Using Photovoice and Photo-elicitation

Frequently Asked Questions and Answers

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Introduction:

We often hear from investigators who are looking to use photovoice or photo-elicitation methods. There are many strengths to these two approaches, and the methods have been well-described elsewhere [Additional resources and references are shared throughout and at the end of this document]. However, using these approaches within the VA environment comes with some challenges. Members of our group have successfully completed several photovoice and photo-elicitation studies in the past; here we share our responses to some frequently asked questions from other VA investigators over the years. Materials and lessons shared here come from two VA HSR&D-funded studies (PPO 10-355 and IIR 13-499, awarded to Gala True with Sarah Ono and Ray Facundo), but others have used these methods in VA-funded work. We provide a list of publications and links to information about these other projects under Additional Resources.

This is not meant to be a comprehensive training guide on photovoice or photo-elicitation methods, but rather some tips on using these methods within VA and a few other helpful lessons we have learned. We have included links to some online training and toolkits for photovoice; however, inclusion of these links is not meant to be an endorsement.

Note: Some of the web links (Example: <u>link</u>PE00) provided for the additional materials discussed cannot be accessed outside of the VA's internal network. If you cannot access them, the GROVE Center can provide a zip file of the supplemental documents and articles. Please send a request by emailing raymond.facundo@va.gov.

Frequently Asked Questions

Where can I learn more about photovoice and photo-elicitation methodology? How do I know which approach is appropriate for my research?

While photo-elicitation and photovoice share many features, they are different in ways that are beyond the scope of this document. We recommend that any researcher think carefully about the aims and goals of a study, as well as what resources (i.e., time, staffing, funds) are available to implement the research plan before deciding which method to use.

Below are a few observations about each approach, as well as links to some resources. We have included some helpful readings under Additional Resources. We often share the article by Deborah Padgett et al., which has a nice summary of some differences between the two methods. Gala True also gave a VA HSR&D cyberseminar PE24 that outlined some of the differences, as well as some ethical and practical considerations of both approaches.

A few words on photo-elicitation (PEI):

- The method originated from Anthropology (Mead and Bateson 1942);
- Visual data is used during interview as a mutual focus for interviewer and participant;
- Images may be produced by participant, or introduced by researcher;
- Control over images and interpretation of images varies—it may be the researcher, the participant, or both;
- The method is not necessarily embedded in an action/advocacy or participatory research agenda.

We are not aware of any online courses focused on photo-elicitation methods but have included some readings in Additional Resources, including an <u>article by Bugos et al</u> PEOO on practical guidance and ethical considerations for PEI research and another on <u>logistical lessons</u> <u>learned</u> PEOO from conducting PEI in one VA medical center.

A few words on photovoice:

- Photovoice methodology was developed by Caroline Wang and Mary Ann Burris in 1992 and is rooted in participatory action research and critical consciousness (Freire 1970);
- Participant-collaborators use cameras to record, discuss, and communicate their lived realities, through their own eyes;
- There is an emphasis on shared authority and ownership of findings, empowerment of participant-collaborators, and advocating for changes in policies that impact participants and their communities;
- The method should include dialogue between researchers, participant-collaborators, and an intended audience (often policymakers), and dissemination of findings beyond traditional academic products.

There are many ways to learn about photovoice, including workshops that are available online. Some examples:

- photovoiceworldwide.com
- Photovoice.org

We have also seen some good "photovoice toolkits" available online at no cost, including:

- Facilitator's Toolkit for a Photovoice Project from United for Prevention in Passaic County- -a 24 page guide with helpful photography tips and examples of forms and interview guides is available here <u>Training Manual for Hosting a Photovoice Project</u> (wpunj.edu) PE20;
- <u>PhotovoiceKit (PVKit)</u> PE23 is a project headed by Drs. Bob Strack and Muhsin Orsini and supported by the National Institutes of Health. The site includes helpful information about sequencing different phases of a photovoice project; it is free to use but does require creating an account.
- The Photovoice Toolkit from The Neighborhood Action Strategy (NAS) PE22 and Public Health Services (PHS) is a 36 page guide that includes helpful prompts for photovoice participants, such as creating a "word cloud" or doing a neighborhood "walkabout."

How do I explain photovoice or photo-elicitation to a participant and provide guidance on how to take photographs and select images for inclusion in the study interview?

We developed a Photovoice Training Handout PE17 as a visual guide to help discuss photovoice methods with participant-collaborators. We begin by providing an illustration that describes the photovoice journey (adapted from Laura Lorenz), explaining study activities to participant-collaborators in a visual format. We cover a number of topics including: the focus of the study and what we are asking them to focus on in their photographs; tips on taking a "good" photograph for the project; discussion of literal and metaphorical images; basic tips on how to use the camera provided and technical aspects of taking a photograph; safety and ethics; what to expect/what will happen at the photovoice interview; and contact information for our team. You may want to cover other topics or additional topics, but we recommend you develop something visual like this to orient your participant-collaborators since the IRB consent process is so densely verbal and formal.

