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# Moving Beyond 'One Size Fits All'

## Research Considerations for Working with Vulnerable Populations

### Insights

- Working with vulnerable populations takes special considerations at all stages of the research process.
- Vulnerable populations have unique concerns with participating in research that are crucial to the success of the project.
- Building relationships with the communities you intend to work with can help safeguard against unintentional harm.

Privacy and vulnerability are distinct yet interwoven concepts. Protecting a vulnerable person's privacy, for instance, is one way to help ensure their safety. For example, the name of someone who reports a sexual assault is often left out of media coverage to protect the victim's privacy. However, along the same lines, some level of personal information disclosure is equally as important as personal privacy, as it contributes to knowledge, which in turn facilitates change. If a person were not compelled to disclose their assault to the authorities, there would be no chance of preventing the perpetrator from committing more

crimes. In this way, privacy is a complex but critically important topic when trying to both protect and empower people who are already vulnerable.

Similarly, as human-computer interaction (HCI) researchers, the level of care we give to issues around privacy and respect for vulnerable participants in our research is worthy of deeper reflection. We turned our attention to this topic in our breakout session during the ACM CHI 2018 workshop on "Moving Beyond a 'One Size Fits All' Approach: Exploring Individual Differences in Privacy" [1]. The overall workshop goals were to highlight and design for various individual differences







(e.g., age, culture, personal preference) that influenced users' experiences and privacy-related outcomes. Working from our own experiences, our group chose to focus on vulnerable populations (e.g., LGBTQ populations, youth, and other marginalized communities). Further, instead of focusing on design in the traditional sense, we focused on *research design* and how privacy and other aspects of human-subjects research could be explicitly used to create guidelines in the form of heuristics for conducting research with vulnerable populations in a responsible and responsive way.

## WHY FOCUS ON VULNERABLE POPULATIONS?

The ACM Future Computing Academy (FCA) recently highlighted the need to address the potential negative impacts of new computing technology that we introduce to society [2]. The emphasis of the FCA's argument was on the impact of the innovations themselves; however, when mitigating negative societal impacts more broadly, it is equally important that we assess the potential harm that computing research may have on our participants and their respective communities. For example, given the current political climate, a study on how undocumented immigrants in the U.S. use technology to seek resources and support could unintentionally put these individuals in more danger than the benefits they would gain from participating in such a study. As HCI researchers, we must consider these nuances and weigh the costs versus the benefit of conducting research with vulnerable populations. *Interactions* has published prior work on the ethics of doing research with vulnerable populations that focused specifically on the experience of conducting research on children living in poverty in Nepal [3]. To build upon this work, we have developed

generalized heuristic guidelines for broader HCI research that involve a wider range of vulnerable populations.

## WHY HEURISTICS?

In user experience (UX) research, heuristics are general guidelines that designers use to evaluate the usability of a system. For example, Nielsen's 10 principles for interaction design [4] include giving users control and freedom so they can accomplish their goals. Heuristics are meant to be general rules of thumb for best practices to follow—when they make sense, as opposed to following them rigidly. You might not want to give the user too much freedom, for instance, to the point that they introduce unrecoverable errors into the system. Heuristic guidelines provide an easy-to-use framework that provokes thought and helps designers (or, in our case, researchers) keep in mind practical expectations of what good design means. We set out to create a thoughtful, yet by no means comprehensive, set of heuristic design guidelines for researchers who work with vulnerable populations. Figure 1 presents these heuristics as questions researchers should ask at each stage of the research process (i.e., pre-research, act of research, and post-research). These questions are designed to highlight areas of potential concern for researchers who are working with vulnerable populations. In the next sections, we will discuss these considerations in more detail.

## PRE-RESEARCH: BEFORE GETTING STARTED

As mentioned earlier, the first question researchers must ask is whether the research has the potential to benefit the vulnerable participants more than it has the potential to cause them harm. Can risks be mitigated sufficiently? In answering this preliminary question,

we as researchers have to be honest with ourselves and acknowledge that our incentive structure of “publish or perish” may at times be in conflict with the best interests of our participants. Therefore, sometimes the most ethical decision might be to not pursue the research at all. If the researchers feel in earnest that the research is beneficial to the target population, the next question to ask is: How will you build and maintain the relationship with the community in question? Researchers, who are often outsiders to a community, need to have a clear idea of how they will initiate and maintain a relationship with the group. This process may look different when working with vulnerable populations, who often have contrasting, more complicated feelings and expectations when it comes to researchers than university students participating in studies. Researchers need to show that they care about the community itself and that their motivation is to be helpful to the community first and foremost. Upon establishing the initial relationship, researchers must then allocate time and attention to maintaining that relationship. Researchers might consider initiating and solidifying a relationship with a community by: participating in community activities, volunteering in the community, and communicating with the community members to understand their issues of interest. To be sure, this work takes time and thoughtful consideration, but it is key groundwork for research that is not only interesting to the HCI community as a whole but also actually relevant to the parties involved.

