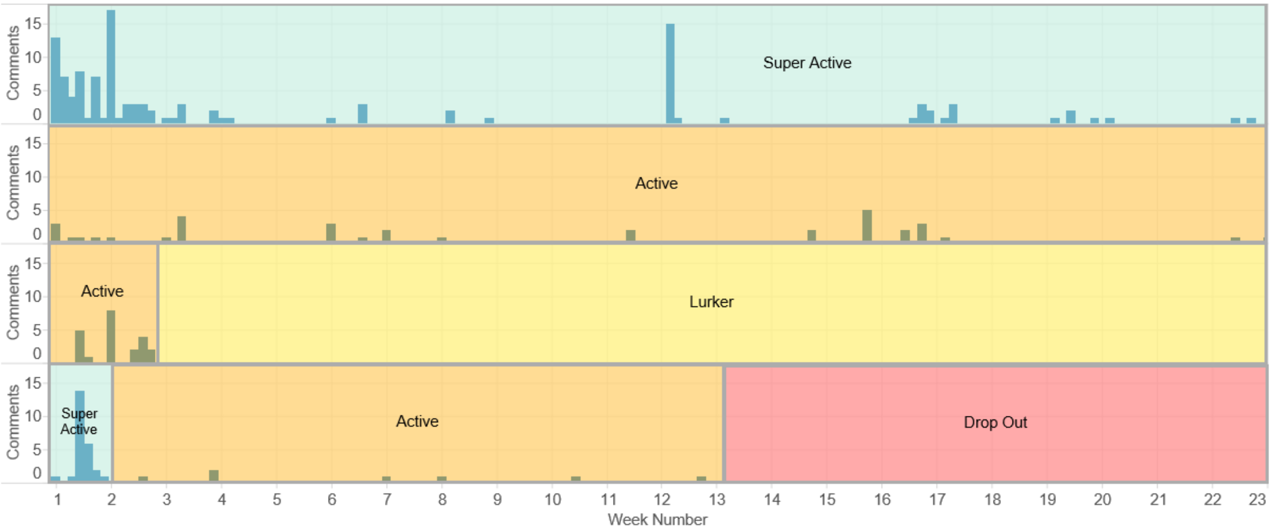

Figure 3: Comment times throughout the study with four examples of levels of engagements.

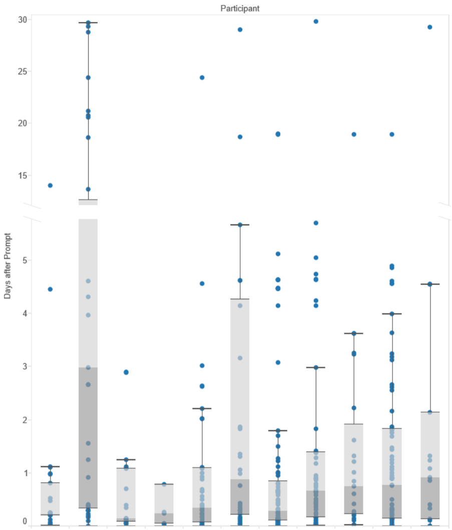

Figure 4: Days until each participant's first comment on a post. P1 and P4 are omitted because they spent the entire study Lurking or Dropped Out very early in the study (and never posted).

4). This is similar to findings from other diary studies showing that people will complete several tasks at once, often shortly before a meeting with a research team [34].

> ***Lesson #8:*** We discourage having activities that build on one another where the sequence is important.

5.4 Relationships between Participants

5.4.1 Social vs. Activity Posts

Participants had mixed views on posts by other participants not directly related to research. We allowed social conversations outside of research activities because we felt that socially connected participants would be more comfortable being honest and sharing their activity responses with the group. However, it was confusing when social threads were mixed in with specific research activities. Especially in the beginning of the study, this caused people to wonder if responses were "required" or not. One participant commented, "...it's mostly been socializing at this point. I was going to chime in when it got more research-oriented." Another requested, *"when you post a question in the group, can you do it as an admin or something? it is confusing ... and I don't want to miss a serious question."*

Most participants enjoyed this aspect of the study; participants rated the social aspect of the study higher than any other activity $(scale 1-7,\ median = 7,\ mode = 7)$: *"It was good getting to know others in the group. I really liked that most were so open and friendly."*. We note that the A11 survey would not have been completed by participants who Dropped Out; we suspect that the overwhelming amount of social activity by people of a different demographic may have been a factor contributing to their decision to leave the study.

A few participants expressed concerns about negativity and found it depressing to hear others' stories: *"...I also found a lot of negativity and some members being trapped and/or defined by their disease so that put me off."* Yet they saw value in having a place to express themselves: *"...if others are like me, they don't have unfettered ability to do that in our family..."*. This social support is an opportunity we have to provide a real benefit to participants [19]. This is especially valuable in this particular population, for whom social support is not otherwise readily available [29].

> ***Lesson #9:*** We recommend providing opportunities for socialization between participants that are separate from formal study activites. Although this may not appeal to everyone, it can help weed out participants who are not interested in this aspect of the study and would likely become frustrated later if social conversations continue throughout the study.

