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Conducting Research with Stigmatized Populations: Practices, Challenges, and Lessons Learned

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Abstract

Conducting research with communities who are at risk of being stigmatized can be a challenging endeavor. It is often difficult to reach and recruit individuals for research purposes regarding a stigmatized condition or situation. Yet, researchers in our field have recognized the importance of work in this area and have individually developed a range of strategies to reach, recruit, and work with these populations. This workshop will invite researchers and practitioners to present, discuss, and compare strategies and experiences when working with stigmatized communities in the context of the ever-evolving nature of technology. The outcomes of the workshop will include an outline for an article that will summarize the strategies and practices discussed as well as identify the approaches that have led to the best outcomes across different populations.

Author Keywords

stigma; stigmatized populations; research with stigmatized populations

CCS Concepts

•**Human-centered computing** → **HCI design and evaluation methods;** *Collaborative and social computing systems and tools;*

Background

Stigma has been consistently linked to negative outcomes such as discrimination, identity devaluation, prejudice and deterioration of physical and psychological health [7, 2]. Both the CSCW and HCI communities have recognized the importance of research in this area, and thus have conducted studies with stigmatized groups, such as those living with chronic mental and physical disorders such as anorexia nervosa, depression, addiction, and HIV/AIDS (e.g., [4, 12, 17, 15, 8, 9].) Studies have also been conducted with those who have experienced stigmatized events, such as homelessness, disability, pregnancy loss, sexual abuse, as well as with those who engage in stigmatized behavior like sex work (e.g., [18, 16, 1, 11, 19].) Most of this research has centred around the design of technologies (mainly in the form of prototypes and mobile/web-based apps) that aim to help people with their symptoms, improve their mood, and change their maladaptive behaviors (e.g., not taking their medication in a timely manner). Studies have also discussed implications and proposed design guidelines based on the exploration of how information and support is accessed and exchanged by individuals who are stigmatized via the use of existing technologies like social media and mobile phones (e.g., [4, 12].) The data collection instruments that have been employed are varied and include semi-structured interviews, focus groups, participatory design, ethnography, content analysis, and survey methods. For data analysis, researchers have mainly used descriptive statistics and qualitative methods such as thematic analysis and grounded theory-based approaches.

A number of challenges exist when conducting research with these populations. Recruitment has been accomplished mostly in-person with the help of organizations such as clinics, charities, shelters, and community groups (e.g., [18, 10].) Researchers have recognized the difficulties in reaching and recruiting participants from stigmatized groups without the help of such organizations, and even with their help, only a limited number of participants can be enrolled for studies that explore sensitive issues [18, 6]. To overcome the limitations of in-person recruitment, researchers in the social sciences have turned to web-based surveys and online content analyses to study stigmatized communities. Yet, studies in our field have seldom employed online data collection instruments due to the limitations that exist when trying to adapt data gathering instruments more attuned with HCI research methods, such as photo elicitation, focus groups, and co-design, to online settings. Maestre et al. [8], has recently attempted to adapt some of these instruments in online groups to conduct research with people living with HIV.

Additionally, whilst some may argue that study participants may not be represented accurately in online samples, research has shown that this limitation may not invalidate findings. Studies have shown that stigmatized populations tend to have higher rates of access to Internet-based technologies while also having a higher proportion of lower educated, lower income, and disabled individuals [14, 13]. Yet, in contrast, more recent research points out that there may be important differences in sampling between offline and online recruitment venues. For instance, a study conducted a comparative analysis of recruitment strategies for men who have sex with men [5] and found that the majority of participants for an in-person focus group were recruited via a nonprofit organization and a mobile application. More African-American, low-income and HIV-positive participants were recruited via the nonprofit, whereas more White, and socioeconomically advantaged participants were recruited via the mobile application. Use of flyers, personal networking, and non-traditional in-person recruitment (e.g., going into bars or coffee shops to engage potential participants)

each yielded a small number of participants. Thus, in this case, the researchers suggested the use of a combination of recruitment venues when working with this particular population.

Another challenge in conducting research with stigmatized populations is related to the ethical management of informed consent, anonymity, and privacy. While researchers attempt to provide anonymity in all data collection procedures, especially for topics that are sensitive, anonymity and privacy may not always be guaranteed in both online and in-person research. Conducting research online, in particular, poses unavoidable risks that could threaten privacy and confidentiality due to the poor user privacy and confidentiality protections of social networking sites. In this sense, Curtis [3] and Rhodes et al. [13], recommend that informed consent should be done in a way that makes it clear to participants that 100% confidentiality could not be assured. The risks of potential breaches of confidentiality should also be understood by prospective participants prior to giving consent. Yet, online environments can make it challenging for researchers to assess whether participants have adequately understood the risks prior to participating in a study. This also brings to mind the use of social media and online community data for research purposes and the importance of being careful when consent can't be obtained. Curtis [3] suggests using interactive procedures so that, apart from providing the informed consent document to participants, they can also ask questions about it. For example, interactive quizzes could be used to verify understanding of all the risks, study protocols and procedures.

