

"I liked just that it was a communal thing": Feasibility and acceptability of engaging with transgender and gender-diverse persons in a digital photovoice research study on commercial cigarette smoking risk and protective factors Digital Health
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Abstract

Background: Commercial cigarette smoking is the leading modifiable risk factor for more than 16 types of cancer. Over one-third (35.5%) of *transgender and gender-diverse* (TGD) adults smoke cigarettes compared to 14.9% of cisgender adults. The objective of this paper is to describe the feasibility of enrolling and engaging with TGD persons in a digital photovoice study to examine smoking risk and protective factors through real-world experiences (Project SPRING).

Methods: The study comprised a purposeful sample of 47 TGD adults aged ≥18 years who currently smoke and live in the United States (March 2019–April 2020). They participated in three weeks of digital photovoice data collection using Facebook and Instagram closed groups. A subsample participated in focus groups to explore smoking risks and protective factors in greater depth. We summarized the enrollment strategies and accrual rates, participant engagement (posts, comments, and reactions) during the photovoice data collection to assess study feasibility, and respondent feedback on acceptability and likability during and after the study.

Results: Participants were recruited via Facebook/Instagram advertising (n=33) and via Craigslist/word-of-mouth (n=14). Costs ranged from \$29 via Craigslist/word-of-mouth to \$68 per recruited participant via Facebook/Instagram advertising. On average, participants posted 17 pictures of smoking risks/protective factors, commented 15 times on others' posts, and had 30 reactions within their group over 21 days. Participants' rating of the acceptability and likability of the study were positive based on closed- and open-ended feedback.

Conclusion: The findings of this report will inform future research to engage with TGD community-engaged research to develop culturally tailored interventions to reduce smoking prevalence among TGD individuals.

Keywords

Digital photovoice, transgender and gender diverse, cigarette smoking

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Introduction

Commercial cigarette smoking is the leading modifiable risk factor for more than 16 types of cancer including lung, head and neck, stomach, liver, pancreas, colon and rectum, and bladder cancers. We refer specifically to commercial cigarette smoking in this article, recognizing that ceremonial tobacco use is sacred for many Indigenous peoples. Despite the decrease in smoking rates nationally, the prevalence of smoking remains high among sexual and gender minorities.² Specifically, transgender and gender-diverse (TGD) adults have 2-3 times higher use of nicotine and tobacco product than cisgender adults.³ TGD persons are individuals who have a gender identity, behavior, or self-expression that does not align with their sex assigned at birth while cisgender individuals are those who have a gender identity, behavior, or self-expression that corresponds to their sex assigned at birth. Research to increase the understanding of factors that contribute to increased smoking rates or protect against smoking is currently lacking and is urgently needed to develop effective and culturally sensitive prevention and cessation interventions for TGD populations.

An estimated 1 million TGD adults live in the United States, which means that \sim 350,000 are at risk of developing smoking-related cancers. As such, the burden of smoking disproportionately impacts the TGD community as compared to their cisgender counterparts.² The increased smoking rates among TGD persons have been attributed to the following: minority stress^{4,5} as a coping mechanism for the persistent social and economic marginalization and exclusion experiences such as stigma, ^{5–8} discrimination, ^{5,9,10} violence, ^{5,8} victimization, ^{5,6,8} abuse, ^{5,6,8} low socioeconomic status (SES), ^{4–6,11} and limited employment opportunities. 4-6,11 Also, these smoking disparities have been influenced by targeted tobacco marketing strategy among lesbian, gay, bisexual, and transgender (LGBT) communities.¹² Compounding the problem is the fact that TGD individuals lack equitable access to health care^{5,6,8} and therefore face numerous challenges in obtaining treatment for smoking cessation.^{5,13,14} Research suggests that, given the appropriate resources and opportunities, TGD adults who smoke are just as likely as cisgender adults who smoke to want to quit. 15-19 However, they may be unlikely to seek cessation resources through clinical encounters. 16 Unlikeliness to seek cessation resources in a clinical setting may be due to structural and financial barriers, and historical stigmatization.²⁰ This leads to a need to provide cessation resources through other means and platforms. Although there is growing interest in utilizing social media for promoting sexual health among LGBT populations, there is limited research on the use of online social media platforms for tobacco-related research and smoking cessation interventions among TGD populations.²¹

