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Logistical Lessons Learned in Designing and Executing a Photo-Elicitation Study in the Veterans Health Administration

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Logistical Lessons Learned in Designing and Executing a Photo-Elicitation Study in the Veterans Health Administration

Abstract

Participatory photography research methods have been used to successfully engage and collect in-depth information from individuals whose voices have been traditionally marginalized in clinical or research arenas. However, participatory photography methods can introduce unique challenges and considerations regarding study design, human subject protections, and other regulatory barriers, particularly with vulnerable patient populations and in highly regulated institutions. Practical guidance on navigating these complex, interrelated methodological, logistical, and ethical issues is limited. Using a case exemplar, we describe our experiences with the planning, refinement, and initiation of a research study that used photo-elicitation interviews to assess the healthcare experiences of homeless and marginally housed United States Veterans. We discuss practical issues and recommendations related to study design, logistical “pitfalls” during study execution, and ensuring human subjects protections in the context of a study with a highly vulnerable patient population taking place in a highly risk-averse research environment.

Keywords

Homeless Persons, Photography, Qualitative Research, Veterans, Veterans’ Health

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Patient perspectives are critical for the design and delivery of patient-centered healthcare within complex healthcare organizations (Peikes, Geneva, Schalle, & Torda, 2011; Epstein & Street, 2011). Qualitative research methods are well-suited for eliciting

patient experiences and identifying pertinent insights for patient-centered healthcare quality improvement (Baudendistel et al., 2015; Tancred, Manzi, Schellenberg, & Marchant, 2016). Visual and participatory-based qualitative research (VPQR) methods, such as photo-elicitation interviewing, participant-generated artwork, or photovoice, offer innovative alternatives to more traditional qualitative data collection methods. Because these methods offer participants the opportunity for creative expression, they can facilitate a better understanding of participants' subjective experiences; the contextual factors surrounding patients' medical, behavior, and social needs; and the collection of complex narratives around health and well-being (Harrison, 2002). Participatory-based photography methods have been used to successfully engage and collect in-depth information from patients whose voices have been traditionally marginalized in clinical or research practices, for example, homeless individuals, and individuals with serious mental illness (Cabassa, Nicasio, & Whitley, 2013; Padgett, Smith, Derejko, Henwood, & Tiderington, 2013).

VPQR methods are increasingly used in organizational healthcare settings (Hudson Hospital & Clinic, 2015; McLean Hospital, 2015; Overlook Medical Center, 2015). The United States Department of Veterans Affairs (VA), the nation's largest integrated health care system, has recently seen VPQR methods in research, evaluation and/or quality improvement (QI) which offers services to including the United States (Balbale, Morris, & LaVela, 2014; Balbale, Turcios, & LaVela, 2014; True, Rigg, & Butler, 2014). However, to date little has been written about the unique challenges encountered by researchers and QI specialists aiming to use VPQR methods within institutional healthcare settings (Bugos, Frasso, FitzGerald, True, Adachi-Mejia, & Cannuscio, 2014). In designing this type of study, researchers must take into account many practical and ethical considerations for the collection, storage, and use of visual data with regard to human subjects' protection and privacy. Researchers who are embedded within healthcare organizations must also address related institutional regulatory barriers that may be even more pronounced in projects involving vulnerable individuals such as those who are homeless or marginally housed, use illicit substances, or have psychiatric disorders. Without practical guidance about how to navigate these logistical, methodological, and/or ethical barriers investigators and QI specialists may be reluctant to use these innovative qualitative methods, even in the face of their promise for giving voice to vulnerable patient perspectives and experiences.

