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Acceptability and Feasibility of Online, Asynchronous Photovoice with Key Populations and People Living with HIV

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Abstract

Photovoice is an action-oriented qualitative method involving photography and story-telling. Although photovoice yields a powerful form of data that can be leveraged for research, intervention, and advocacy, it has arguably been underutilized within HIV research. Online, asynchronous photovoice methods represent a promising alternative to traditional in-person methods, yet their acceptability and feasibility with key populations and people living with HIV (PLWH) have yet to be explored. The current study describes the methods and evaluation of an online, asynchronous photovoice project conducted with 34 members of key populations and PLWH in Malaysia in 2021. A HIPAA-compliant website incorporating a series of instructional videos was created to facilitate participant engagement and data collection. Quantitative and qualitative indicators suggest that participants found the project to be highly acceptable and feasible. Online, asynchronous photovoice methods hold potential for increasing the scale of this powerful and versatile qualitative research method with key populations and PLWH.

Keywords HIV · Key populations · Photovoice · Qualitative methods

Resumen

La fotovoz es un método cualitativo orientado a la acción que usa fotografía y narración de historias. Aunque la fotovoz produce una poderosa forma de datos que se puede utilizar para la investigación, la intervención y la promoción, podría

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decirse que ha sido poca aplicada en la investigación del VIH. Los métodos de fotovoz asincrónicos en línea representan una alternativa prometedora a los métodos en persona tradicionales, pero aún no se ha explorado su aceptabilidad y viabilidad con los grupos de población clave y las personas que viven con el VIH (PLWH por sus siglas en inglés). El estudio actual describe los métodos y la evaluación de un proyecto de fotovoz asincrónico en línea realizado con 34 miembros de grupos de población clave y PLWH en Malasia en 2021. Se creó un sitio web compatible con HIPAA que incorpora una serie de videos instructivos para facilitar la participación y la recopilación de datos. Los indicadores cuantitativos y cualitativos sugieren que los participantes encontraron el proyecto altamente aceptable y realizable. La fotovoz asincrónica en línea es un poderoso y versátil método cualitativo de investigación la cual tiene potencial para usarse más con los grupos de población clave y PLWH.

Introduction

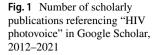
The use of photovoice has been increasing in health research generally, as well as HIV research specifically, in recent years [1, 2]. Photovoice is a qualitative research method that enables individuals to represent their lives and communities through photographs and stories [3]. Photovoice, which has long been used as a method to engage communities affected by HIV in participatory action research [4], has recently been gaining in popularity among HIV researchers [1]. Scholarly publications referring to HIV and photovoice have more than doubled in the past decade (see Fig. 1), reflecting a trend that has been observed with photovoice research more generally [2]. Photovoice may be increasing in popularity, in part, because it is a culturally- and trauma-responsive method [2] that yields an insightful form of data that can be leveraged for several purposes. Photovoice can be used to answer descriptive research questions [5] and has yielded insight into the needs and experiences of diverse people living with HIV (PLWH¹) [1]. Photovoice can also be used in interventions to contribute to attitude and behavior change. As examples, photovoice has been used to build empowerment [8, 9] and support disclosure processes [10] among PLWH as well as to reduce stigma towards key populations among clinicians [11]. Finally, photovoice can be used for advocacy to promote social change [1, 3, 12]. Photovoice projects are often shared with communities, including via public exhibits, which can facilitate consciousness raising, community building, and action planning [9].

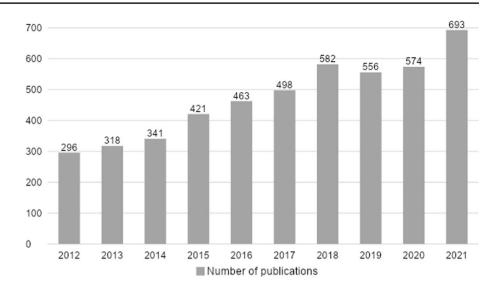
Teti et al., who recently reviewed photovoice studies with PLWH, concluded that although photovoice has been successfully used as a research method with PLWH and has potential to transform practice and policy, it is currently underutilized within HIV research [1]. Photovoice projects have traditionally been conducted in person and synchronously. Yet, this format may not always be feasible and acceptable due to participant locations and/or concerns related to confidentiality (e.g., in places with strong HIVrelated stigma) or safety (e.g., during COVID-19 surges). Conducting photovoice projects online and asynchronously (i.e., not live or in real time) represents a promising alternative to confidentially and safely engage more members of key populations [e.g., men who have sex with men (MSM), transgender women (TGW), female sex workers (FSW), and people who inject drugs (PWID)] and PLWH in photovoice projects and responds to calls to engage in "responsive innovation" in photovoice methods [2]. The current study describes the methods as well as acceptability and feasibility of an online, asynchronous photovoice project to contribute to increasing the scale of this highly versatile and actionoriented qualitative method for HIV research.