5.4.2 Sub-Communities

Our modularity analysis showed that, aside from two participants who were Lurking or Dropped Out for the entire study, there were two sub-communities in this study; one with two rare diseases and

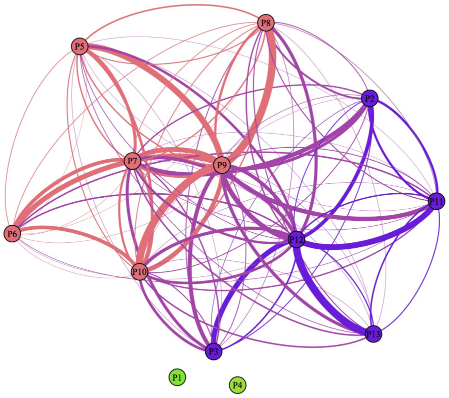

Figure 5: Participant sub-communities in the Facebook group. We observed two clusters; one with three diseases and one with two diseases.

one with three rare diseases (Figure 5). Participants with the same conditions were recruited from the same Facebook groups, so it is likely they had an existing familiarity with each other before beginning the study. This was especially true in the case of Super Active participants who, we have observed, tend to be prominent figures in their other Facebook groups as well. It is also likely that participants related to people with the same disease better.

We did not observe clusters by other demographics, however age and gender appeared to be factors in determining activity levels. Both men enrolled in the study ultimately Dropped Out, and almost all of the younger women in our study (under 40) were Lurkers.

> ***Lesson #10:*** We recommend giving careful consideration to the makeup of the group when recruiting, targeting either a highly homogenous population [15] or targeting several homogenous groups.

5.5 Researcher Perspective

5.5.1 Moderating

An online group differs from an in-person group in the weight and permanence of each post. In person, comments may be easily ignored if they are deemed irrelevant, uninteresting, or rude. Some others may simply not hear the comment in the first place. Online, each comment is given equal weight in the conversation. At first, this might indicate that a participant who is normally soft spoken and easily dismissed could contribute more to a conversation happening online than in person. In reality however, we found that conversations became dominated not by the weight of a particular post but by the volume of posts from certain participants (the Super Active participants). It was easy to forget about Lurker participants. Several participants rarely contributed — one participant did not contribute the entire study, despite remaining in the group the whole time.

Inappropriate comments are easily written off in-person, but linger online. Removing a post or deleting a comment is a much more deliberate action than redirecting an in-person conversation. We deleted one post where a participant explicitly asked the group to donate money towards medical and living expenses. We removed the post and contacted the participant to politely explain our concerns. S/he seemed understanding, stating *"i understand.Life just sucks right now and I nee all the help I can get. My apologies."*, but dropped out of the group shortly after.

Although the majority of the posting in the group was done by one researcher (to make things easier for participants and to build rapport), there were four researchers in the group who could be alert and quickly address a problem should one arise. We considered using a secondary Facebook account to maintain boundaries between research and social uses of Facebook, but ultimately chose to use our personal Facebook accounts partly to ensure that we were notified of new posts (and could intervene quickly). We also wanted to engender trust with participant; we felt moderators should be portrayed as themselves [10] and not as a group account for the whole team, as if an occult hand were conducting the study. The researcher who communicated most directly with participants had been using her personal Facebook account for well over a year to build rapport in rare disease groups.

5.5.2 Data Analysis

One of benefit of conducting this study on Facebook was the amount of data available at the end of the study. The challenge was the overhead involved in compiling it all, especially as the data comes from a number of different sources. We were not aware of any tools that met our needs for exporting all of the data we needed in a form useful for analysis. We resorted to a lot of manual gathering and coding; in a longer study or larger group it would be worth further investigating methods of doing this automatically. The time spent managing this data was substantial. However, in this case, the benefits of using a well-established social networking platform that participants were already familiar with outweighed the time required to collect this data

> ***Lesson #11:*** We recommend being mindful of the number of input mechanisms (e.g., Google Voice, email, survey platforms, etc.). Structuring activities to capture data from a range of different sources adds to the richness of the data but means data will be distributed in different locations and need to be collected and organized. Each additional input mechanism introduces additional overhead.

6. FUTURE DIRECTIONS

This is a first step in understanding how group-based research can be conducted using a common social platform like Facebook. However, there were several aspects of this method which could not be explored here and warrant follow up. First, the order of activities could impact participation, especially as participation in longer studies tends to decline over time [24, 18]. Using a different order of activities would illustrate how participants react to different types of activities, regardless of when they appear in a study.

The nature of this population made it impossible to perform an in-person study to compare between in-person and remote methodologies. It is possible that participants would have felt just as distressed when some of the activities made them think about the limitations of their social life in an in-person study, or it is possible that the remote nature gave them more time to reflect and think. Having laid the groundwork for how to conduct a study on Facebook, a future study could compare local and remote methods within a single population.

Finally, our study focused on needs and design directions. Further work could study other parts of the design cycle, including adapting existing design and evaluation techniques. This can enable our community to reach populations that are geographically distributed, and thus under-represented in the technology design literature.

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