# "Normally I try and capture a moment, and with this I had to create a moment": Implications of anonymous photography protocols in Photovoice research with people who inject drugs

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## Introduction

The United States is experiencing a devastating opioid overdose epidemic. The national media has focused extensively on the role of excessive opioid prescribing in the upward trajectory. Indeed, sharp increases in prescribing precipitated higher rates of opioid use disorder, which have been associated with a rise in heroin use and fatal overdose (Kolodny et al., 2015). Yet, national mortality rates from prescription opioids have declined, while the mixing of illicit opioids with other drugs (methamphetamine, cocaine) has increased (Wilson et al., 2020) and recent estimates show elevated death rates attributable to heroin and illicit fentanyl (Seth, Scholl, Rudd & Bacon, 2018). The role of synthetic opioids (namely, fentanyl) has increased dramatically, accounting for 67% of opioid overdose mortality in 2018 (Wilson et al., 2020). Exposure to illicit fentanyl mainly occurs via contamination with the heroin supply or the replacement of local heroin markets with fentanyl (Wilson et al., 2020). These increases disproportionately affect people who inject drugs (PWID).

PWID and those who use crack cocaine are the most criminalized and stigmatized of all individuals who use substances (Chang, Dubbin & Shim, 2015). This stigma can affect both mental and physical health, and discriminatory encounters with health providers often cause PWID to avoid care entirely (Treloar, Rance & Backmund, 2013). The evidence of this stigma has failed to prompt meaningful policy or practice change to improve health outcomes. Advocacy is needed, and personal testimony is a critical component of advocating for change. However, PWID often suffer social or legal consequences when publicly identified, making personal testimony too risky, yet their voices must be heard to humanize the epidemic. Safer opportunities for participation in advocacy are urgently needed.

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Photovoice (Wang & Burris, 1997) may represent such an option. Photovoice was created as a participatory action method to engage communities in documenting issues that need change with photography and narrative. These products are used to inspire critical consciousness and to change policy. Facilitating opportunities for communities to engage in Photovoice is one way to ensure that their interests are represented in public health policy. Photovoice products can invoke powerful emotions and illuminate injustices among marginalized groups by providing voice to concepts that are often unspoken (Harley, 2012). Research study participants become equal partners on the team and are empowered with choice and creative vision.

Photovoice was designed to circumvent traditional power dynamics by recognizing that participants are experts who can best represent their own stories (Wang & Burris, 1997). The potential to infuse advocacy with authentic voices makes this method particularly exciting for use with PWID or other criminalized groups. Photovoice has been used with populations that face stigma, such as those in the sex trade (Desyllas, 2014), homeless persons (Bredesen & Stevens, 2013), and people experiencing addiction (Miller Heery, 2013). PWID, specifically, find value in the opportunity to voice their experiences through a visual medium, and the potential to help their own community by educating others (Drainoni et al., 2019).

However, the use of photos in research with marginalized communities poses certain ethical challenges. The use of photos requires additional documentation that increases participant burden (Switzer et al., 2015) which may be disproportionately experienced by marginalized groups. Participants may also be concerned about how images of identity are interpreted by the viewer and inappropriately generalized to entire communities (Holtby, Klein, Cook, & Travers, 2015). Perhaps most concerning is confidentiality, which may be unintentionally compromised by photos that capture identifying characteristics (Clark et al., 2010; Gubrium & Harper, 2013). Participants may also identify themselves, and individuals with stigmatized identities may experience both empowerment and negative consequences as a result (Teti, Murray, Johnson & Binson, 2012). This is even more problematic where such identification might result in discrimination or other harms. Drainoni and colleagues (2019) noted these fears among PWID who worried about being identified. While identifying portions can be blurred, Bagnoli (2009) reminds us that blurring may cause additional stigma. This also affects participant autonomy – if a participant sees the content as essential to the message, the researcher is altering that vision, directing the scope of the image, and ultimately silencing participant voice (Hannes & Parylo, 2014).

One way to address these concerns is to design a protocol in which only anonymous photos are taken. For PWID, anonymous photos may be the safest option. What is not well understood is how this human subjects' protection may affect PWID experience with the method. This study aims to augment the growing Photovoice ethics literature by exploring PWID experience in a study that allows only anonymous photography.