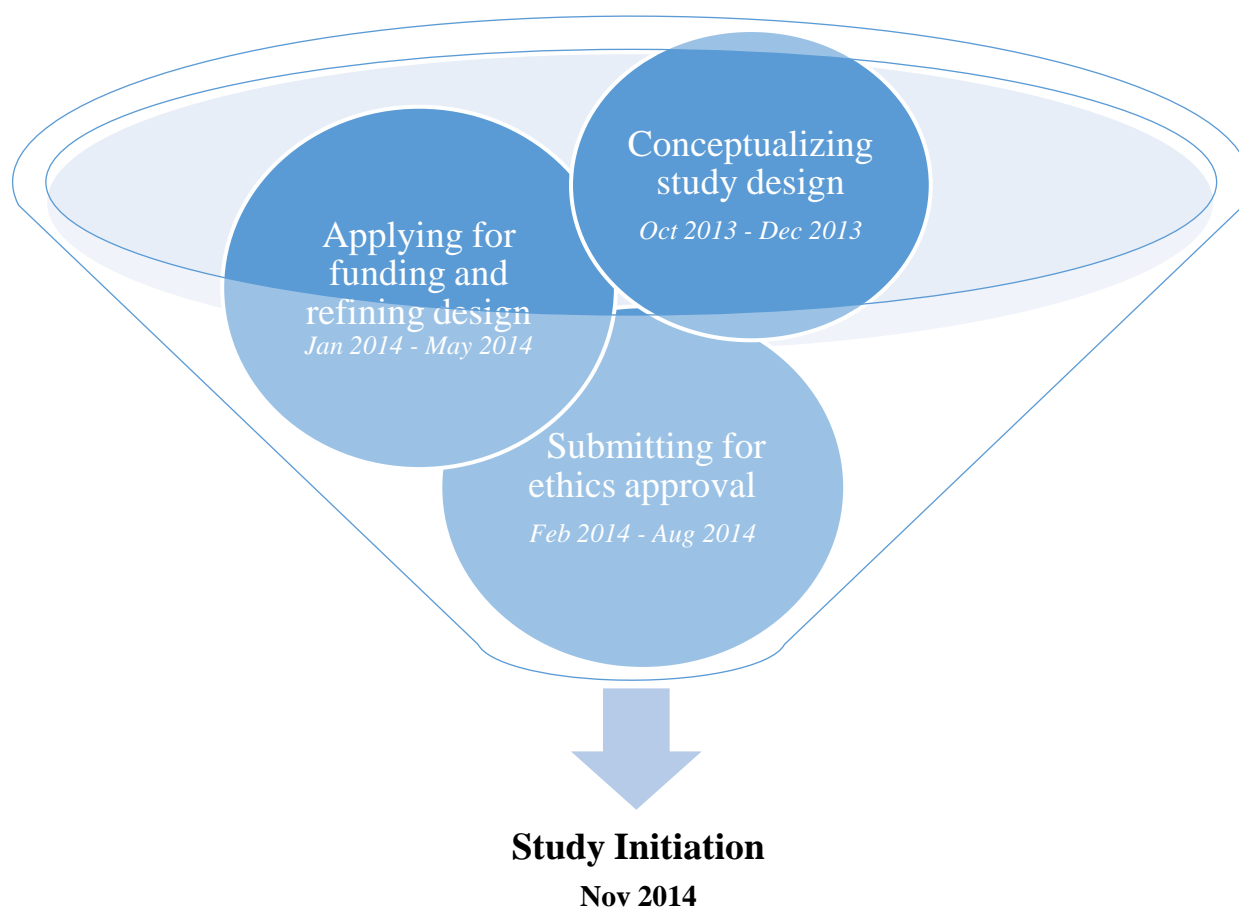
The purpose of this paper is to discuss our experiences conducting a study that used photo-elicitation interviews to identify perspectives on health and well-being, self-management behaviors, perceived quality of care, and factors which influence access to care among homeless Veterans. In addition to describing our experiences with study design, receiving funding, and submitting for human subjects research approval, we offer strategies and implications for investigators interested in conducting research, evaluation, and/or QI projects in highly regulated organizational healthcare settings such as the VA. We provide recommendations based on the practical, formative lessons learned during the study execution.

Study Overview

The study title was, "Homeless Veterans Opinions of Integrated Care Environments: A photo-narrative study (U.S. Department of Veterans Affairs, 2015a). We recruited participants from a local VA medical center in Pennsylvania, United States that recently established a patient-centered medical home specifically for Veterans who are homeless or at-risk for becoming homeless (see U.S. Department of Veterans Affairs, 2014). The final study plan included better understanding how Veterans enrolled in a local VA's patient-centered medical home described their health and wellness, perspectives about their health care, and

impressions with being a research participant. Study planning began approximately one year prior to study initiation. The major components leading up to successfully launching the study included conceptualizing study design, applying for funding, refining study design, acquiring funding, and finally, navigating regulatory process with human subject research. These parts are represented in Figure 1 to show an iterative journey that eventually funneled towards successfully launching the study. We will share our experience during each of these components.