How do I address potential concerns from my facility's Institutional Review Board and/or Privacy Officer?

When we conducted our first photovoice study, it was the first time the members of the facility's IRB, including the Privacy Officer, had reviewed a research study where the participants had the option to share their private health information publicly and to be identified in dissemination of findings. We found it was helpful to include background about participatory action research and photovoice in the introduction section of the research protocol, including an explanation for how participant-collaborators would maintain autonomy through making informed decisions about the sharing and use of their photographs and narratives (see below for more detail). We also outlined principles that would guide us in

addressing any unanticipated ethical considerations that might arise during the study. These include (but are not limited to):

- Informed Consent as a multi-step process in addition to the standard VA informed consent form, which we review and complete with a participant prior to study enrollment, we developed and use additional consent forms. These are discussed in more detail below; these forms provide an opportunity for a participant to indicate how they want to be identified in dissemination products, whether they want a photograph or photographs to be treated differently, and obtain consent from other people included in a photograph.
- Participant safety as the priority in our introduction to photovoice, we talk with participants about the importance of maintaining their safety. This includes refraining from entering dangerous places or situations to get a photograph. It also means making sure a photograph will not result in emotional or financial harm to themselves, including harm to their reputation, opportunities for future employment, etc. We tell participants we can work with them to come up with an alternate way to make the point they want to make, through metaphor or sharing their narrative without an accompanying image.
- Protect other individuals from harm we discuss and consider the importance of protecting other individuals being represented in a picture from harm. If a photograph and/or text could potentially cause harm to the reputation or safety of an individual, it is not included in dissemination products.
- Be careful not to perpetuate stigma or stereotypes/protect the community being represented in the project from harm—we do not include any photograph that could be taken out of context or perpetuate a stigmatizing stereotype about the community being represented in the project (or any other community).

What can I do to protect a participant if they take a photograph of illegal activity, etc.?

Again, this is not specific to the VA, but we have found it useful to obtain a <u>Certificate of Confidentiality</u> PE13 from the National Institutes of Health (an example of one we received from the National Institute of Mental Health is included). This CoC protects participants from any involuntary disclosure that could expose them or their loved ones to adverse economic, legal, psychological and/or social consequences.

How do I get consent for use of photographs and other artifacts in dissemination of findings? And who "owns" the data?

We have developed a process using two consent forms. We use VA form 10-3203. This document is updated from time-to-time; to locate the most recent version you can search online or ask someone in your facility's Public Affairs Office. When a participant-collaborator

completes and signs this form, they are permitting the study investigator to use <u>all</u> photographs and images in educational products that result from the study, without any restrictions. This signed and completed document is the one we provide when asked to show proof that a participant-collaborator has approved the use of their images (for example, when a journal editor asks for such proof).

In addition, we developed and use our own <u>Study Participant Photo Release Form</u> PE18 as a fairuse agreement between the VA Investigator and the participant. This form covers two topics not addressed in the VA photo consent form. First, it allows the participant to indicate how they want to be listed in any publications or other dissemination products. On our version, the participant can write their name as they would like it to appear (for example, full name, first name plus first letter of last name, a pseudonym, anonymous, etc.). Second, the form provides space for a participant to indicate their preferences and permissions regarding one or more specific photographs. For example, they might give permission to the study investigators to use all photos with some version of their real name but select one photo that can only be used with a pseudonym. This form has been very useful over the years, helping us build trust with participants and keep track of their preferences for use of their photographs and sharing of their stories in ways that the VA form does not.

What if a participant submits a photo with someone else in it?

In our introduction materials (see above), we advise participants that they can take photographs in public that include others in such a way that they are not the clear subject of the photograph (i.e., crowd shots, where the person is in the background) without getting the person's written permission.

In cases where a participant may want to take and include a photograph of a non-participant where they are clearly a subject (i.e., they are one of the only people in the photograph, they are in the center of the photograph in close-up, the participant discusses the person during the interview), we provide participants with a form we developed, Consent to Photograph Non-Participants PE14. This form can be used by the participant to explain the purpose of the project, how the photograph(s) may be used, and to obtain written permission from the subject(s) of any photographs. This form can be completed and signed when the photo is taken or submitted by the participant-collaborator at any time before use in dissemination materials. If the subject of the photo is under 18 years old and is not the child or guardian of the study participant, there is a section for the minor's parent or guardian to sign.

Note: there have been times where a participant included a photo from deployment with others in it-- for example, the members of a squad or platoon they served with—and it was not feasible for us to obtain written consent from everyone in the photograph. We have included some of these photographs in photovoice exhibits, with the rationale that the quote that accompanied the photograph was of a positive valence and was not referring to one specific person in the photograph.