The larger objective of this project was to examine TGD individuals' experiences of risk and protective factors of smoking using a photovoice approach. Previous research has examined the experiences of TGD individuals using photovoice. We elected to use photovoice in order to empower TGD individuals to not only understand risk and protective factors that influence their smoking habits but also to empower TGD individuals to work collaboratively with researchers to inform our understanding and future interventions. Further discussion of the photovoice methodology as well as the findings of this study can be found in our previously published work.

The objective of this article is to describe the feasibility of enrolling and engaging with TGD persons in a digital photovoice study. The findings of this study will inform future research to engage with TGD digital-enabled community-engaged research to develop culturally tailored interventions to reduce smoking prevalence among TGD individuals.

Methods

Participants and eligibility criteria

In order to be eligible for the study, participants had to be 18 years old or older, currently smoke cigarettes, identify as transgender, nonbinary, or any other gender different from their sex assigned at birth, speak English, and be a regular user of Facebook or Instagram. Current smoking was defined as having smoked cigarettes at least once in the past 30 days. A regular user of Facebook or Instagram was defined as checking the platform at least once per day.

Enrollment and attrition

In order to reduce attrition rates, particularly after data collection began, we designed a study protocol with several early contacts via Zoom and phone prior to enrolling in the study. The first step involved a screening call in which we ensured that participants were eligible for the study and then a virtual training session where we went explained the study procedures in more depth. After this, participants consented, emailed the baseline survey, and enrolled in a secret Facebook group or Instagram group chat, depending on which platform we were enrolling at the time of contact. All groups were enrolled sequentially and not randomly. Within this group, participants posted pictures of the risk and protective factors of smoking they experienced in their daily lives over 21 days. After 21 days, participants were invited to a focus group where the images they had shared were discussed as a group. A feasibility survey was completed during the focus group as well. Additional details of the study protocol are described in a previous article based on this study.²² The data collection and recruitment protocols were reviewed and approved by the HSPH IRB. Forty-seven total participants enrolled in the

study, with three withdrawing before posting any pictures, one after one week of posting pictures and 43 completing the full three weeks. Twenty-nine participants completed the initial focus groups. Scheduling was a factor in the attrition rates for focus groups.

Overall, there were five Facebook groups with a range of 2–6 active participants in each group and three Instagram groups with a range of 7–9 active participants. We selected a start date for a group when we had at least three participants enrolled and ready to enter a study and would enroll new participants into that group until the launch date. In the group with only two, other participants were enrolled but withdrew after the start date and we did not want to disrupt the study for the active participants.

Recruitment strategies

Online recruitment via social media is frequently used to reach research participants beyond recruitment through specific organizations or common spaces. This approach also allowed us to reach TGD individuals who did not connect with the community in other ways or were geographically distant. Our primary recruitment method was Facebook advertising, supplemented by Craigslist ads, word of mouth, flyers, and attending conferences with flyers. However, we will primarily describe our method of recruitment on Meta.

We used Meta ads to recruit participants, alternating our campaign strategy based on ads that were more successful according to Meta impressions and removing ads that were less successful. Meta, then Facebook, maintains an ad platform that allows ads to appear on several platforms, including Facebook, Facebook Messenger, and Instagram, all of which we utilized. Our campaign strategy included a total of six ad campaigns run on Facebook's ad campaign platform, with various, images, and geographic targeting. The text remained consistent within a campaign but did change slightly over time. Targeting by age was set at 18–65 + and gender was set to all genders as Facebook did not permit targeting based on gender identity. Ads were determined to be successful based on the number of messages we received and the individuals enrolled.