In-Person, Synchronous Photovoice: Traditional Method

Photovoice projects traditionally involve in-person, synchronous interactions between facilitators, participants, and other stakeholders such as community members and policymakers. Key elements and steps for photovoice projects have been described by Wang and Burris [3], who first introduced the method in 1997, and others who have reviewed the use of photovoice since its introduction [5, 12, 13]. Photovoice projects often begin with in-person trainings where facilitators and participants interact. Trainings vary in duration and content, with most addressing photography skills and some additionally addressing issues of research methods, safety, ethics, and social power. Trainings represent an opportunity for reciprocity between researchers and participants. In addition to receiving a stipend for their time, participants can build photography and other skills via these trainings. Participants then take photographs in their communities that are related to the goal of the project. Next, facilitators and participants typically re-convene to select significant photographs, add captions to photographs, and identify themes and issues captured by the photographs and captions via discussion. Finally, photovoice projects that aim to engage in advocacy or social change may culminate in a public exhibit that could include the facilitators, participants, and other stakeholders such as community members

¹ We recognize that preferred terminology within the HIV field evolves. As recommended by the current UNAIDS Terminology Guidelines [6] and National Institute of Allergy and Infectious Diseases HIV Language Guide [7], we use the term people living with HIV (PLWH) in this manuscript.





and policymakers. Such public events also have the potential to facilitate dissemination.

Photovoice projects have yielded valuable insights into the lives, needs, assets, and priorities of a wide range of populations over the past 25 years, including key populations and PLWH. Golden argued that photovoice is well-aligned with health equity goals and is well-suited for research that engages with stigmatized topics and vulnerable populations [2]. In their review of photovoice studies in the health and public health literatures, Catalani and Minkler found that photovoice as a research methodology has been almost exclusively applied to descriptive research questions and analysis typically involves triangulating several forms of data (e.g., photographs, written reflections, and group discussions) [5]. They concluded that photovoice projects yield improved understanding of community needs and assets. In their review of photovoice studies with PLWH, Teti et al. found that this is also the case for HIV research [1]. As examples, photovoice projects have yielded insights into aging and HIV among Latino/a activists-artists living with HIV [14]; challenges, resilience, and hope among women living with HIV [15]; disclosure among PLWH [10]; priorities for HIV/STI prevention among rural American Indian communities [16]; and situations and locations that place rural, African youth at risk for HIV [17]. Over half of the studies reviewed by Teti et al. involved an advocacy or action component, most often occurring via an exhibit of participants' work [1].

In-person, synchronous photovoice may not always be acceptable to or feasible for key populations and/or PLWH. In places where key populations and PLWH are geographically dispersed, it may not be feasible to physically gather for a multi-phase in-person project. Barriers to in-person care experienced by rural key populations and PLWH, such as transportation [18], are also often barriers to participation in research. Additionally, traditional photovoice methods may not be feasible during COVID-19 or other similar infectious disease surges, when in-person gatherings could threaten the health and safety of key populations and PLWH. Finally, inperson photovoice may not be acceptable to key populations and PLWH in places with strong cultural or structural stigma associated with HIV, sexual and gender diversity, drug use, and/or sex work. Key populations and PLWH may decline participation because they fear consequences ranging from gossip to arrest if their key population or HIV status were to become known due to their participation in a project related to HIV or key populations. In these places, it may not be safe to hold in-person photovoice projects and/or individuals who fear gathering in person may not participate, threatening the generalizability of results. Indeed, disclosure of HIV, illicit drug use and/or sexual activities, and stigmatized statuses has been identified as an ethical challenge for photovoice projects involving key populations and PLWH [19].

Online, Asynchronous Photovoice: New Method

The widespread, global uptake of smartphones (i.e., internetenabled mobile phones with computing functionality) and engagement in social media may create new opportunities for photovoice. Over 80% of people worldwide were estimated to have smartphones as of 2022 [20]. Global disparities in smartphone access persist; yet, smartphone access is increasing in low- and middle-income countries [21] and are becoming increasingly popular resources for HIV interventions in these settings [22, 23]. The global uptake of smartphones means that many key populations and PLWH now have access to and experience with a camera and an internetenabled device, the key tools needed for online, asynchronous photovoice projects. Moreover, rates of social media engagement are also increasing worldwide [21]. Instagram, one of the world's most popular social media sites, revolves around sharing photographs and captions. Many key populations and PLWH globally have experience with taking, captioning, and sharing photographs via social media platforms.

Researchers have begun to explore the possibility of conducting online photovoice projects. Lichty et al. found an online photovoice project to be acceptable and feasible with American youth [24]. This project involved both synchronous and asynchronous components: training workshops were held with participants synchronously, whereas participants uploaded and commented on photographs asynchronously. Researchers identified benefits of online photovoice, including increasing the scale of the project by involving more participants and preserving project resources. To our knowledge, the methods for conducting asynchronous, online photovoice projects as well as the acceptability and feasibility of these methods with key populations and PLWH have yet to be described.

Current Study

Online, asynchronous photovoice methods offer a promising alternative to in-person, synchronous photovoice methods in cases when members of key populations and PLWH cannot gather due to geographic constraints and/or concerns regarding confidentiality or safety. Yet, online, asynchronous photovoice methods with key populations and PLWH have yet to be described, representing a barrier to the adoption of this methodology. Therefore, the first goal of this manuscript is to describe the methods that our team used to conduct an online, asynchronous photovoice project with sufficient detail that they could be replicated by other research teams. The second goal is to assess the feasibility and acceptability of the online photovoice project, as indicated by responses to an online survey and completion of photovoice submissions.