What if a participant wants to take photographs on VA property?

As you may already know, due to government guidelines and patient privacy concerns, photography and videography are not allowed on VA property without prior consent of the local (facility) Public Affairs Office. We have worked with the PAO at several VAMCs to enable participants to take photographs on VA property, as long as there are no VA patients or employees visible in a photograph. At one VA, the PAO required us to inform them any time someone from the study wanted to take a photograph; at another VA, the PAO issued a memo for participants to carry with them when taking photographs for the project. We recommend that you meet with the PAO at your facility to explain the study methods and goals and discuss options for allowing participants to take photographs on VA property, as long as they do not include other patients or VA staff.

How can I help participant-collaborators keep track of the photographs they take or select for the project, including their thoughts about what they want to convey with a particular image?

This is not particular to the VA, but we have discovered that it can be helpful to provide participants with a simple, optional document where they can jot down notes about the photographs they take or select to contribute to the project. This <u>Photo Notes Handout</u> PE16 includes questions like "Record anything else you want here such as: was the photo taken during the day or at night? Is there anyone in the photo? How were you feeling when you took the photo? Does the photo represent something?" This can be particularly helpful when there is a long time between when a photo is taken and the photo elicitation interview. Participants with memory issues may find this document particularly helpful.

Can you publish on data from photovoice and PEI studies? How does use of these approaches facilitate engagement of participant-collaborators in dissemination of findings?

We have successfully published findings from photovoice research in peer-reviewed journals ranging from Qualitative Health Research to the Journal of Head Trauma Rehabilitation; journal

editors have included photographs as Figures in these articles. (See <u>Additional Resources</u> for a list of publications from photovoice and PEI studies conducted within VA).

Over the years, we have found that use of these methods has led to opportunities for researchers and participants to collaborate on dissemination of findings. Due to the coownership and accessibility of the "data," most participants remain deeply engaged in the research (some of us have worked together for nearly a decade) and invested in disseminating findings to diverse audiences through traditional and more novel venues. For example, we have presented research findings on VA HSR&D webinars with <u>Veteran</u>PE25 and <u>caregiver</u>PE26 collaborators, as well as co-authoring publications in peer-reviewed journals:

- "Institutions Don't Hug People:" A Roadmap for Building Trust, Connectedness, and Purpose Through Photovoice Collaboration

 PE10
- <u>"If You Don't Name the Dragon, You Can't Begin to Slay It:" Participatory Action Research to Increase</u>
 Awareness Around Military-Related Traumatic Brain Injury PEO4

To disseminate findings to broader audiences, we created a website that features photonarratives from our first photovoice collaboration From War To Home and two self-published photobooks. We also created two traveling exhibits of photo-narratives that have been installed in over two dozen locations around the country, including VA medical centers, public libraries, and university art galleries.

What are possible impacts of research using these methods?

It is beyond the scope of this FAQ to delve into the impacts of photovoice and PEI research, but we can share a few observations from our work and suggest two important articles that touch on this topic.

Impact on participant-collaborators: We have heard from dozens of our collaborators over the years that the impact of using visual-narrative methods has been profound and largely positive. While some people have observed that it can initially be quite painful to revisit and share past traumas or other negative events, in the long-term they experience a sense of catharsis from being able to make some sense of events and convey their experiences and insights to others. In addition, many participants report deriving a sense of purpose from their involvement in photovoice and PEI research, particularly because these methods can lead to more creative products that are accessible to the public (i.e., photobooks, art exhibits) and facilitate opportunities for participants to be involved in dissemination activities. Several participants have used their involvement in our research projects as catalysts for furthering their education and/or advocacy activities, and all have expressed positive experiences with sharing their research participation with family and friends through our books and traveling exhibits. Some collaborators have written about the impact of being involved in photovoice research

Impact on VA investigators: We have found great satisfaction and personal enrichment from conducting research using these methods. While engagement of communities and individuals at this level is a great deal of work (some of it unrecognized), the richness of the relationships we have developed with our participant-collaborators and the sense of purpose fuels our emotional investment in our work. We have written more about this in an article in the Journal of Humanistic Psychology referenced elsewhere in this document and below.

Impact on policy: in the case of photovoice, there is an implied or explicit "promise" that the project findings will have an impact on policy at the local or national level. Lisa Bowleg PE19 has written about the power of photovoice to "prioritize dismantling of social-structural inequalities as a prerequisite to health equity." In our experience, this is possible. For example, Dr. Nipa Kamdar (in collaboration with Gala True and other researchers) conducted a photovoice collaboration with student Veterans who were living with food insecurity; one article about this work was identified and disseminated by seniors advisors on the US House Rules Committee. However, Tasha Golden PE21 has observed there are limitations to photovoice and cautions against over-promising to participants. Whenever we are working with someone who is interested in using one of these methodologies, we recommend they read both Bowleg's and Golden's articles.

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