Figure 1. Study Components from Study Planning to Initiation



Part 1: Conceptualizing the Initial Study Design

The catalyst for this project was the recognized need for direct patient perspectives in the healthcare improvement process. Specifically, we identified a need for patient perspectives with VA's new primary care medical home model (referred to as "Patient Aligned Care Teams" in VA; U.S. Department of Veterans Affairs, 2015b) for homeless Veterans. VPQR methods provide an engaging, partnered set of strategies for eliciting and understanding the experiences of Veterans who are traditionally marginalized due to their complex medical, psychosocial, and psychiatric needs. This orientation was aligned with our

organization's transformation in healthcare from disease-focused to holistic, Veteran-centric health care (Krejci, Carter, & Gaudet, 2014; U.S. Department of Veterans Affairs, 2014).

Throughout this initial phase, we reached out to several VA colleagues in order to access specific expertise regarding VPQR methods. These informational meetings included (1) a local investigator studying the neurological features of food cravings whose protocol included Veterans photographing their foods, as well as (2) a research staff member [SNB] using photovoice methods to understand Veterans' perceptions of patient-centered care in a QI project with Veterans and VA staff (Balbale, Morris, & LaVela, 2014; Balbale, Turcios, & LaVela, 2014). These meetings presented an opportunity for us to learn about their experiences in using these methods in the organization and to help facilitate our own study process. For example, we discussed the pros and cons of using digital cameras. While the upfront expense was the most noteworthy concern, the digital cameras offer considerably more flexibility and freedom with the pictures than the disposable cameras which would require staff to develop the film (and depending on the organization, may require contracts and additional safeguards to protect any sensitive data). See Table 1 for meeting discussion prompts.

Table 1. *Photovoice research inquiry with experienced investigators.*

<i>Camera-related issues</i>	<ul style="list-style-type: none"> • What type of camera (e.g., digital vs. disposable)? • How did you develop or print the pictures? • Did you encounter any problems with missing or lost cameras?
<i>Participant acceptability</i>	<ul style="list-style-type: none"> • What were participants' reactions like with taking pictures and the interviews? • Did participants actually use the pictures during the interview? • What did you do if participants wanted copies of their pictures?
<i>VA-specific policies or regulations</i>	<ul style="list-style-type: none"> • What were your procedures for taking pictures on medical center property? • Do you have suggestions or recommendations for IRB submission?

Establishing early partnerships with institutional gatekeepers. We anticipated that the use of VPQR methods, particularly with vulnerable patient populations, would be unfamiliar to our institutional gatekeepers, for example, members of the institutional (human subjects) review board and the privacy/information security offices. In anticipation of the many questions and issues of concern would arise, we presented our preliminary research ideas to a small group of representatives from the aforementioned boards and offices to cultivate an ongoing relationship of collaboration and transparency. The purpose of these meetings was two-fold. First, we aimed to bring awareness and credibility about VPQR methods and the feasibility of these methods in the VA, as evidenced by their use among other VA investigators. Second, we aimed to brainstorm potential pitfalls and major concerns about data collection methods and dissemination, together. We also discussed potential solutions to the overlapping web of logistical concerns, ethical practices with human subjects, privacy protections, and information security challenges that we anticipated. For example, during an initial meeting, we discussed the option of using disposable cameras for

participants to take pictures and the process by which participants could return these cameras, such as by United States mail or via drop off boxes located at the VA.

Preparing the budget. When preparing our budget as part of the grant, it was vital to carefully consider the cost of equipment and the potential that participants might lose or even sell their cameras, particularly individuals who may not be attentive to their security due to medical or mental health care conditions (e.g., schizophrenia, substance use disorders, traumatic brain injury) or socioeconomic conditions (e.g., poverty, homelessness). Therefore, we budgeted for an additional five cameras to account for lost, stolen, or otherwise diverted cameras. We designed the study so that participants would keep their cameras as part of their study remuneration and, at the end of the study, receive a brand new memory card in exchange for the memory card used throughout the study.