Methods

The photovoice project was part of a program of research focused on addressing HIV-related stigma among clinicians in Malaysia. This program of research involved a partnership between clinicians, social scientists, and community members from Malaysia and the United States. The project was designed to serve two purposes, including (1) answering descriptive research questions regarding key populations' and PLWH's experiences of stigma in healthcare settings, and (2) providing intervention content to reduce HIV-related stigma among clinicians in the context of a longitudinal randomized controlled trial. The project was conducted in Malaysia in the fall of 2021. Below, we provide information about the study context. To achieve the first goal of the current study, we describe our methods for conducting this online, asynchronous photovoice project. To achieve the second goal, we describe our methods for assessing perceived acceptability and feasibility of online, asynchronous photovoice.

Context

Malaysia is a high, middle-income country in Southeast Asia. The national language is Bahasa Malay, and English is the common language spoken by multi-ethnic, multi-lingual Malaysians. HIV is concentrated among Malaysian key populations, including MSM, PWID, TGW, and FSW, and prevalence ranges from 15.8 to 54.0 times those of the general population [25]. Yet, members of these key populations are, at best, half as likely as members of the general population to know their HIV status [25]. Stigma towards key populations is structurally sanctioned in Malaysia, where secular and/or Shariah laws criminalize same-sex sexual practices, gender expression of transgender persons, drug possession and use, and sex work [26-28]. Protecting the identities of key populations and PLWH is therefore critically important. The project took place in 2021 when in-person data collection was challenging due to the COVID-19 pandemic. To curb the spread of COVID-19, periodic Movement Control Orders issued by the government restricted movement and public assembly within Malaysia. Although our team had initially planned to conduct a traditional, in-person photovoice project, the pandemic made it challenging to safely gather participants. We therefore conducted the photovoice project online.

Photovoice

The online photovoice project was conducted in four phases. First, we built a custom website to host the project and facilitate data collection. Second, we collected data by recruiting participants as well as monitoring participant engagement in the study and submissions of photographs and captions. Third, we reviewed and de-identified submissions to ensure confidentiality. Fourth, we disseminated the photovoice submissions. These phases are described in detail below.

Phase 1: Website Design

The project website served three main purposes, including to: (1) introduce participants to the photovoice project and facilitate the informed consent process, (2) teach participants photography skills and an understanding of visual literacy, and (3) collect photovoice submissions from participants. We created a series of short videos to accomplish these goals and facilitate participant connection, comprehension, and engagement with the project [29]. These videos featured 10 Malaysian clinicians, a photographer (i.e., a professional photographer and professor of photography) who was a member of the study team, and an exemplar participant. The website included a password-protected participant portal. After entering their password, participants landed at the homepage. From the homepage, participants could navigate to a series of pages designed to introduce them to the project and photography, and facilitate completion of the photovoice submissions. Prompts for the photovoice submissions were framed as "challenges" to enhance engagement by gamifying participation [30]. The webpages and videos are described in Appendix 1.

The website was accessible in both Bahasa Malay and English. Participants could switch between the two languages using a toggle button at the top of the website. On the Malay version of the website, all text and downloadable forms (e.g., consent forms, photograph recipe card) were translated from English to Malay by a member of the study team. Most clinicians and the photographer spoke in English in the videos. The videos on the Malay version of the website included either written Malay captions or Malay voice-overs. One clinician spoke in Malay in the videos, and their video segments included English captions on the English version of the website.

Participant confidentiality was prioritized in website design. The website was compliant with the U.S. Health Insurance Portability and Accountability Act (HIPAA) [31]. Data were encrypted at rest and in transit. Participants did not have to create an account for the website; therefore, they did not have to provide their name or any other identifying information to use the website. They were given dummy email addresses and passwords to log into the site so that they would not have to use their personal email addresses. Additionally, the website instructed participants to not submit photographs of their own or other people's faces.

Phase 2: Data Collection

Participant recruitment and data collection occurred on a rolling basis and lasted for 5 weeks, starting in early October and lasting through mid-November 2021. Our recruitment strategy was developed in partnership with members of our Scientific and Community Advisory Board, and leveraged approaches that our team has successfully used to recruit key populations and PLWH for previous studies in Malaysia. Participants were recruited through digital flyers that were shared via social media and WhatsApp by local community organizations serving key populations and PLWH. Flyers were shared in Bahasa Malay and English. Eligibility criteria included: 18 years or older, access to a camera phone with internet connection, and belonging to a key population group (i.e., MSM, TGW, FSW, PWID) or living with HIV. Interested individuals contacted a research assistant via a study-specific WhatsApp number. The research assistant, who spoke Bahasa Malay and English, screened individuals for study eligibility.

The research assistant scheduled appointments with eligible individuals to introduce the project and complete the consenting process by phone. During this appointment, the research assistant shared a dummy email address and password with each participant so that they could log into the website. The research assistant then prompted participants to watch the project introduction video and reviewed the consent form with participants. Participants were also asked whether they would like to have their photographs shared with general audiences for advocacy purposes. After participants consented to the study and indicated whether they were willing to share their photographs for advocacy purposes, the research assistant introduced participants to the rest of the website. Participants were given the option to watch the photography introduction videos during the appointment with the research assistant or at a later time on their own. The research assistant additionally showed participants how to access the six photovoice challenges. Participants were encouraged to respond to one challenge per day over the course of a week but were told that they could complete the challenges faster or slower. After the call, the research assistant sent participants a COVID-19 safety sheet over WhatsApp that included tips to avoid COVID-19 exposure while engaging in the project (e.g., wear a face mask, practice social distancing, avoid crowded areas).