We used ad targeting to direct our ads to users who are more likely to identify as TGD. Using interests identified by previous research studies, we selected relevant interests to use for our targeting. We also added new interests over time as we became aware of different potential interests. Smoking was occasionally included as an interest on an experimental basis to interests focused on gender identity. When included, the audience had to match interest in "gender identity interests" and "smoking" interests in order to be shown our ad. However, having smoking as a separate interest was not successful in recruiting participants and was eventually removed. The interests we used to target are listed in Appendix A, however, most were removed by Facebook as of March 2022. This was done

by Meta to improve user experience and to remove topics some users might view as sensitive.

Geographic targeting initially focused on only one Northeast city and we subsequently expanded recruitment to include the entire United States. We began using a radius of 25 miles from the center of the Northeast city, then expanded to 50 miles, allowing us to incorporate most of the large cities within the state. Additionally, we used a summer vacation spot known to be friendly and welcoming to the LGBT community with a radius of 16 miles for certain summer weekends. Finally, after expanding our eligibility criteria, we expanded the geographic targeting to the entire United States.

In addition to Facebook advertisements, we also recruited through flyers at local community organizations, word-of-mouth, local Craigslist pages and in-person conferences and other venues. The text of flyers and Craigslist postings was consistent with the Meta ads. Word of mouth, particularly from previous participants letting acquaintances know about the survey was the best method for recruiting participants. Many of the initial participants were recruited through Facebook advertising.

In total, 80% of the screened participants who were recruited by word of mouth through flyers, Craigslist, community organizations, or referrals were enrolled in the study. In comparison, 62.5% of the screened participants recruited through Facebook were enrolled.

Incentives

We provided incentives in the form of e-gift cards from two major retailers. Participants received gift cards in the amounts of \$10 for completing the baseline survey, \$90 for completion of the 21 days of Facebook posting (broken up into increments of \$20/week with a \$30 bonus), and \$150 total for attending a two-part focus group.

Measures

We used several measures to assess the effectiveness of our social media ads. Reach was reported by Facebook as the number of unique individuals who saw our ads. Impressions refer to the number of times the ads were shown to individuals but do not capture views by unique individuals. The cost per message is the total cost of ads divided by the number of messages received. The cost per participant is the total cost of ads divided by the number of enrolled participants.

Engagement metrics during photovoice data collection

We collected the engagement metrics of each participant by reviewing their completion of daily posts of photos, whether they left a comment for another participant's post and reactions such as likes for messages posted by the study team and other participants.

Survey measures

Prior to or at the beginning of the focus group, we asked participants a series of nine survey questions on their experiences with the study procedures including their ratings of convenience in participating, the usefulness of the instructions, whether they had problems posting a photo, and how comfortable they felt in engaging with other participants on social media. Response options were on 5-point Likert-like scales (e.g., very convenient to very inconvenient). We further asked participants an open-ended question, "Before we begin the focus group, do you have any final thoughts or comments that you would like to share regarding the data collection and social media interactions?" We summarized the descriptive statistics of the quantitative measures, coded open-ended comments as favorable versus unfavorable about the study protocol and included illustrative quotes.

Statistical analysis

In order to describe the feasibility and engagement of participants, we ran several descriptive analyses. For engagement metrics, we conducted descriptive statistics to summarize each group and engagement method. Means were also calculated for feasibility measures to obtain a general sense of perceived feasibility. Due to the small sample size, we did not run any tests of significance as we were not powered to do so.

Results

Participant demographics

In total, 47 participants enrolled in the study. The mean age of participants was 26 years and a majority (53%) identified as nonbinary or gender nonconforming, 15% identified as male/trans male/trans man, 17% identified as female/trans female/trans woman, and 15% identified with other gender identities. The majority of participants identified as nonheterosexual (95.7%) and 47% identified with multiple sexual orientations. About half the participants (55%) smoked daily and half smoked occasionally in the past 30 days. The majority of the participants (85%) were non-Hispanic, with 55% identifying as White, 13% Black, and 32% other racial/ethnic identities. Additional details of participant characteristics are summarized in Table 1.