## Methods

An exploratory, qualitative approach guided this project. The project was phenomenological, exploring how restrictions on identifiable photography are experienced by PWID. Phenomenology facilitates the understanding of specific concepts, particularly when incorporating semi-structured interviews to ascertain participant voice (Creswell & Poth, 2018; Patton, 2015). In order to capture real-time perspectives, the study was conducted in conjunction with a Photovoice project focused on the impact of drug-related stigma on the lives of PWID, and embedded in a harm reduction program operating in a large urban setting where the Principal Investigator (PI) had prolonged engagement. The PI trained a Research Assistant (RA) to conduct the interviews to reduce social desirability bias. A Community Advisory Board (CAB) of PWID and program staff vetted both the protocol and the instrument. The study was supported by a RETI NIDA/NIH Fellowship, and approved for use with human subjects. The research protocol prohibited the collection of any identifying information and included a Waiver of Documentation of Informed Consent to protect participants from being identified as a PWID.

Participants were recruited from an outreach van in urban communities with high rates of opioid overdose. Inclusion criteria included: participation in the Photovoice study, being 18 years of age or older, current opioid use with injection as the primary route of administration, and ability to speak English. The purposeful sample was designed to approximate the gender distribution and racial/ethnic diversity of the PWID community in the prioritized recruitment areas.

Recruitment for this study occurred simultaneously with the Photovoice study. As part of the Photovoice portion, participants were trained in safety procedures and in keeping photos anonymous. They were also informed in advance that any submissions of photos with identifying characteristics would be blurred. Each participant visited the outreach van two times, with a minimum of a week between visits. The first visit included the informed consent process and photovoice training. Participants were offered the choice of taking photos on their own smartphone or camera, or a disposable camera provided by the research team. The second visit involved submission of photos, individual consent questions for various dissemination options for each photo (peer-reviewed articles, local gallery exhibits, internet campaigns about stigma, exhibits at local conferences, written testimony for legislation), and more detailed questions about the motivation behind each photo, and the messages participants hoped to convey.

Following those procedures, participants were reminded of their consent to the interview about the experience of participating in the study and asked to confirm that consent. Each participant was interviewed in private space behind closed doors within the outreach vehicle. Open-ended interview questions explored key phenomena, including participant feelings about the use of anonymous photography, perceptions of differences or similarities to daily picture taking, any challenges or concerns that arose in the project, perceived benefits of participation, and perceptions of safety. The research team used member-checking to establish credibility and trustworthiness (Lincoln & Guba, 1985) by having participants vet notes taken during interviews to ensure accuracy. The interviews lasted approximately 30

minutes, were audiotaped and transcribed by a professional service. The transcriptions were verified by the PI and uploaded as documents into software designed to assist with analysis of qualitative data.

Interviews were initially coded two ways: using an index code list developed to examine key phenomena included in the interview guide (a priori coding), and by creating codes from the data to explore unanticipated concepts (inductive coding). The PI and RA coded a small subset of interviews separately and met to discuss definitions and emerging inductive codes, resulting in a more expansive codebook. Following that discussion, the PI and RA coded all interviews separately, with additional discussion as needed to discuss any new inductive codes. Following coding, a Cohen's Kappa was calculated (Cohen, 1960) to assess interrater reliability and to enhance trustworthiness by employing "triangulating analysts" (Silverman & Marvasti, 2008). Queries of coded data were used as a foundation to identify potential themes using Weiss' (1995) issue-based analysis for its strength in identifying key phenomena in a vast amount of data. Common themes emerged and were considered alongside any negative or discordant cases. Peer debriefing and member checking were used again to vet themes with program staff and CAB members.

## Results

### Sample

Attrition was expected with this population of sometimes homeless individuals, as most recruitment occurred over the cold winter months. While 45 individuals were recruited for the Photovoice study, only N=24 returned with photographic data and completed the interview. All participants chose to use their own smartphones to take photographs, citing two reasons: a desire to see the photo immediately, and a preference to take photos in a manner that was consistent with their usual photography patterns. Demographics among those who did not return were not different from those who completed the study. Those who did not complete the study cited a lack of time or competing priorities as barriers. The sample consisted of 60% males and 40% females, which closely approximated the intended gender distribution. The mean age of participation was 36, with a range of 26–59. The racial/ethnic breakdown was as follows: 77% white, 14% Hispanic, 5% black, and 5% multiple race. All were current PWID, with heroin as their drug of choice.