The next question to ask when considering research with a vulnerable population: How is this research relevant to the community involved? In other words, upon completion of the research, how will the community benefit? Oftentimes, ideas and issues that are relevant to HCI researchers drive the desire to connect with vulnerable populations. Researchers are the ones who eventually benefit through producing publications, while the questions and concerns of the vulnerable population remain unsolved.

When dealing with vulnerable populations, compensation also needs particular attention. As research involves labor on behalf

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## Heuristics for Research Design with Vulnerable Populations

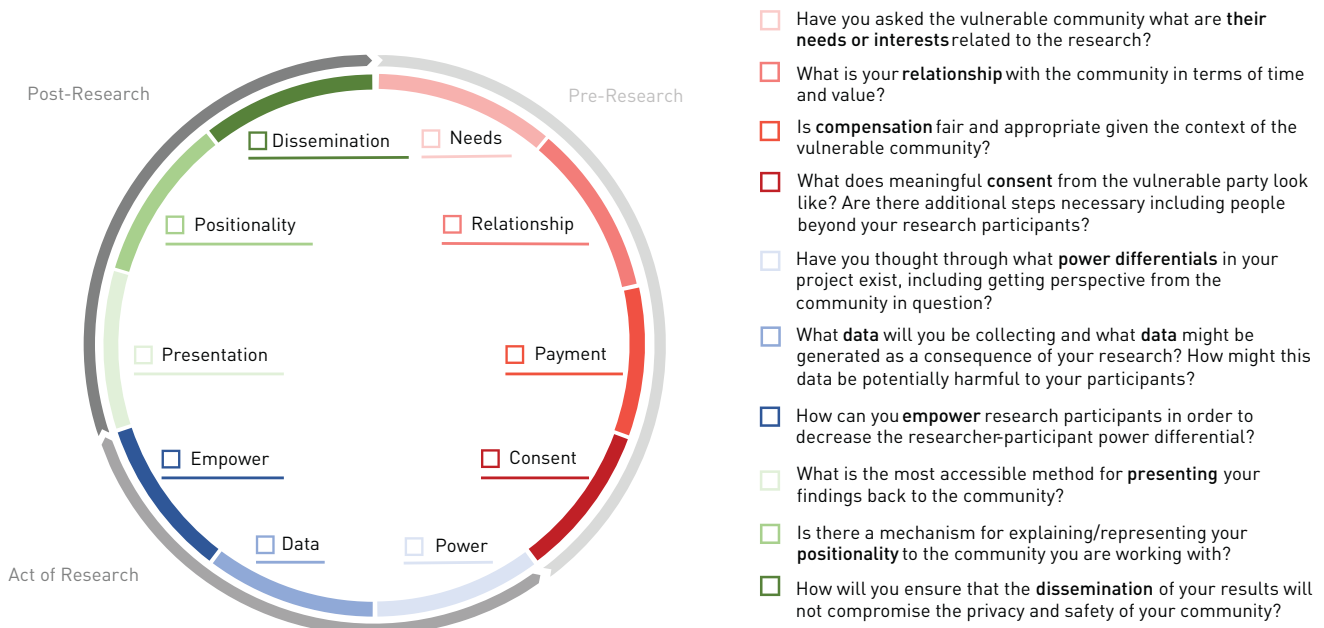


Figure 1. Heuristics for research design with vulnerable populations: pre-research, during the act of research, and post-research.

of the participants, it is crucial that we consider the appropriate kind of compensation for the time and attention participants spend on research; this, after all, is how we show respect. This is especially important to consider when working with populations whose opinions and knowledge may be systematically undervalued. Researchers should work to ensure that payment is commensurate with the effort the researchers will need from the participants, considering the specific context of the participants, other benefits, time required, and the task involved.

We need to remember that cognitive and emotional work are labor. In particular, asking participants to recount emotional events or reflect deeply on activities in which they may not have expertise might take more effort than other kinds of research tasks. In some cases, changing the task to better support the context may be the solution. For instance, instead of conducting an interview that forces a participant to recount pain and trauma, having them do a generative participatory design task to help be part of the solution may be a more positive and empowering use of their time.

Another question to keep in

mind is: What is the most effective way to notify the participants regarding the benefits and risks of their participation? Researchers normally use consent forms as a way to inform the participants, but for some vulnerable populations (e.g., children), consent forms could be too complicated for them to understand. Thus, an assent form might be a better option. In addition, the consent/assent form is not just a procedural product so that researchers can get the IRB approval; it needs to be informational. Researchers should think deeply about the potential impact of the study, drawing from their understanding of the context of their participants as established by their relationship with the community, and inform the participants deliberately.

### ACT OF RESEARCH: CONSIDERATIONS WHILE CONDUCTING RESEARCH

Keeping in mind the inherent power asymmetry in conducting research is crucial while collecting data, even after gaining participant consent. Consider: Have you explored all the ways in which the power differentials in your project may not work the way you think they do?

Have you considered power in your project through the lens of financial vulnerability, race, gender, sexual orientation, and so on? How about the researcher-participant power difference? How can you empower research participants and decrease that differential?