Enrollment process

As a result of Facebook and Instagram advertisements, we were able to successfully enroll n = 32 participants, with an additional 15 people enrolled via other recruitment methods, for a total of 47. Table 2 is a summary of the overall reach and pathway of participants who saw our advertisements and contacted us asking for information,

Table 1. Participant characteristics.

Characteristics	M (SD)	N (%)
Age (in years)	26.0 (8.4)	
Sex assigned at birth		
Male		17 (36.2)
Female		30 (63.8)
Gender identity		
Male/trans male/trans man		7 (14.9)
Female/trans female/trans woman		8 (17.0)
Nonbinary/gender nonconforming		25 (53.2)
Other		7 (14.9)
Sexual orientation		
Heterosexual		2 (4.3)
Gay or lesbian		4 (8.5)
Bisexual		8 (17.0)
Pansexual		4 (10.6)
Queer		6 (12.8)
Multiple identities		22 (46.8)
Race		
White only		26 (55.3)
Black only		6 (12.8)
Other		15 (31.9)
Ethnicity		
Hispanic		7 (14.9)
Smoking status		
Occasionally smoke		21 (44.7)
Smoke daily		26 (55.3)
Other tobacco product use in the past 30 days		
Electronic cigarettes		16 (34.0)
		(continued)

(continued)

Table 1. Continued.

Characteristics	M (SD)	N (%)
Cigars		10 (21.3)
Pipe		4 (8.5)
Hookah		8 (17.0)
Snus		1 (2.1)
Kreteks		6 (12.8)
Education		
High school or below		12 (25.5)
Some college or Associates degree		25 (53.2)
Bachelor's degree or higher		10 (21.5)
Employment		
Employed		25 (53.2)
Unemployed		7 (14.9)
Homemaker		1 (2.1)
Student		8 (17.0)
Disabled		4 (8.5)
Other		2 (4.3)

either via comment or direct message. The goal of the Facebook ad was to send a message to the team to which we would respond with information about the study and attempt to set up a screening call. The table shows the number of total impressions and overall reach of the Facebook ads and how those resulted in messages to the study account. Once a participant had reached out to the study, the research team would send multiple messages in an attempt to remind them about the study and increase enrollment.

Online recruitment was effective, but was more expensive than initially expected. In total, Facebook advertising cost approximately \$2229.73 (\$47.47 per eligible participant; \$67.57 per enrolled participant). Despite the high cost, we were able to recruit a sample from across the United States, allowing the study to include more diverse experiences.

Engagement during photovoice

On average, participants posted 17 pictures of smoking risks/protective factors, commented 15 times on others'

Table 2. Enrollment (meta reach).

Status	Meta recruitment
Impressions	330,971
Reach	205,282
Messages	330
No response	169
Not interested	73
Referring a friend	4
Ineligible-did not smoke cigarettes	15
Ineligible-Spanish speaker	2
Ineligible-not transgender	20
Ineligible-under 18	1
Ineligible-unclear	5
Could not travel	2
Other reason	7
Enrolled	32

posts, and had 30 reactions within their group over 21 days. The average number of pictures posted by Facebook participants (14) and Instagram participants (18) were similar. However, there was more discussion on Instagram (an average of 27 comments per person) over the course of the three weeks compared to an average of 2.5 comments on Facebook.

Survey responses

The feasibility survey was completed by 30 participants, as it was a part of a first focus group. Table 3 shows the means and SDs of each of the nine survey items on feasibility, which showed participants felt positive about the study in general (all means were below 2 on a scale ranging from 1 to 5 where lower scores indicate more favorable perceptions). Their qualitative feedback suggested important areas for improvement in future research utilizing this approach. One respondent found the instructions to be challenging in terms of finding reasons for smoking or not smoking as they felt that physical addiction rather than environmental triggers was more associated with their smoking. Therefore, finding a photographic form of reasons to smoke was difficult for this participant. They also suggested rephrasing survey

Table 3. Feasibility.