We were also particularly sensitive to the potential for inappropriate coercion of our target population through our participant remuneration practices. There are no easy answers in achieving the delicate balance between appropriate compensation for a participant's time, energy, and unique perspective on one hand, and coercive offerings on the other. At the same time, certain regulations in one part of an organization may be at odds with specific research needs. For instance, during our study planning phase, VA policy restricted options for participant remuneration to (1) electronic direct deposit into a bank account, or (2) gift certificates at the VA medical center's cafeteria and gift/convenience store. We opted for gift certificates (and the provision of bus tickets for travel assistance) out of concern that our population may not have bank accounts to utilize electronic direct deposit. Finally, we included the study camera and a new memory card as part of participant remuneration for two reasons. First, we wanted to follow best practice from the VPQR literature, particularly photovoice literature, where participants keep their digital cameras in the name of self-empowerment and have the opportunity to continue telling their stories outside of the research context. Second, we believed that by making it known at the outset that the cameras are the participant's property (and not that of the government or another entity), participants would be more likely to take ownership of, and exercise more precautions with handling and storage of the camera.

Part 2: Applying for Study Funding and Refining Study Concepts

In January 2014, we submitted the research proposal to an internal funding grant mechanism. This funding mechanism is directed toward pilot projects that are innovative or that address a specific need of the organization. This internal review process was somewhat different from a competitive funding mechanism such as the National Institutes of Health, but is fairly typical for healthcare organizations that have competitive calls for proposals but with an emphasis on wanting to nurture internal work and new investigators within the organization. Our initial proposal submission received a "Revise and Resubmit" notification. The reviewers focused on four primary issues, described in detail below, which were all subsequently addressed in the revision, including (1) study design, (2) study team qualifications, (3) federal policies limiting taking pictures on government property, and (4) participant engagement and retention.

Revising study design. Reviewers had several concerns with our study design, including issues related to methodology, sampling and generalizability, and analysis plan. One reviewer commented that the data collection methods were not consistent with existing photovoice and community-based research designs. In the original proposal, we presented our study methodology as a "modified-photovoice community-based research project." We recognized that typically a community-based research study incorporates stakeholder engagement throughout the entire research process. It was our intent to incorporate specific

elements of photovoice methodology, namely the participant-generated photographs and community-based dissemination plan via a participatory art exhibit. One reviewer suggested pursuing a clinic-based, qualitative design with semi-structured interviews. As a result, we re-designed the study methods to clearly delineate our use of a photo-elicitation approach (rather than photovoice).

This emphasis on photo-elicitation methods and re-design away from the photovoice component may be a minor nuance depending on the grant organization and/or reviewer, but is an important distinction in the research literature (Lapenta, 2011). We maintained a distinction between the two methods borrowing both ideological and pragmatic tenants from Wang and Burris (1997) that that photovoice includes (1) participant-generated prompts and photographs, (2) focus groups to discuss the pictures, (3) collaborative analysis, and (4) emphasis on action and community change. In contrast, photo-elicitation includes (1) researcher-generated prompts with researcher and/or participant-generated photographs, (2) individual interviews to discuss the pictures, (3) researcher controlled analysis, and (4) emphasis on providing insights to organizational leadership and dissemination in the form of scholarly products, such as publications and academic presentations (Mitchell et al., 2014). In summary, although photovoice may be more desirable in some research based on the goals, e.g., community engagement), photo-elicitation interviewing aligned with our specific research goals to elicit Veterans' perspectives and experiences, while not necessarily engaging Veterans as advocates in the research. As part of our study re-design and to complement our first two aims focused on identifying perspectives on health and quality of care, we added a third study aim to evaluate feasibility of the study from the researcher's perspective and acceptability of participation in a photo-elicitation project from the patient's perspective.