The research assistant monitored participant engagement and submissions daily. They sent participants messages to encourage engagement. As examples, they messaged participants who were not uploading submissions to ask if they had questions or problems with the website and they messaged participants who were uploading submissions with compliments about submissions. The research assistant additionally screened the photographs for identifiers, including people's faces, and asked participants to upload new submissions if photographs included identifiers.

Participants were compensated for each step of the project, including completing the introductory call with the research assistant and for each photovoice submission. Photovoice submissions were compensated on an increasing scale, with each submission compensated at a higher rate than the previous submission. Participants were eligible for a bonus if they completed all aspects of the project. Participants could earn 400 Malaysian Ringgit (approximately \$100 U.S. Dollars) for participating in all aspects of the project. The monthly minimum wage in Malaysia is 1500 Malaysian Ringgit (approximately \$375 U.S. Dollars). Participants could choose to receive their

compensation via an online bank transfer or by collecting it from the research site.

Phase 3: Submission Review

A photograph de-identification protocol was developed based on HIPAA guidance and recommendations for deidentifying photographs in medical settings [32]. Using a photograph de-identification form (see Appendix 2), two members of the study team independently screened each photograph for four different categories of identifiers. Categories included: any facial photography, identifiers intrinsic to the participant (e.g., anatomic anomalies, birthmark, scar), identifiers on the participant (e.g., unique clothing, jewelry, piercings, tattoos), and identifiers around the participant (e.g., unique setting, surrounding, location). Photographs were characterized as: (1) not including identifiers and thus eligible for inclusion in photovoice presentations, (2) including identifiers that cannot be edited out and thus must be permanently deleted, or (3) including identifiers that can be edited out and thus would be edited and re-reviewed.

After completing their independent screenings, the two team members met with an additional team member to discuss the screenings as a panel. Consensus regarding screenings was achieved through panel discussion. Photographs that were determined to include identifiers that could be edited out were then edited by a member of the team. The panel then re-convened and re-reviewed the edited photographs according to the de-identification protocol.

Phase 4: Dissemination

Our dissemination plan prioritized sharing results of the photovoice study with several audiences: clinicians enrolled in our randomized controlled trial, members of the key population and PLWH communities, and members of the general public. The dissemination plan was developed and executed in partnership with members of our Scientific and Community Advisory Board. To disseminate results to clinicians in our randomized controlled trial, we created a series of videos that featured montages of participant submissions. Each video featured one key population (i.e., MSM, PWID, TGW, or FSW) or PLWH group and lasted approximately 3 min. To disseminate results to members of the key population and PLWH communities, we created two brief videos that could be shared via social media. To disseminate results to members of the general public, we posted photovoice submissions to a university website that could also be shared via social media. Photovoice submissions from participants who agreed to share their photographs with general audiences for advocacy purposes were featured in the videos and website.

Assessment

Data used to assess the feasibility and acceptability of the project were drawn from several sources, including participant responses to surveys and open-ended questions embedded in the website as well as the photovoice submissions. Information regarding whether participants belonged to a key population group or were a person living with HIV were collected to determine study eligibility. Data regarding participant socio-demographic characteristics, however, were not collected during this study. As noted in the introduction, key populations and PLWH are highly stigmatized and often criminalized in Malaysia. Any information that could be used to identify participants was therefore carefully considered by the study team and Institutional Review Boards in Malaysia and the U.S. Moreover, collecting sociodemographic characteristics could increase participants' perceived threat to confidentiality, even if this threat were to be minimized with data management. Ultimately, given that data regarding socio-demographic characteristics were not needed to achieve study aims, the risk of collecting socio-demographic data was deemed to outweigh potential benefits.

Measures and Indicators

Acceptability and feasibility were measured using quantitative and qualitative methods. Data regarding participants' perceived quality of the videos and website were collected given that they were hypothesized to be associated with participants' perceived acceptability and feasibility of the project overall. Indicators of fidelity included measures of photovoice completion and confidentiality of photovoice submissions. All self-report measures are included in Appendix 3.

Acceptability and Feasibility Acceptability and feasibility of the project was assessed using a validated implementation outcome scale [33], which participants completed after the final photovoice challenge. Scale items were adapted to refer to the photovoice challenges and rated on 5-point Likert-type scales ranging from *strongly disagree* (1) to *strongly agree* (5). Acceptability was measured with three items (Cronbach's alpha=0.79), and feasibility was measured with two items (Cronbach's alpha=0.81). Mean scores were created to represent acceptability and feasibility. Participants were also asked two open-ended questions about the photovoice challenges, including: "What did you like about the photovoice challenges?" and "What should we change about the photovoice challenges?".

Video and Website Quality Ratings of video quality were developed for the current study and included following vid-

eos introducing the project and photography. Scale items were rated on 5-point Likert-type scales ranging from strongly disagree (1) to strongly agree (5). Video quality was assessed with three items for both the introduction to project video (Cronbach's alpha=0.82) and introduction to photography videos (Cronbach's alpha=0.85). Ratings of website quality were assessed using items from a validated measure of quality of website user experience [34]. Ratings of website quality were completed after the final photovoice challenge, alongside ratings of project acceptability and feasibility. Three items assessed usability of the website (Cronbach's alpha = 0.94), three items assessed trust in the website (Cronbach's alpha = 0.92), and three items assessed the appearance of the website (Cronbach's alpha = 0.87). Mean scores were created to represent video and website quality. Participants were additionally asked two open-ended questions about the website, including: "What did you like about the website?" and "What should we change about the website?".