	M (SD)
In general, how convenient was participating in this study (1-very convenient, 5-very inconvenient)	1.70 (0.92)
How do you rate the instructions provided (1-very useful, 5-very unuseful)	1.42 (0.86)
How often did you have problems posting pictures (1-never, 5-everyday)	1.90 (0.92)
How often were you hesitant posting a picture (1-never, 5-everyday)	1.93 (1.05)
How do you rate this kind of study (1-very positively, 5-very negatively)	1.43 (0.68)
How comfortable did you feel engaging with other participants on social media? (1-very comfortable, 5-very uncomfortable)	1.8 (1.06)
After this study, how comfortable would you be to participate in similar studies in the future? (1-very comfortable, 5-very uncomfortable)	1.13 (0.35)
How easy or hard do you think a social media study is to participate in (1-very easy, 5-very difficult)	1.53 (0.90)
How effective do you think a social media study is for transgender and gender nonbinary persons? (1-very effective, 5-very ineffective)	1.72 (0.84)

questions to be more TGD-sensitive including using nonbinary pronouns and ensuring the study team included TGD researchers who could relate to their community's experiences. Another participant commented on not knowing if it was appropriate for them to contradict what the group was discussing and suggested closer moderation of the group's conversation. One participant commented that they were hesitant about posting images about other drug use that makes them want to smoke and suggested clarifying boundaries with other participants early in the study:

One reason I was sometimes hesitant to post was because I was unsure of what the boundaries were for what was okay to post. For example, I smoke weed, and being high often makes me want to smoke cigarettes, so I considered sending a picture to that effect, but I was worried about whether images of or references to drugs might be problematic. I think it might help if guidelines about posts were made a bit more specific, and if there was an opportunity at the beginning of the study for participants to clarify boundaries with each other.

Other participants included comments about their positive experience during the study and appreciated having interactions with other participants and helping to improve the understanding of TGD issues in relation to smoking:

This was a fantastic experience and my fellow group members made it all super easy to want to keep pushing for positivity. I'm glad to have seen others such as myself want to do their best to try and stay away from the tobacco.

Thank you all for being so patient with everyone and being attentive! I hope we can help you all get a better gauge of trans issues and their relation to smoking.

I am still not convinced that smoking is the most important thing to focus on for most LGBT smokers but seeing and watching people's stories and understanding where there at helped me to better get this study's goal.

Qualitative feedback from focus groups

Focus group participants reiterated that the study was easy to participate in and provided an opportunity for reflection by asking for daily posts on why they smoked. One participant described both frustration and appreciation in having to think deeply about why they wanted to smoke:

that was really cool to me to be able to try and analyze these underlying reasons of why I'm smoking. And so, I liked that, but I was very frustrated because I really had to think beyond like, okay. It's time for another cigarette.

Another participant mentioned that they appreciated the sense of community that developed within the focus group:

But I liked that, and I also liked just that it was a communal thing. And I've done other research projects before and studies and things like that—research projects—research studies that it's just you, and I've done sleep studies and things. But it's like interesting to see how other people communicate with each other in those dynamics, and that was really cool.

While the primary objective of the focus groups was not to discuss the feasibility of the data collection portion, some participants expressed that completing the study protocol was feasible and they enjoyed being a part of it.

Discussion

Overall, we found that this study was feasible to conduct with TGD adults who smoke cigarettes. Online recruitment allowed participants to join the study from anywhere within the United States. This allowed for a wider variety of perspectives and experiences to be shared. Due to the increase

in internet and online connectivity and socializing, particularly during the COVID-19 pandemic, it is important for research studies to include greater online connection.

Before enrolling in the study, potential participants were required to complete a screening call and online Zoom call training. Because of this time investment at the start, attrition during the 21 days of actively sharing and posting was relatively low. However, the high barrier to enrollment may have impacted the effectiveness of recruitment strategies, both online and in person.

More traditional in-person recruitment was also effective and had lower costs than internet recruitment. This is important to note, especially with online recruitment policies on Facebook changing, the cost and effectiveness of Facebook recruitment will be impacted.