We also responded to a concern about the lack of heterogeneity in our sample by referencing (1) the patient characteristics for the clinic we would be recruiting from (e.g., majority at-risk for homelessness) and (2) past conversations with the local Health Care for Homeless Veterans Peer Support Liaison for the clinic. The Peer Support Liaison position was created by the VA to be occupied specifically by a Veteran who has made the transition to civilian life. Peer Support Liaisons assist other Veterans in making that transition and also facilitate peer support groups, advocate for Veteran consumers, provide crisis support, communicate with clinical staff, and provide outreach and education to staff and the larger community (Chinman, Henze, & Sweeney, 2013). During our conversations, the Peer Support Liaison described the broad spectrum of housing situations for Veterans receiving primary healthcare services in the Pittsburgh primary care medical home, such as limited-to-no housing, transitional housing, and independent housing but at-risk for losing such housing. As a result, our socio-demographic questionnaire included 2 items inquiring about housing status prior to clinic enrollment, and housing status over the past 2 weeks.

Finally, the same reviewer who critiqued the community-based study methodology also expressed concern that the data analysis section did not adequately describe methods for coding and analyzing the photographs or linking the photographs to the interview transcripts; coding and analyzing the photographs and/or linking them to the interview transcripts is typical for community-based participatory research studies. As described earlier in this paper, the unit of analysis for this project is not the photographs per se, but rather the interview transcripts containing discussions prompted and guided by the photographs. Due to the diversity of approaches that exist within participatory photography (i.e., photovoice vs. photo-elicitation), we further detailed the specific function the photographs would serve in our study, as a tool for data collection as opposed to data/artifacts that would undergo analysis themselves. This orientation is congruent with the literature describing photo-elicitation interviews where photographs represent a "tool to expand on questions and

simultaneously, participants can use photographs to provide a unique way to communicate dimensions of their lives” (Clark-Ibáñez, 2004).

Study Team Qualifications. One reviewer commented on our research team’s limited experience with visual research methods. We strengthened our foundation in photo-elicitation methods by inviting a medical anthropologist (GT) to join our study team as a Co-Investigator. GT was, at the time, one of only a few investigators working in the VA who had experience and expertise in visual-based research methods. Since the initial grant submission, she provided extensive methodological and practical guidance regarding study design, study execution, and human subjects’ protection. We also described maintaining consultations and networking with other VA staff and investigators who have been successful in their pursuit of using visual-based research methods, including a research investigator (Dr. Sherri L. LaVela) and study coordinator (SNB) at the Center for Evaluation of Practices and Experiences of Patient-Centered Care, Edward Hines Jr. VA Hospital.

Participants Taking Pictures On-Site. Because our study is focused on Veterans’ perceptions of health and health care, the possibility existed that Veteran participants would want to take photographs of (or at) our VA facility, or of their VA healthcare providers. Based on the proposal reviewers’ knowledge about VA policies prohibiting unauthorized photography on federal property (38 CFR 1.128.23, a United States federal code detailing security and law enforcement at VA facilities), they also raised concerns about Veteran participants’ permission to take photographs on site at our medical center. Our response to reviewers provided considerable detail about how we would address such concerns, including partnering with [de-identified for peer-review] operations, educating study participants on the specific protocol for taking pictures on-site, and encouraging participants to take creative photographs in their community and to use the interviews to describe how photographs can be taken as representations, instead of literal figures (persons, places, or things).

Participant Engagement and Retention. We responded to concerns about feasibility of participant engagement and retention in the study by referencing projects that have successfully used photovoice or photo-elicitation interviews with homeless individuals (Padgett et al., 2013; Wang, Cash, & Powers, 2000) as well as Veterans (Balbale, Morris, & LaVela, 2014; True et al., 2014). These studies described relatively minor retention challenges and, in fact, describe study participants as having generally positive experiences with the data collection procedures. We proposed the following strategies to potentially maximize Veteran participants’ understanding of and engagement in the project while simultaneously minimizing study attrition: (1) review the interview guide with the key informant (i.e., a direct support staff member from homeless Veterans’ healthcare clinic at the hospital), (2) review the study design with study participants (e.g., recruitment and retention strategies, data collection instruments), (3) employ engagement and retention strategies with study participants (e.g., telephone follow-up contact between research visits to remind participants about instructions and inquire about any issues with the camera).