### Major Themes

**Protecting Privacy—**The majority of participants acknowledged and appreciated the effort to protect their identity through anonymous photography. Most participants mentioned the specific need for protection from accidental disclosures of their status as a PWID, such as these individuals:

> I was just more worried about the anonymity than anything and after I was relieved of that. The stress or concern, it didn't bother me. I was cool with it. I wouldn't want someone to take a picture of me and then show it to other people for something like this. Then especially something so private as, these are pictures for an experiment about addicts. I think it's far better that, that be a guideline rule,

> instead of having to say, "Well we can't use this picture now," or "We have to take our time and blur out this." It's far better in the long run.

Some participants articulated this responsibility as falling under the realm of the research team, indicating comprehension of the informed consent process, and awareness of the role the research team has in making decisions about safety. Still others considered how identifying photos or accidental disclosures of PWID status have caused them harm in the past, such as this participant:

> I could see why you did it. It made sense… I was making really good money when I first came out here. And this lady was telling me that she was taking these pictures of me for this school project. And I found out that she put his huge article on the internet using my picture on the top of this article. And it was about heroin, I guess. And ever since that article came on to the internet, it's been so fucking hard for me to make money.

**Safety Considerations—**The potential reactions of people in spaces where participants were taking photos was understood to be potentially unsafe, particularly in areas where people might be using or purchasing drugs. While this issue was covered in Photovoice training, participants noted the need to be careful:

> Strangers were weirded out. But everybody else who knew me, knew what was going on.... Like when I was listening to the things about safety, I thought this: They must be anticipating people taking pictures at their dope spot, 'cause that I could see to be extremely dangerous.

> I think it was good because you could actually get hurt and going out there taking pictures of people that don't want to be taken...

While the understanding of protections was the dominant opinion, a vocal minority felt strongly that this decision should not be made by the research team. Those who did expressed frustration with constraints restricting their vision, or that it was not appropriate for the research team to limit participant choice. Even those outside the minority opinion discussed how the protections affected "human" presentation. For example, one participant explained,

> I'm not in the field, but I'd just say sometimes you have to get people's facial expressions. Stuff like that. Not only their expressions, but facial expressions. Facial expressions can say it all, so try doing some without a face.

Another participant discussed whether they should be the subject of their own photo or not, weighing some of the advantages (openness) with the disadvantages (stigma and discrimination). Yet another refused to adhere to requirements and returned with a photo of her own face, citing her rights and ability to make her own decisions about the risks. Despite her strong feelings, the IRB protocol stipulated that the photo must be blurred– see Figure 1. While this was minority opinion, those who did speak out had firm beliefs about making their own decisions regarding vision and disclosure.

**Revisioning the Vision—**While most participants understood the protections, they did so while simultaneously describing how those protections limited their vision. This was a universal challenge for participants. One person explained,

> I just had to figure out how to interpret them a different way, 'cause I had other ideas at first. I had other ideas that would have involved people. Or parts of people, you know?

When compared to daily picture taking, participants described a less organic "in the moment" process to an often-staged construction of a visual concept. They shared:

> Normally I just take pictures randomly, just willy nilly, like if I just see something that I like. Just the way something looks. I really don't think of any kind of an idea of the subject matter that I take a picture of until after I take it and then I give it some thought, but this is giving it thought and then taking a picture. It was an opposite, like a chicken and the egg kind of thing.

> Different in that, again, instead of just taking a portrait of the group at the bar or some family or some friends, taking a picture that was closer and more zoomed in, like the suboxone with just the thumb on it, or just the person's arm while he was injecting. It was different than I would normally ever take a shot.

**From Snapshots to Art—**While more organic photography might yield an authentic depiction of daily life, the study restrictions required participant planning to achieve their vision, described by one individual as "digging deep". This process was described as hard work, but also as something beneficial. Participants found this process to be creative, and several described it as "art". One participant explained,

> It was harder because we generally just take a snapshot. It is very portrait orientated. This is more artistic, and you had to think about "how can I communicate my message without just taking an easy picture of somebody's face?".

Participants took a variety of approaches, for example, a participant created a collage and took a picture of it (figure 2), while another altered the back of a t-shirt to send a message (figure 3). Others staged their own possessions to achieve their vision.

For **the majority of** participants, the creative process became both thoughtful and enjoyable. One participant explained,

> They were things that really made you think and find creative ways … especially with the no faces thing…It forced you to find other creative routes, which I thought was really cool.

Despite the enjoyment, participants did struggle to express themselves. They often described the process as complicated or confusing. The consent process and training were not always helpful in alleviating confusion.