Issues of consent, anonymity, and privacy are further exacerbated when researchers working in stigmatizing domains utilize public social media data, which in most institutional settings negates the need for traditional ethical procedures like informed consent and privacy measures. In Pater et al., they used public social media data as the primary source for their study about the characterization of eating disorders [12]. Because they were dealing with a stigmatized population, they chose to directly contact the individuals whose content was to be published, alerting them that their content had been collected through a public data collection and that they had the opportunity to opt-out of having their anonymized content published. Out of 17 people, 3 responded that they could use their content while the rest never responded. Yet, this approach also has ethical implications as it could have had unknown negative impacts on the individuals that they contacted.

Ultimately, a comprehensive discussion about experiences working with stigmatized populations is needed to understand these and other challenges. We need to come together to discuss these in an ongoing manner because of the ever-evolving nature of technology (think of all the scandals related to data use recently,) then specifically hit on how these issues may be even more important to stigmatized populations. Furthermore, while researchers are developing and utilizing various strategies to overcome these challenges, we do not have a set of general "best practices" for working with stigmatized populations specifically in the context of HCI and CSCW. Particularly in the context of technology-based research (technology creation and technology used to conduct research), we need to have ongoing discussions about conducting research with individuals who face stigma because the technology that we develop as well as the methods and approaches that we use could further stigmatize these individuals [18].

In this sense, we propose to gather a diverse group of researchers and professionals who have worked with a variety of stigmatized populations. The outcome of the work-

shop will be the generation of a zine and an outline for an article documenting the challenges as well as the best practices and approaches used by researchers to work with individuals who are stigmatized. These outcomes based on the discussions of workshop participants' experiences will complement current related literature on conducting research with stigmatized populations in our field.

Topics

The main topic areas and questions that would be discussed during the workshop are the following:

Recruitment: What are the current methods used to reach and recruit participants to conduct research with stigmatized populations? What are the differences, advantages, and challenges between online and offline recruitment strategies?

Data collection/analysis: How do researchers collect and analyze sensitive data? Do researchers need to create rapport with participants before or during data collection? Are there any data collections methods that work better than others? Does the methodology depend on the type of stigmatizing context? How do we create safe spaces for data collection?

Research outcomes: What types of outcomes are typically produced by research with stigmatized communities? Are findings/results of research being disseminated? How do we assess whether the outcomes could further stigmatize or harm individuals who are stigmatized?

Privacy and confidentiality: How can research ensure privacy and confidentiality? How much privacy and confidentiality is possible in any given setting or context? What are the current practices and protocols used to protect participants' information and identities? Should existing method-

ologies be further adapted to ensure anonymity for stigmatized populations? Is complete anonymity always desirable or practical?

Ethical considerations: What are the most important ethical considerations that need to be discussed and addressed when working with stigmatized populations? Should the current informed consent process be improved so that participants are aware of all the potential risks? Are there better ways to conduct informed consent? How can we design technology that does not further stigmatize people? Should we, and how could we validate our findings with the communities they affect?

Workshop Organizers

Juan Fernando Maestre is a PhD candidate in Informatics at Indiana University Bloomington. His research applies novel methods to recruit and conduct research with stigmatized populations such as people living with HIV and those living with substance use disorders. Ultimately, he strives for a successful integration of novel research methods in order to design and assess the impact of technology-based interventions that support stigmatized, marginalized, and vulnerable populations.

Elizabeth Eikey, PhD is a postdoctoral fellow with the Institute for Clinical and Translational Science and the Health and Informatics Lab in the Department of Informatics at the University of California, Irvine (UCI) and serves as a Research Advisor for the iSchool Inclusion Institute (i3) at the University of Pittsburgh. Her research broadly focuses on understanding and designing technology to support and promote mental health and well-being. This involves studying perceptions, use, and effects of mobile health applications, self-tracking devices, social media, online communities, and health interventions. Her current work investigates

how to put users' psychological and emotional needs at the forefront of technology design by working with different populations, such as immigrant students with depression and individuals with eating disorders.