One way to support the agency of participants is to emphasize that the study is voluntary and that they can leave the study at any point. Consider how you will handle payment should they choose to drop out of the study. Financial incentives can deepen power asymmetries, and being clear about how you will handle this question can help make it easier for participants to stop when they feel uncomfortable.

Also consider: Are there ways to reduce the information asymmetry between you and your participants? Can you provide context around who and why information is being collected from participants? For example, you can film introduction clips about the researchers for when the study does not have any direct researcher-participant contact. This way, the data doesn't just flow toward the investigators, and participants can have a better understanding of how the information is being used and

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for what purposes.

Do you come from a different cultural background or country from the population you are studying, and how does power play into that? If so, are there ways you can ensure comfortable communication between you and participants? For example, having a trusted community member accompany you when meeting participants, or training a community member to conduct the study for you, can help you establish a good relationship with the community. Having another person in the room who is clearly looking out for the participants' needs may help them feel more comfortable speaking with you about what they think—not what they think you, the researcher, want to hear.

Another helpful heuristic to consider is the language used to categorize or analyze the data. Are you using your words and definitions to categorize a participant's lived experience, or are you using their words and definitions? For example, a participant can describe their own sexuality and gender, rather than using the categories proscribed by societal norms. These discrepancies can also arise between people born in different generations or in different countries. It is good to capture and define these details, making space for complexity and multivocality in your results.

One final thing to consider is what data you will collect from participants, and what data might be generated, purposefully or not, as a consequence of your research. Even if it is not your intention, there can be potential for the data you publish to negatively impact your participant population.

## POST-RESEARCH: OBLIGATIONS ONCE THE RESEARCH IS DONE

After completing your data collection and analysis, in addition to preparing your work to present to your academic community, it can also be helpful to consider how the work that you have done relates to the community or population with whom you conducted research.

Academic researchers have a long history of using people, particularly marginalized communities, as resources from which to extract knowledge rather than as active stakeholders in the research process. One of the ways that we as academic researchers can begin the work of repairing the relationships between academia and the communities and populations that our research engages is by making sure we reflect back what we learn to the groups we work with. Keep in mind that this may not be what is interesting or useful to you as a researcher. Drawing on the relationships that you have built with the community and your knowledge of their issues and questions, let them help you identify what is most relevant to your participants.

Notably, this is not as simple as making the final published product available on a personal website or even writing a blog post summarizing the results, although these are both possible steps. What is interesting to your academic community is not necessarily the results that are useful or interesting to laypeople. One useful way to understand what is interesting or useful to people who participate in your research is to ask, whenever possible, what questions participants have for you, what drew them to the study, and if participating

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in this study made them reflect on any existing issues in their own life. This information should be a complement to the groundwork that you have already laid in the pre-research steps, a way to deepen and complicate your understanding while being responsive to your actual participants. For larger-scale work where this kind of attention might not be possible, creating mechanisms, such as a Google form, in which participants ask you not just about their study participation but also about how this research relates to their own experiences, is helpful.

Another factor to consider when presenting findings back to a community is your positionality, or the stance of the researcher within the social and political context of the study, in relation to the group, and how to represent it to your audience. Are you a member-researcher who does research of particular interest to your own experience? Do you have some kind of personal connection to the group or issues at hand? Why are you interested in this research, what is your relationship to the group, and why is your work interesting or relevant to them? When people can conceptualize you as someone other than a faceless lab coat, there may be a big difference in how you and your work are perceived and whether you can continue working with this group.

Representing relevant findings back to your participants can take many different formats. It is an excellent way to experiment with different kinds of representation, depending on what is useful for your audience and the kinds of information that you are presenting. Short videos, informal visual representations, and infographics can all be interesting, impactful ways to represent information in a way that is more accessible to people than an academic article. Consider the ways in which you like to consume information in fields outside your area of expertise. What is compelling to you when learning new information about complex topics? Longform writing in a more accessible style is not always the best choice, even if it does tend to

be the way many researchers are most comfortable communicating. This is a chance to be creative while also demonstrating your respect for your community of participants by demonstrating that you understand how they like to communicate.

## CONCLUSION

Many HCI researchers are motivated to investigate societal issues, including those that focus on the welfare and perspectives of marginalized and underserved populations [5,6]. In order for our research not to appear patronizing or insensitive, however, care must be taken to formulate and conduct the research in an inclusive and respectful manner. This article presents some heuristics (Figure 1) that may assist when planning an HCI research project involving marginalized populations. In particular, researchers should make sure that their work is properly designed by building strong community relationships, making sure that the work is relevant to their respective populations, providing adequate compensation, and clearly delineating the risks and benefits of the research process. While conducting the research, investigators need to be aware of power and information asymmetry problems, and to avoid categorizing people inappropriately. Finally, after the research is conducted, investigators should consider how the information will be returned to the community, how to position it so it doesn't come off as outsider intervention, and ways in which it can be presented well for the specific populations.

## ENDNOTES

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