> At first, I thought it would be very hard, and the whole thought of it when I explained it to other people and stuff, they were like, "You're insane. I'm not doing

that. What are you crazy? How does that make any sense?" And then, I explained it to them to sort of how more you explained it to them, because when you read this whole thing, when you read it, it's sort of hard to do it.

**Performance Anxiety—**Participants reported anxiety related to fulfilling expectations. Many were concerned that their photos would be inadequate. Even with advance assurance that there was no "wrong picture", the confusion and fear persisted. Participants explained:

> I was confused with this photo thing at first, and not only was I confused, I was nervous I wasn't doing it right, and that some of my things didn't make sense.

> That I'm stinking, I guess. That maybe people wouldn't relate to the photos. That maybe they would think it was corny. Or unhelpful, I don't know. I don't know. That the pictures might not do anything in the end. Change anything.

When doing projects with PWID, researchers need to consider how anonymous photography may affect participant perceptions of their competence and in turn, their motivation.

**Everything is Identifiable—**For most participants, fear was prompted by the need to work around the use of identifying imagery. Restrictions made the process more difficult, and they expressed doubt in their own capabilities to complete the study. One participant explained when asked about the use of anonymous photography,

> It was difficult because how do you find a picture that represents judgment? How do you find something that, not only does it mean judgment to me, but it might mean something to my audience? It was harder to try and find the right representation.

For some, the difficulty was in maintaining a human element. This was a significant barrier for participants, made more complicated in a population that often has identifiable marks on hands and other body parts, for example:

> Like handshakes maybe, like two hands coming together, something like forming bonds in the community or something, you know, stuff like that. And you could still do that, but you'd have to avoid people with tattoos, right, so if you're taking pictures of hands and stuff like that, they can't identify someone. So, I suppose if you were loaded with scars that were really identifiable, or a tattoo or something, but you're not the only one out here with hand scars. Pretty much everybody has them.

Participants also shared strategies that helped to address initial competence challenges, such as the individual below. Such strategies might be useful in training on protocols that require only anonymous photography.

> I actually took a sheet of paper and I wrote down a keyword and I kept asking myself, over a couple days, "what image or picture might represent that?" I jotted down a bunch of ideas until I finally came up with the right concept and then I went out and took a picture. Then I found that once I took a picture, everything else changed.

**Benefits of Photovoice—**Despite the initial challenges and need to revision, participants expressed appreciation for Photovoice, citing a variety of benefits. For some, the project inspired self-reflection:

> Really, I learned a lot about myself, I guess, having to actually think about it. I just learned a lot about my own head, on the whole level of judgment.

> It felt good. The whole thing felt good because it helped me think. Thinking about how things are messed up and how they could be better, I guess. Gave me a better perspective, a better grip.

The most prevalent benefit discussed by participants was the ability to express themselves and the potential for the content to communicate what is often ignored. They explained:

> I think it's important for other people to see how people feel or how they feel when they're treated a certain way. I think that's the only way to really change people's views on things, is if you show how people feel from their own eyes.

> I thought it was good to talk about people's perceptions and feelings. I think too often we talk about statistics and facts and we don't actually get to talking about how a person feels or how does this IV user … It made me feel good that somebody cares to ask me how I feel and how I'm perceived.

Participants also discussed how their experience with Photovoice differed than that of other studies, describing it as more meaningful and purpose-driven:

> It's a lot more unique. You actually have to go out and express yourself. The other ones, you just sat in a room and just filled in A, B, or C bubbles or wrote down … There was no real identity. We were just numbers.

> The other ones were just stupid questions about "How long have you been using?" Stupid shit that's not gonna help anybody, really… If someone could see people like us expressing ourselves, they could see us as human beings a lot easier.

## Discussion

In this study, the majority of participants understood and appreciated protections designed to protect their anonymity as a person who injects drugs. The use of anonymous photos provided practical protection from identifying participants as members of a group participating in illegal activities, which might prompt further marginalization or harm. Anonymization may also mitigate researcher struggles with questions of morality regarding the marginal representation of the poor and oppressed in photography discussed by Harley (2012) and Schratz & Walker (1995), and some of the concern about presenting people or issues in a negative light (Wang & Redwood-Jones, 2001). Further, anonymous photography may alleviate researcher and participant concerns about safety while taking photos of others (Creighton et al., 2018), particularly in settings where illegal activities occur. The restrictions also reduce participant burden in collecting photo releases from those who might be in their images, while eliminating the difficulties researchers may face in obtaining ongoing consent from those photo subjects. Finally, this removes concern about creating yet

another power imbalance noted by Harley (2012), between photographer and the subject of the photograph.