Fidelity As a measure of fidelity, we examined the number of photovoice submissions completed by participants. There were a total of six photovoice prompts, and a higher rate of photovoice completion was considered an indicator of greater fidelity. We additionally explored the number of participants who engaged in the English versus Malay versions of the website, as well as the number of participants who volunteered to have their photographs shared with general audiences for advocacy purposes in addition to research purposes.

Submission Confidentiality A central question was whether this online, asynchronous form of photovoice would yield non-identifiable submissions that could be used in photovoice presentations for intervention and advocacy purposes. Therefore, the number of non-identifiable photovoice submissions was determined following photovoice submission review.

Analysis

To analyze the quantitative data, we explored descriptive statistics and correlations between key variables. To analyze the qualitative data, we employed elements of Rapid Qualitative Inquiry methods [35]. Rapid Qualitative Inquiry was chosen for several reasons. First, it focuses on developing an insider's perspective on an issue. We sought to understand our participants' perspectives on and experiences with online, asynchronous photovoice. Second, Rapid Qualitative Inquiry requires teamwork. We prioritized a team-based approach given that our team included individuals with unique perspectives and expertise (e.g., key population, clinician, photographer) that we believed were invaluable to the analysis process. Third, it is recommended for evaluation, and our goal was to evaluate the acceptability and feasibility of online, asynchronous photovoice. Finally, Rapid Qualitative Inquiry is a targeted qualitative method designed to reduce lengthiness of qualitative research. Given the timeline of our overall program of research, we sought a method that would reduce our time on this phase of the project without sacrificing analysis quality.

Analyses were iterative and team-based. Initial findings were summarized and then discussed with members of the team. Team members focused on reaching consensus around conclusions, and triangulating qualitative and quantitative data. Findings were re-summarized and again discussed with members of the team, and conclusions were refined. As a trustworthiness check, results were then shared with members of the project's Scientific and Community Advisory Board as well as community partners from a local community-based advocacy organization to verify the team's conclusions.

Results

Thirty-four participants completed the photovoice challenges, with 12 (35.3%) identifying as MSM, 8 (23.5%) as PLWH, 7 (20.6%) as TGW, 7 (20.6%) as FSW, and 6 (17.6%) as PWID. Five participants (14.7%) identified as MSM and PLWH, and one participant (2.9%) identified as TGW and PLWH. Two individuals (n = 1 PLWH, n = 1 PWID) met with the research assistant to learn about the project and provide consent to participate, but then did not engage in the project or respond to the research assistant.

Acceptability and Feasibility

Responses to the final survey demonstrate that the photovoice project was viewed as both acceptable and feasible by participants, with mean scores for acceptability and feasibility both above 4.5 out of 5 (see Table 1). Participants evaluated the photovoice project positively in response to the open-ended questions. Participants enjoyed the opportunity to express themselves through photography, with one noting: "I love it because it gives me the opportunity to convey my heart and words through pictures, in a unique way." Several participants liked that the challenges were anonymous, with one stating that they appreciated "expressing who we are without revealing ourself." Participants enjoyed learning new photography skills. For example, one participant stated "I like how the challenges help us exercise our minds and how we are able to learn new skills." Several participants reported that the challenges were fun, with one stating: "Unlike an ordinary survey, the photovoice allows participants to do something fun."

Table 1	Participant	assessments	of	indicators	of	acceptability	and
feasibili	ity, and quali	ty of videos a	ınd	website (n:	= 34	+)	

Construct	Mean (SD)	Correlations		
		Acceptability	Feasibility	
Photovoice implementation	outcomes			
Acceptability	4.65 (0.46)	_	-	
Feasibility	4.56 (0.56)	0.60**	-	
Video quality ratings				
Introduction to project	4.46 (0.53)	0.55**	0.61**	
Introduction to photog- raphy	4.38 (0.52)	0.59**	0.56**	
Website quality ratings				
Usability	4.63 (0.52)	0.74**	0.72**	
Trust	4.52 (0.63)	0.71**	0.64**	
Appearance	4.47 (0.53)	0.56**	0.71**	

All constructs were evaluated on 1–5 point Likert-type scales, with higher scores indicating greater approval of construct

**p<0.001

When asked what could be done to improve the photovoice project, many participants responded that nothing should change. For example, one suggested that the team "proceed without changing what is already there." Yet, several participants provided valuable ideas to improve on future photovoice projects. Participants requested more challenges focused on religion, stigma, and HIV and STI treatment. One participant suggested that participants choose questions themselves, noting: "Maybe in the future, we should give flexibility to participants to make 1 or 2 questions." Two participants requested the option to submit responses using videos, with one stating: "Making the challenge of recording video to make the message easier to convey." One participant suggested that the project be offered via an app instead of a website. Finally, one participant suggested that the challenges be leveraged to empower individuals and communities, stating: "Photovoice projects entail the opportunity for empowering participants. Future research using photovoice should assess the influence it has on participants' empowerment changes and how to sustain those individuals and social changes."