Experience with Facebook recruitment

A major plus to recruiting through Facebook advertising is the user-friendly platform for researchers with minimal experience in marketing. Resources such as courses on Lynda (now LinkedIn Learning), news and tech articles and other researchers' experiences aided study team members to learn how to conduct recruitment on Facebook. Additionally, Facebook had interest groups that allow for the indirect targeting of the LGBTQ community. While no platform currently allows for targeting ads based on sexual orientation or gender identity, Facebook did allow targeting ads on interests central to the LGBTQ community and allies at the time of this study. This allowed for more efficient use of funds. However, most targeting options were no longer available as of March 2022 with changes to the advertising policy on Facebook.26 Interests related to smoking are also an option on Facebook advertising. While we found less success targeting those interests because of our study's focus on TGD individuals, they are a potential targeting option.

One important downside to Facebook recruitment is receiving negative messages and comments on our ads. By leaving comments open, ads showed more engagement and had the potential to reach more people. However, this had to be balanced with a desire to avoid discriminatory messaging through community posts on our ads. Team members all took an active role in hiding these comments when they saw them. However, in some instances, negative comments may have been inadvertently viewed by potential participants. Additionally, these comments elicited mental stress on the research team that may have been greater if they were members of the TGD community themselves and/or if they had been exclusively working from home and did not have support from other team members during the study.

Limitations

The initial focus on bringing participants to a single geographic location reduced the effectiveness of advertisements in the first several months. This also led to difficulty in recruiting because participants were ineligible to participate if they could not attend the focus group, increasing costs for recruitment.

Feasibility measures during the study were among a small sample and therefore cannot be generalized to a larger study including more participants. Engagement across the two platforms differed. This may be due to the majority of Facebook groups (4) being limited initially to a Northeast city while the fifth group began as strict lockdowns to prevent the spread of COVID-19 were taking place across the United States in March 2020. Instagram groups also tended to have more participants and two out of the three Instagram groups took place before any lockdowns in the United States, while the third began immediately prior to lockdowns taking place and continued through the first two weeks of lockdowns.

Feedback about the study protocol was also limited to participants who attended the focus group and may therefore omit feedback who were unsatisfied with the first part of the study. The post-survey was primarily completed by participants who participated in the focus groups as it was an activity during the focus group.

The sample was not racially diverse and involved primarily young adults, although adults of any age were invited. Additionally, the requirement that participants provide their own phones and consistent internet access may have provided a barrier to some participants, particularly those of lower SES. Additionally, participants had to be regular users of Facebook or Instagram, potentially excluding participants who primarily use other platforms. Overall the study was not representative and future research should use large-scale representative surveys to address this. Future research may also consider comparisons with cisgender sexual minority and/or heterosexual adult smokers to illustrate similarities and differences across groups. Future research should also aim to reduce barriers to participation due to varying digital access and pay attention to intersecting identities that may impact a participant's experience within the group, particularly the role of age and their comfort with social media or platforms primarily used, as this may vary across generations.

Conclusion

The findings of this report will inform future research engaging with the TGD community, particularly in developing acceptable and feasible interventions to reduce smoking prevalence across the community. In particular, it illustrated the feasibility of using Facebook groups and Instagram chats to conduct health research and potentially an intervention among TGD individuals. It also showed the need for researchers to plan for various recruitment methods when conducting research studies involving TGD individuals. Future research should incorporate

online research with the TGD community and utilize social media as a way to connect with geographically distant groups.

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Appendix A

• List of interest used to create target audience on Facebook Rainbow flag (LGBT movement), Transsexualism, Pride, LGBT parenting, Lady Gaga, Pride parade, Gender-specific and gender-neutral Transgender Day of Remembrance. pronouns. Genderqueer, The Advocate, LGBT culture, LGBT Gender identity, community, Human Rights Campaign, Transgender activism, LGBT rights in the United States, The Trevor Project, Transgenderism, National Center for Transgender Equality, Gender equality, LGBTQ Nation, LGBT social movements, Beyoncé, Laverne Cox, The Lesbian, Gay, Bisexual and Transgender Community Center, BuzzFeed LGBT or LGBT in the United States.