Despite these advantages, participants described a limiting of initial vision that prompted participants to doubt their capacity to fulfil study expectations. Circumventing traditional researcher-subject power dynamics is central to the method (Golden, 2020). Participants in Photovoice projects should feel competent in the partnership and in their evolving role. In this case, participants experienced challenges meeting their own goals within human subjects' protocol constraints. Most significant in this challenge was the desire to have a human element in photos when everything was potentially identifiable, including arms and other human body parts germane to the route of drug administration. The limits may have affected attrition, since participants who did not complete the study often cited lack of time, and participants who did complete the study talked about the extra time needed to plan photos.

Participants often responded to the challenges with creativity, describing the end products as "art" and taking pride in their contributions, an unanticipated benefit of the shift to more staged constructions. This may not be entirely unique to anonymous photography, as Harley (2012) notes that Photovoice often involves more staged constructions than other photography.

There were a few exceptions to the support of anonymous picture taking, with those participants citing the need for more autonomy, and one refusing to comply with the protocol altogether. As researchers often underestimate the ability of those who use drugs to make competent decisions, these moments illustrate a thoughtful and clearly articulated opinion about disclosure risk. This is consistent with other studies demonstrating that PWUD are capable of considerable reflection related to the morals and ethics that govern research (Fisher, 2011).

A lingering and unresolved dilemma is the power dynamic inherent in making safety decisions on behalf of participants. Experiences of the vocal minority in this study support the role of participants in driving decisions. Early engagement of a CAB of PWID might weigh the pros and cons of identifiable photography. While collaboration is ideal, researchers or IRB members may still struggle with a CAB choosing identifiable photos, fearing harms related to identification, or concern about participants changing their minds later, noted by Creighton et al. (2018). Indeed, the lived experience of those who use drugs may shift with time as individual use fluctuates, creating concerns about photos that no longer represent someone's identity. While anonymous photography alleviates that concern, these researcher conflicts are part of the scientist-citizen dilemma (Fisher & Goodman, 2009) in which interpersonal moral obligations as a citizen complicate scientist decision-making. This may be even more mired in cases where prolonged engagement engenders more obligation and alignment with the participant population.

Taking photographs in the digital age compounds this concern. While a social media platform might be a very effective method for spreading the participants' message, photos can be captured by others and used in pejorative ways. Creighton and colleagues (2018)

noted that these risks may persist even in the light of digital protections, due to the risk of taking 'screenshot' images of an entire page. It may be impossible to ensure images are used according to their intent in the digital age, putting the responsibility for disclosing that risk on the research team. While images from this study have not been shared by the research team online, it is possible images may have been shared by participants themselves or captured by individual cell phone cameras during community photo exhibits or presentations and subsequently shared.

While these risks exist, the benefits of digital photography are considerable. Perhaps most important is the capacity for this medium to offer greater control for the participant, who can immediately see whether they have captured their vision and carefully select which images to share with the research team (Murray & Nash, 2017). In this case, participants were given a choice and all selected digital, citing a preference to see images immediately and the desire to align with normative picture taking patterns. Given the anonymous-only protocol, images are not individually identifiable and therefore not a risk to participants personally if captured and reused by others. This may be a good choice for other marginalized communities.

Despite these questions, PWID talked about Photovoice as inherently different and more meaningful than previous research experiences. Benefits included: having a more significant role in the partnership, prompting reflective insight, and facilitating opportunities to speak out. This is consistent with existing research demonstrating PWUD appreciation for Photovoice (Switzer et al, 2015), and PWID finding meaning in telling their stories (Drainoni et al., 2019). Such findings support the use of more empowering, partnership-based protocols when working with PWUD.

### Study Limitations

While this study fills gaps in our understanding of how PWID experience Photovoice, certain limitations exist. First, while most participants felt the restrictions were an acceptable price for protection, the dissenting perspective is critical, particularly where social desirability bias might result in in face-to-face interviewing. Efforts were made here to reduce the potential for this bias, but do not eliminate the risk altogether.

Second, the purposeful sample used in this study may only be transferable to very similar contexts and populations. Further study is needed to understand how this phenomenon might be experienced with other populations, particularly others that experience stigma and discrimination when identified publicly. A final limitation is the inability to describe how PWID might navigate more autonomy related to that identification, and what factors influence the decision to use or avoid identifying images.