Video and Website Quality

Participants rated the quality of the videos introducing the project and photography as high, and agreed that the website was usable, trustworthy, and pleasing in appearance (see Table 1). Participant ratings of video and website quality were positively correlated with their ratings of project acceptability and feasibility, suggesting that participants who viewed the videos and websites as higher in quality also found the project to be more acceptable and feasible. Participants also evaluated the website positively in response to the open-ended questions. They appreciated that the website was simple and easy to use, with one participant noting that: "It's very simple and clean. It's very easy to navigate." Several participants who completed the project in Malay reported that the two language options facilitated understanding, with one stating: "Easy to understand because you can choose two languages, namely English and Malay." Participants additionally noted that they enjoyed learning about photography, with one stating that the website was "packed with knowledge." One participant liked that they did not have to share any identifying information to participate, stating: "I do not have to fill in any details about myself to register. I feel comfortable and safe."

When asked what could be done to improve the website, many participants again responded that nothing should change. One participant stated: "I like the website, nothing should change." Participants gained access to photovoice challenge prompts one at a time. For example, they were able to view the webpage describing the fourth photovoice challenge only after viewing the webpage describing the third challenge. Two participants requested the ability to view a summary of all of the photovoice challenge prompts at the beginning of the project. One of these participants stated that:

It would be nice if we could have the whole idea of how we should answer all our questions with being able to access all the challenges before answering them. That will give me [a] better view on how to select my photo and write [my] captions.

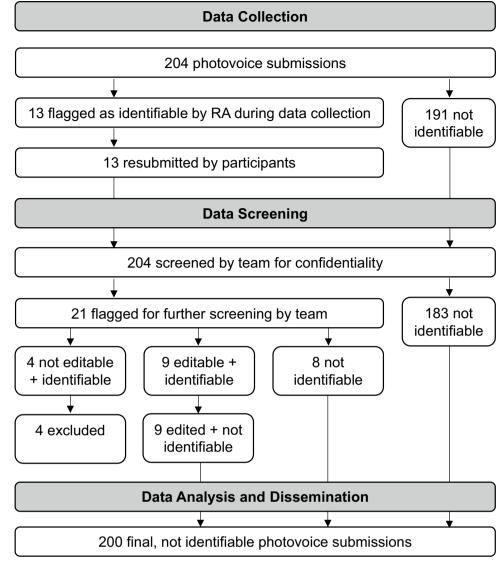
Fidelity

All participants completed all photovoice challenges (i.e., 100% completion rate), indicating a very high degree of fidelity. Half of participants (n = 17) engaged in the Malay version of the website, and half engaged with the English version. Most participants (n = 27, 79.4%) volunteered to share their photographs with general audiences for advocacy purposes. Participants who preferred to have their photographs used only for research purposes included 3 PWID, 2 TGW, 1 PLWH, and 1 PLWH/MSM participant.

Submission Confidentiality

There were 204 total photovoice submissions (i.e., 34 participants completed 6 photovoice submissions; see Fig. 2). Thirteen (10.3%) of the photovoice submissions were flagged as identifiable by the research assistant during the data collection period (e.g., an identification card that included a photograph of a participant, a tattoo, people's faces). All of these submissions were replaced by

Fig. 2 Submission confidentiality screen (n = 34 participants)



participants, resulting in 204 submissions for the panel review. The majority of submissions (n = 183, 89.7%)were rated as unidentifiable by the panel and eligible for inclusion in photovoice presentations. Of the remaining 21 (10.3%) submissions, 4 (19.01%) were rated as including identifiers that could not be edited out (e.g., unique houses in identifiable settings, a distinctive silhouette of a person), 9 (42.8%) were rated as including identifiers that could possibly be edited out (e.g., a distinctive watch on an arm, a license plate number, address numbers on a building), and 8 (38.01%) were rated as not identifiable. The editable photographs were edited by blurring identifiable aspects of the photographs, and all of the edited photographs were subsequently rated by the panel as unidentifiable. This process resulted in 200 total photographs (n = 191, 95.5% unedited; n = 9, 4.5% edited) that were considered appropriate for inclusion in the final photovoice analysis. In sum, the vast majority of photographs submitted by participants were either not identifiable or were easily editable to protect confidentiality, yielding a rich final dataset for analysis and dissemination. Examples of photovoice submissions are included in Fig. 3.

Discussion

Results of this project suggest that online, asynchronous photovoice methods are acceptable to and can be feasibly used with key populations and PLWH in Malaysia and perhaps more broadly, potentially holding promise to increase the scale of this highly versatile and action-oriented qualitative method within the field of HIV research. This approach was especially feasible and acceptable during stringent lockdowns in Malaysia during the COVID-19 pandemic. Supporting the acceptability of this method, participants enjoyed expressing themselves through photography and

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What makes you happy? "I am a sea lover. Seeing the sea stretch out and hearing the roar of the waves made me happy. It is a must every month for me to stop by the beach to see the vast sea." Female sex worker



What is important to you? "For me, health, serenity, honesty and wisdom are important in my life. Although not surrounded by many friends, do not have property but I am happy with what I have now. Be thankful always, God always bless us." Person who injects drugs

What makes you sad?

"People comes & go in life just like how day will turn into night. Those who was once friends are now strangers. That's sad." Man who has sex with men



How do doctors see you? "Dot in emptiness. No matters how empty my life's feeled, the doctor still can see the dot and guide me to it. It's really nice to have doctor who's understands people like my situations. They don't judge on anything, just want me to be healthy so that my 'skies' bright and shine again." Man who has sex with men &

Person living with HIV



What challenges do you face?

"As a transwomen, we faced a lot of stigma and discrimination from the society. Since we are visible, some people tend to hurt and bully us. So, we need protection like how this grill protect the house. But who gonna protect us?" Transgender woman



What do you want doctors to know about you?