Part 3: Submitting for Human Subjects Research Approval

In February 2014, we prepared the initial human subjects research protocol through our institution’s Institutional Review Board (IRB) and carried out a second meeting with institutional gatekeepers to review study documents and procedures (e.g., informed consent, data management, dissemination efforts). We submitted the protocol to our local IRB in March 2014. Our second meeting with the institutional gatekeepers raised some concerns, which caused significant delay in the IRB approval process. The most notable of these concerns, which were time consuming to resolve and the possibility of illegal activities and/or substance use paraphernalia being documented in the photographs. Throughout our

discussions, we maintained that research staff would explicitly instruct participants not to take pictures of any illegal behavior but, instead, to take pictures that represent things and take their place, such as photographing a picture of substance paraphernalia.

Nonetheless, as a result of this meeting, we encountered a significant delay of nearly four months (until June 2014), where one of the institutional stakeholders sought chain-of-command approval about the picture-taking processes, subsequently advising our research staff to seek legal advice from general counsel before any final study approval. VA regional legal counsel determined explicit instructions during the photography orientation would suffice and a Certificate of Confidentiality could be an option, but not necessary given the project's scope is not exclusively focused to alcohol, drug use, or any other explicit criminal behavior. It was this key issue which most influenced the time between our IRB submission in March 2014 and its official approval by the local IRB in August 2014.

Part 4: Study Initiation

One of the most significant issues that we faced during study initiation was the extensive delay with purchasing and acquiring the digital cameras. Furthermore, because in the VA, direct communication between manufacturer and study investigator who initially requested the purchase is procedurally absent, information had to be relayed on several occasions between the research administrative staff and local facility purchasing department. For example, on two separate occasions the manufacturer contacted the purchasing officer to inform him or her that the digital camera that was initially requested was out of stock. This is particularly relevant for photo-elicitation studies because extensive research is needed on selecting the most suitable camera considering usability (i.e., ease of use by participants), power source, quality, and cost (i.e., cost for the project due to a limited budget).

Once the study started, we encountered very few logistical issues with the cameras. After testing the printing quality of our network printer we were more than satisfied with the results. Only a small handful of participants required additional batteries beyond the spare set included in their camera cases. We did not have any participants report lost or stolen cameras who remained active in the study. Veterans' attitudes about the study were positive throughout recruitment and data collection phases. Participants generally found the cameras to be user-friendly. Some participants found the process of photo-journaling to be intimidating or otherwise difficult on a conceptual or artistic level. Participants asked few questions during the photography orientation sessions, and for the most part their photographs were not only in step with the picture prompts, but also generally avoided any issues that would require further adjudication (e.g., personal identifiers without consents or illegal activities). A limited number of participants took pictures on VA property and were accompanied with study staff to mediate any concerns from hospital staff or police. One participant resided on VA property, in which case study staff contacted VA police in advance for guidance on how to proceed. This individually was permitted to independently take pictures on site after VA police received a memorandum from our VA director that we acquired before study initiation granted an exception. This letter outlined the photo-elicitation project and described Veterans may be on-site taking pictures as part of the project.

The study enrolled a total of 30 Veterans, with 2 self- withdrawn and 16 completing all three research visits (n=20 completed up to RV-2). Interim findings indicate Veterans find participating in the research project acceptable, as demonstrated in both their closed- and open-ended responses to questions from the study's acceptability exit survey. Participants took an average of 15 pictures for each photo-elicitation interview, ranging between 2 up to 75. Each interview averaged 35 minutes. We collected over 300 photographs and over 20 hours of audio-recording from the photo-elicitation interviews.