### Conclusion

This study explored PWID experience in a Photovoice project that maximized privacy, but at a cost. While participants appreciated the protections, the experience was more challenging. Nevertheless, they cited many benefits of Photovoice and expressed enthusiasm about future participation in similar projects – illustrating a need for more collaborative research that empowers PWID. Results support a need for critical reflection on the part of researchers to create protocols that offer substantive protection while maximizing participant autonomy.

Future efforts need to explore this balance, as PWID are motivated to share their images and stories to inspire change:

I wish that there were maybe a couple more that were like this, maybe so people could see how we live almost a little more. If people are forced to see how we live and what we have to go through, then maybe they'd be more willing to help…

**Best Practices—**In this study, anonymous photography protection provided safety to participants and addressed a host of researcher concerns about photo-based images, power and representation. Whether the benefits of researcher-imposed limits outweigh participant concerns about autonomy and representation is the critical question. Direct inquiry about how participants feel about measures implemented to protect them is a necessary step to ensure more ethical research practice. These complex questions should be part of all ethics conversations in Photovoice research planning, and no such research should occur without advance ethics discussions.

The choice to use only anonymous photos may best be made in in collaboration with a CAB of participants or left to participants themselves. However, a decision to use identifiable photography with PWID might impose researcher or IRB concerns of potential harm from loss of privacy. In these cases, it is critical to remember that consent in Photovoice should be an "iterative process" (Murray & Nash, 2017), allowing for multiple opportunities to shift perspectives about the use of photos, and transparent discussion of how photos will be used, and any risks associated with their use in the digital age.

**Research Agenda—**Future studies should include diverse samples to explore how additional stigmas related to race or sexual minority status compound or mitigate the need for anonymity or choice in representation. Current discussions of structural racism, mass incarceration, and drug-related harm necessitate purposeful exploration of how African American PWUD experience studies like this one and affect perspectives of privacy, competence, and creative autonomy. Of additional importance are studies that explore how participants whose behaviour is stigmatized make choices about identification or disclosure of self in photos.

Finally, future research should continue to address risks and benefits of digital photos, with or without anonymity, and navigating ongoing consent in a digital context. Switzer and colleagues (2015) remind us that research context is also critical to making these decisions, as it dictates how individuals will engage with photography. As Bugos et al. (2014) posits, the need to understand participant experience with the method is a critical path forward.

**Educational Implications—**These findings have broad implications for researchers who use photobased methods with marginalized communities, and for members of institutional review boards who are considering these proposals. The most salient lesson is the need for critical reflection about human subjects' protections and any effects on participant competence or agency, and the importance of understanding participant perspectives about those protections. Ethics education should assist both researchers and members of IRBs to critically reflect along the Belmont principles to illuminate the balance between protection

and participant rights. Further, such education should provide tools for researchers to prepare for purposeful conversation with CABs to ensure participant perspectives are not only validated but also incorporated into ethics protocols.

## Acknowledgments

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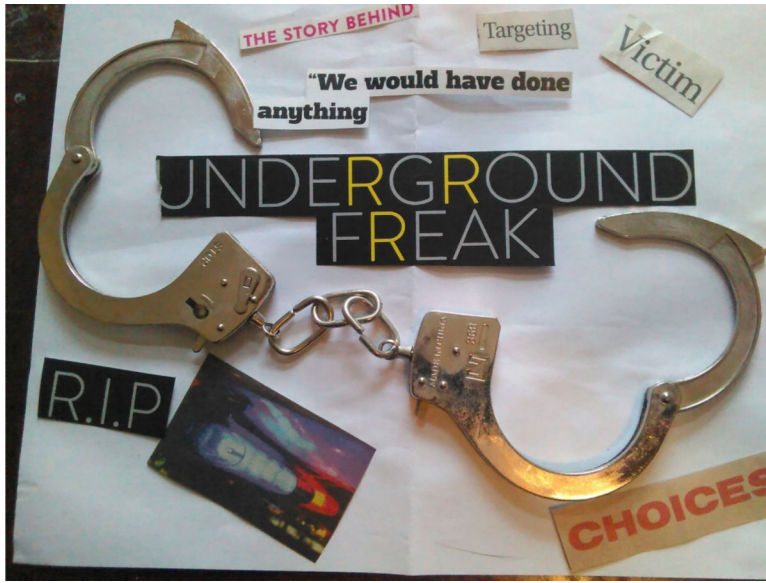
**Figure 1:**
The Vocal Minority

**Figure 2:**
Participant Re-visioning Example

**Figure 3:**
Participant Re-visioning Example