"The stopover - People just be in my life for temporary. People come and go without knowing that I keep a lot of pain. My life miserable, all that they saw just a stopover." Female sex worker

Fig. 3 Photovoice examples

learning new skills, and noted that photovoice was more fun than other commonly used data collection methods such as surveys. Participants reviewed several features of the website positively, including its simple design, dual language options, and content about photography. Participants' ratings of the videos and website quality were positively correlated with their ratings of project acceptability and feasibility. It is possible that an online interface that is perceived as high quality and easy to use may contribute to the acceptability and feasibility of online, asynchronous photovoice projects. Further supporting feasibility, participants completed 100% of the photovoice assignments and several participants noted that they would have liked to respond to more assignments. Additionally, almost all photographs (98%) were either non-identifiable when submitted or easily editable to remove identifiers. In total, this project yielded many photovoice submissions (n = 200) that could be used for research, intervention, and advocacy purposes.

Online, asynchronous photovoice methods may enhance participant safety and address confidentiality concerns, particularly in places with pronounced stigma towards key populations and PLWH. Previous researchers have highlighted the importance of carefully considering ethical concerns when engaging in photovoice projects with communities affected by HIV [19]. Online methods address some of these concerns given that participants do not have to physically gather-they can remain anonymous to other participants and will not be observed going to a study site for key populations or PLWH. Participant safety was additionally promoted in several ways through the design of the website and project protocol. First, the website was designed so that participants did not need to use their own email address to register or login, and no identifying information (including socio-demographic characteristics) were collected from participants during the study. Participants reported that they appreciated the ability to maintain anonymity on the website. Second, the website was HIPAA-compliant, with data encrypted both at rest and in transit. This ensured a high level of protection for participant data, comparable to that afforded to private health-related data in the U.S. Third, measures were taken to ensure that identifiable photographs were not taken or kept. Participants were instructed and reminded to not submit photographs of faces. Photographs were screened as they were submitted, and participants were asked to resubmit photographs with identifiable content. Additionally, all submissions were reviewed and deidentified following a protocol based on HIPAA guidance.

Strengths, Limitations and Future Directions of Online, Asynchronous Photovoice

There are both strengths and limitations of online, asynchronous photovoice methods that researchers, community members, and other stakeholders may consider as they decide whether to adopt this method for research, intervention, and advocacy purposes. Strengths include the high levels of confidentiality afforded to participants, which is important in places with substantial stigma towards and criminalization of key populations and PLWH. Additionally, online methods can enable individuals to participate from dispersed geographic locations. This may be particularly advantageous when trying to engage individuals from rural locations, where key populations and PLWH may experience barriers to transportation to research sites. Online methods may also be safer during COVID-19 surges, when gathering in person may threaten the health of participants. Online, asynchronous photovoice projects additionally have potential to engage participants at large scales, allowing for larger reach in implementation. Although this study was relatively modest in size, with 34 participants, a recent online photovoice project engaged 120 participants across one U.S. state [24]. Finally, findings from this study suggest that online, asynchronous photovoice methods are highly acceptable to and feasible for participants.

Despite these benefits, there are limitations of online, asynchronous photovoice methods that may lead researchers and community partners to choose in-person, synchronous methods. Individuals needed to have a camera phone with internet connection to participate in the current study. Although smartphones have been increasing in popularity worldwide, this inclusion criteria may have excluded some individuals without smartphone access. The markedly high reach and use of smartphone ownership, including among key populations and in emerging economies, may make this limitation less concerning [21–23]. Future studies may explore the feasibility of providing camera phones with internet connection to participants. Designing a HIPAA-compliant website including instructional videos for one study can be resourceintensive and may not be feasible for projects with limited budgets or personnel. Strack et al. describe the development of a web-based tool that could be used by multiple studies [36]. Such a resource may be very useful for increasing the scale of photovoice studies within HIV research. Moreover, some participants may prefer formats other than websites, such as apps. As researchers develop infrastructure for such online data collection, they will have to continue to grapple with evolving data privacy issues (e.g., handling meta-data associated with digital photographs [32]).

An additional limitation of this study was that participants did not engage in participatory analysis after submitting their photographs and captions. Depending on the aims of photovoice projects, this can be a critically important component of photovoice methods [2, 3]. Our team met with members of our Scientific and Community Advisory Board as well as community partners from a local community-based organization to reflect on themes that emerged from the data and design a dissemination strategy for advocacy purposes. Other studies have facilitated online engagement of participants in the analysis stage, including via blogs [24]. Future studies employing online, asynchronous photovoice methods may continue to explore strategies for participatory analysis that maintain participant confidentiality and safety. Future studies may additionally explore strategies for facilitating participant engagement and interaction at other stages

of photovoice projects, including choosing the photovoice prompts, engaging with the website content (e.g., instructional videos), and directing the dissemination strategy.

Conclusions

Although photovoice is a unique and powerful form of participatory action research, it is currently underutilized within HIV research [1]. Online, asynchronous methods have potential to substantially enhance the scale of this method. The acceptability and feasibility of online photovoice methods have been explored with other populations [24], and this study suggests that these methods may also be acceptable to and feasible for key populations and PLWH. Researchers, community partners, and other stakeholders may balance the strengths (e.g., high levels of confidentiality) and limitations (e.g., barriers to participatory analysis) of this approach in relation to their study aims and context. The development, testing, and use of diverse photovoice methods may ultimately better contribute to qualitative HIV research, interventions, and advocacy.