Mark Warner is a PhD candidate at the University College London Interaction Centre (UCLIC) and a Marie Skłodowska-Curie fellow in the Privacy&Us ITN (www.privacyus.eu). His research focuses on understanding the impact of introducing HIV status information into online sex-social environments used by men who have sex with men (MSM). He is exploring issues related to privacy and disclosure, identity management, and stigma to understand how diagnosed individuals manage the disclosure of their HIV status within these environments. Prior to joining UCLIC, Mark worked in Digital Forensics for various law enforcement and government agencies in the UK and the Middle East.

Jessica Pater is a PhD candidate in the Human Centered Computing program at Georgia Tech. Her studies focus on how social computing technologies can impact everyday wellness and behavior. She is specifically interested in how technology use and participation in online communities impact social and emotional health, especially as it relates to eating disorders and self-harm.

Maia Jacobs, PhD is a Postdoctoral Fellow in the Center for Research on Computation and Society at Harvard University. Her research involves the development and assessment of novel approaches for mobile health tools to support chronic disease management. Her recent work focuses on connecting patients in rural communities with personalized health information, and assessing the influence of personalized and adaptive mHealth systems on patient barriers to care.

Svetlana "Lana" Yarosh, PhD is an Assistant Professor

of Computer Science Engineering at University of Minnesota. Her research in HCI focuses on enhancing social relationships in critical contexts. Lana has spent the past five years designing and evaluating supportive technologies with people in recovery from substance use disorders (e.g., addiction, alcoholism).

Gabriela Marcu, PhD is an Assistant Professor in the University of Michigan School of Information. She studies how stigma and marginalization affects the use of technology-based health interventions, and engages individuals in participatory design to address these barriers with human-centered design. She has worked with a range of populations, including communities at risk for opioid overdose, children with behavior disorders, and adults receiving outpatient treatment for bipolar disorder.

Patrick C. Shih, PhD is an Assistant Professor of Informatics at Indiana University Bloomington. His research focuses on the study of sociotechnical systems and mechanisms to enhance physical and mental well being and to facilitate civic engagement and environmental stewardship. 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 health informatics interfaces and civic engagement platforms.

Workshop Outline
Pre-workshop
The organizers will present and discuss the structure of the workshop as well as all the activities and materials with other researchers who have previously worked with stigmatized populations.

The call for participation will be sent out through relevant

mailing lists, organizers' professional and student network, and via word of mouth. In addition, a website and a Facebook page will be created in order to share all the information regarding the workshop structure as well as to inform about the guidelines and directions for preparing and submitting position papers.

Workshop structure and schedule
This would be a one-day workshop. The target participant is any student, researcher, or practitioner who is or has worked with any type of stigmatized population. We expect to have between 10 to 15 participants in total. Those interested in being part of the workshop will have to submit a 4-6 page-long position paper that contains a description of the their research and their experiences working with a stigmatized population or topic. Participants will also be asked to highlight the challenges, lessons learned as well as the practices and/or approaches that have worked best (and worst) in their research projects. Accepted papers should cover a variety of populations, topics, methods, and research areas in order to ensure a productive discussion.

The workshop will begin with short interactive presentations from all participants with the aid of a projector. Each presenter will talk about their experiences, challenges, and lessons learned while conducting research with a stigmatized population. Participants will also be asked to compare and contrast the challenges and methods in order to identify what works across different populations and research areas. After lunch, groups will be formed based on key elements and related themes such as challenges, methods/techniques, and approaches identified in the position papers and during the presentations. After the breakout group session, all the groups will prepare an artifact that could be in the form of a poster or small zine (using markers and post-it notes.) They will share their insights using

their artifacts in an oral presentation to all the workshop participants. The organizers will be taking notes at all times regarding all aspects of the workshop. All the output artifacts will be collected as well in order to facilitate the preparation of a digital zine and an outline for an article based on the themes and final insights presented at the end of the workshop day. In this sense, the preliminary schedule for the workshop is presented in Table 1.

Time	Activity
9h00-9h30	Welcome and introductions.
9h30-10h30	Short interactive presentations and discussions on participants' work: description of population, practices, lessons, and challenges.
10h30-11h00	Coffee break.
11h00-12h00	Short interactive presentations and discussions on participants' work (cont.): description of population, practices, lessons, and challenges.
12h00-13h30	Lunch.
13h30-15h30	Group sessions: key challenges and related themes (in teams).
15h30-16h00	Coffee break.
16h00-16h45	Team insights and artifacts (e.g., poster, zine, etc.)
16h45-17h00	Conclusions and future work.

Table 1: Workshop Schedule

Post-workshop
The workshop organizers and interested participants will collaborate to write an article on the outputs from the workshop.

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