Discussion and Recommendations

Throughout all phases of the study, we identified and engaged early with key stakeholders to anticipate their concerns and questions, and then collaboratively develop responses to these issues. Our key informants could be classified into three main categories based on their experiential knowledge: content, data collection methods, and policy navigation, and provided critical, insider guidance regarding identifying best practices for collecting and managing our types of data. Meeting simultaneously with the IRB chair, information security officer, and privacy officer at our facility enabled us to share concerns and troubleshoot potential solutions in the context of overlapping policies and agendas. In another instance, we found that an integral component to the study design and eventual initiation of this study was maintaining a relationship with a key informant from clinical operations, the peer support specialist. As a Veteran himself and an experienced member of the care team who regularly interacts with the Veterans in the homeless clinic, he was able to provide valuable insight regarding many phases of the study, including participant recruitment strategies, data collection procedures, photography prompts, and the wording of interview guides. As a result, we made pertinent revisions designed to ensure patient acceptability and overall ease of use, such as revising language with photography prompts and the interview guide. We recognize that identifying the peer support specialist as a valuable study informant was facilitated by his official position at the VA and that studies operating in a non-VA research environment may not so easily benefit from such feedback. Despite this fact, we would encourage other research teams to seek out similar informants, which could be care providers, organizational leaders, or even community members themselves who are familiar with the experiences of the population of interest. Although these collaborative, iterative activities require substantial investments of time, the rapport and relationships established streamlined processes later on, prevented misinterpretation and institutional sanctions, and overall, facilitated study execution within the clinic.

As part of new VA facility-level procedures, all new investigators were required to meet with the local Research Education and Outreach Coordinator to review local and national research policies, as well as their current IRB protocol. We found this quality assurance meeting to be very helpful in clarifying certain logistical operations with our protocol. For instance, during the meeting, the principal investigator brought up the concern that missed research visits may be designated as protocol deviations. However, after further discussion with the study team, we presented to the local Research Education and Outreach Coordinator that, since we were looking to examine feasibility and acceptability as our third study aim, we would be reporting on the average amount of time between participants taking photographs and returning for their photo-elicitation interview. As a result, the research windows for this amount of time were presented as suggestions, rather than strict timelines.

The methodological presentations assisted us with closely examining our protocol and data collection procedures again, provided critical feedback, and gave a glimpse of the project's overall positive reception by other researchers. During the waiting period between IRB approval and study start-up, the study's principal investigator participated in another VA project as a qualitative interviewer. This served as a valuable opportunity to learn more about VA-specific procedures with data collection and both local and national-level regulations (e.g., notation in the patient's electronic medical record; faxing consents to Research Compliance Officer; use of a Philips digital audio recorder during interviews as mandated by VA Central Offices); we also gained some initial experience with interviewing Veterans about their healthcare experiences. Table 2 contains an outline of global recommendations.

Table 2. Summary lessons learned from conceptualizing to initiating the photo-elicitation study with homeless Veterans.

Study Phase	Facilitator	Global Recommendations
STUDY DESIGN	<ul style="list-style-type: none"> • Reaching out to staff with VPQR experience • Identifying and maintaining working relationship with key informants” including institutional gatekeepers 	<ol style="list-style-type: none"> 1. Identify and maintain a working relationship with project-specific key informants (both study methodology as well as content) and institutional gatekeepers 2. Partner with clinical services to facilitate recruitment/retention efforts 3. Be sensitive and accommodating to facility-specific requests, including concerns for human subject research 4. Engage scholarly and clinical community early in study to present methodology and increase project awareness
BUDGET	<ul style="list-style-type: none"> • Considering lost, stolen or diverted cameras given the population 	
PLANNING	<ul style="list-style-type: none"> • Researching features about different cameras 	
PROJECT MANAGEMENT	<ul style="list-style-type: none"> • Reviewing facility-specific policies (e.g. unauthorized photography on campus) • Gaining approval from facility leadership 	

Conclusion

Our research team navigated previously uncharted methodological and regulatory territory by initiating this VPQR research study with a particularly vulnerable homeless Veteran population within the context of the highly conservative and risk-averse research environment of the VA. Our approaches to planning and refining this study may serve as a relatable case example to investigators who are less familiar with VPQR methods both within and outside of the VA. With a specific study in mind, these global recommendations can help guide investigators and research staff with navigating early phases of a photo-elicitation research study. For instance, Table 1 can serve as a discussion template for engaging with co-investigators and regulatory stakeholders. While the aims, target population, and institutional context for different research studies and QI initiatives vary widely, the broad planning considerations and commonly raised stakeholder concerns discussed in this exemplar can help others set a course for the successful use of VPQR methods.

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