Appendix 1: Outline of Website

Participants accessed the following website pages in sequential order.

- Homepage (one page): the homepage featured a 2-min video with four Malaysian clinicians who welcomed participants to the project, introduced themselves, and described why they chose to become infectious disease clinicians. From the homepage, participants could navigate to a series of pages designed to introduce them to the project and photography, and facilitate completion of the photovoice submissions.
- 2. Introductions (two pages): two pages introduced participants to the project and photography.
 - a. Project: included a 3-min video of a clinician who further welcomed participants. The clinician described the purpose of the project as to help doctors connect with and understand the lives of patients from key populations and/or living with HIV. The clinician additionally introduced the concept of photovoice and invited participants to share their experiences with doctors by responding to a series of photovoice prompts. This page also

included the project consent form and a form where participants could indicate whether they agreed to share their photovoice submissions with clinicians and other audiences outside of the project (e.g., local community advocacy groups).

- b. Photography: included four videos featuring the photographer teaching about photography. Individual videos focused on composition, color, and light. Videos included example photographs and brief animations to demonstrate concepts, and lasted 3–5 min. The page also included a photo recipe card summarizing tips from the videos, which participants could download and reference as they took photographs for the project.
- 3. Photovoice prompts (six pages): six pages introduced participants to specific photovoice prompts. Each prompt was accompanied by a brief video (length = 1.5–2.5 min) featuring up to three clinicians responding to the prompt verbally and one clinician stating why learning about participants' responses would help them provide better care to patients. Videos additionally featured an exemplar participant sharing their own photovoice submission in response to the prompt and the photographer reinforcing photography techniques from the introductory videos. Below the videos were places for participants to upload photographs and enter accompanying captions. Prompts included:
 - a. What makes you happy?
 - b. What makes you sad?
 - c. What is important to you?
 - d. What challenges do you face?
 - e. How do doctors see you?
 - f. What do you want doctors to know about you?

Appendix 2: Photograph De-identification Form

Reviewer ID:

Photo ID: Date:

Instructions: Two independent reviewers will screen each photograph for identifiers. Their reviews will be compared, and discrepancies will be discussed as a team.

Each reviewer should follow the following steps:

- Step 1: Review the photograph for identifiers.
- Step 2: Check any boxes that apply and make note of the identifier.

- Step 3: Mark the location of the identifier in the photograph.
- Step 4: Check recommendation regarding whether photograph includes identifier.

Appendix 3: Self-report Measures

Participants responded to the following items:

1. Photovoice implementation outcomes: Acceptability

Identifier	Notes						
Any facial photography Face			Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Intrinsic to the participant Anatomic anomalies		I liked doing	1	2	3	4	5
Birthmark		the photovoice challenges					
Scar		I would recom-	1	2	3	4	5
Other		mend the photovoice challenges to a friend					
On the participant							
Unique clothing							
Jewelry			1	2	2	4	-
Piercings		The photovoice challenges were enjoy-	1	2	3	4	5
Tattoos							
Other		able					
Around the participant							
Unique setting							
Unique surrounding		2. Photovoice	e implem	entation	outcomes:	Feasib	ility
Unique location							
Other			Ctuon also	Discorrec	Naithar	A	Ctuon also

Recommendation:

- Category 1: Photo does not include identifiers.
- Category 2: Photo includes identifiers that cannot be edited out.
- Category 3: Photo includes identifiers that may be edited out—this photograph may be eligible for inclusion in photovoice presentation after editing and re-review.

Next steps:

- Compare reviewers' category assignments. Disagreements to be resolved via discussion.
- The following steps will be taken with photographs from each category:
 - Category 1 photographs can be included in photovoice presentations.
 - Category 2 photographs will be permanently deleted.
 - Category 3 photographs should be sent to the photographer for editing. Edited photographs will be assigned a new photo ID and then re-reviewed following this protocol.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The photovoice challenges took the right amount of time	1	2	3	4	5
The photovoice challenges were possible to do in my everyday life	1	2	3	4	5

3. Video quality ratings: Introduction to the project

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
This video was clear	1	2	3	4	5
This video was the right length, or amount of time	1	2	3	4	5

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I understand the goals of the project	1	2	3	4	5

4. Video quality ratings: Introduction to photography

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
These videos were clear	1	2	3	4	5
These videos were the right length, or amount of time	1	2	3	4	5
I learned about photography from these videos	1	2	3	4	5

5. Website quality ratings: Usability

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The website is easy to use	1	2	3	4	5
It is easy to move around on the website	1	2	3	4	5
It is easy to submit photographs and captions through the website	1	2	3	4	5

6. Website quality ratings: Trust

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I feel com- fortable sending my photographs through the website	1	2	3	4	5

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I trust the website	1	2	3	4	5
I'm not worried about other people seeing my photo- graphs and captions	1	2	3	4	5

7. Website quality ratings: Appearance

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I like how the website looks	1	2	3	4	5
The website has a clean and simple look	1	2	3	4	5
The videos were well-made	1	2	3	4	5

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Data Availability Data may be available from the corresponding author upon request.

Declarations

Conflict of interest The authors declare no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study received institutional review board approval from the University of Delaware (1588354) and University of Malaya Medical Centre.

Consent to Participate All participants provided informed consent.

Consent for Publication In addition to consenting to the study, participants consented to have their photographs shared via publication.

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