



# Operation PCOR: A Community Engagement Project Preparing Veterans as Full Partners in PTSD-Related Research

## PROGRAM PROFILE

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## ABSTRACT

Due to the dearth of veteran-centered research, gaining the unique perspective of veterans' engagement in research is essential to address their health needs. Veterans have expressed desire in shaping treatment options for post-traumatic stress disorder (PTSD), however many veterans are hesitant to engage in the research enterprise. This community engagement project was designed to train veterans as full partners and join forces with researchers on PTSD-related patient-centered outcomes research (PCOR) and comparative effectiveness research (CER).

A National Advisory Board (NAB;  $n = 8$ ) of veterans and key stakeholders were created. The NAB developed the Veteran-Driven Research Participation Training Program (VDRPTP). The VDRTP consists of four modules narrated by veterans: 1) Research Bootcamp-Basic Training; 2) Ethics, Participants Rights, and PCOR and CER research; 3) Communicating About Research; and 4) Time for Action! The VetResearchHub was also created to provide a platform for veterans to engage directly with researchers and collaborate on veteran-centered PCOR and CER.

The VDRPTP was appraised by veterans who provided feedback about the VDRPTP. The VDRPTP was revised for ease of access. 96% of veterans exhibited overall satisfaction with the modules. Veterans also expressed an increase in willingness to participate in research projects.

This project supports a promising first step toward reducing existing barriers between veterans and research teams. The provision of free, accessible, web-based education about the research process, designed for veterans, combined with a networking infrastructure-VetResearchHub-may ultimately support the advancement of veteran-focused PTSD-related PCOR and CER.

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The Iraq and Afghanistan conflicts have been the longest military operations in US history (Armed Forces Health Surveillance Center, 2011). Many service members have deployed multiple times, and the high operational tempo over such an extended period is unprecedented for the US military. Combat-related post-traumatic stress disorder (PTSD) is the most commonly found psychological health problem among veterans who experienced these military deployments (Committee on the Assessment of Ongoing Efforts in the Treatment of Posttraumatic Stress Disorder, Board on the Health of Select Populations, & Institute of Medicine, 2014). Over the past decade, significant advancements have been made in the treatment of combat-related PTSD using cognitive-behavioral therapies such as cognitive processing therapy (Resick et al., 2015, 2017) and prolonged exposure therapy (Foa et al., 2018). Studies have also shown that such treatments can be adapted for use in primary care settings (Cigrang et al., 2011, 2015, 2017) and even modified and abbreviated (Peterson, et al., 2020). Yet, findings from these studies also indicate that, on average, only about half of service members and veterans no longer meet the criteria for PTSD after receiving these cognitive-behavioral therapies. Additionally, PTSD therapy programs offered by the US Department of Veterans Affairs (VA) only reach approximately 1% of veterans with PTSD (Bradley et al., 2005; Haagen et al., 2015; Shalev et al., 1996; Watts et al., 2013).

Clearly, further research is needed to enhance the availability, acceptability, and efficacy of PTSD treatment options within the veteran community. Efficacious treatment options must be developed that recognize the unique combat-related experiences associated with PTSD among veterans and the distinct challenges related to veteran healthcare. Thus, there is an urgent need to explore robust programs of patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) to identify treatments for PTSD that are effective, acceptable, and meaningful to the veteran population. Foundational to the future success of increasing engagement of veterans in PTSD treatment options is their willingness to participate in research studies and act as research partners.

The participation and engagement of veterans in research, however, has been problematic as veterans have historically been reluctant to participate (Braun et al., 2015; Bush et al., 2013; Funderburk et al., 2015; Haibach et al., 2020; Littman et al., 2018; Williams et al., 2012). Our experience in working with veterans on previous veteran-driven engagement projects taught us that veterans want to participate in shaping approaches to PTSD treatment. However, they remain skeptical because they report that the research process is not synchronous with their daily life experiences.

Recent findings from our previously funded, veteran-focused Patient Centered Outcomes Research Institute

(PCORI) project, Veterans' Action League (VAL): Building Capacity to Engage Veterans in PCOR and CER Activities (Flynn et al., 2019), provided valuable insight regarding factors that contribute to this skepticism. Key factors included avoidance of engaging with researchers and mistrust of the research enterprise. In addition, veterans believe that there is a lack of transparency in the purpose of research studies with veterans, which further contributes to hesitancy and resistance of veterans participating in important research that would benefit their healthcare needs and quality of life. This project was developed to help fill that gap by engaging veterans as partners in understanding and developing a veteran-centered training program designed to increase their engagement in current research important to the veteran community.

## **RATIONALE INFORMING THE PROJECT**

Unfortunately, PTSD is widespread within the veteran community affecting up to 30% of veterans (American Psychological Association [APA], 2013; US Department of Veterans Affairs, 2015) and remains a strong predictor of suicidal intentions (Stefanovics & Rosenheck, 2019). PTSD is challenging and costly to treat with traditional pharmacologic and psychological interventions. The US Department of Defense and VA spent \$3.3 billion on PTSD treatment in 2012, yet current therapeutic and pharmacological approaches (Frueh et al., 1995; Harvey et al., 2003; Ipser & Stein, 2012; Rauch et al., 2009; Tuerk et al., 2011) show only moderate improvement of symptoms in veterans with PTSD. Compounding the problem, despite outreach attempts, veterans are often reluctant to seek treatment for PTSD. Veteran-centered research is needed to identify treatment options that are acceptable and accessible to veterans with PTSD and that effectively contribute to positive treatment outcomes.

A patient-centered approach to research facilitates a partnership between patients, as the end-users, and the research team. This partnership allows input from patients—veterans in this case—into the acceptability of the treatment modalities to be investigated, the research design, and the selection of dissemination venues. Consequently, “patient centered outcomes research produces useful evidence to inform patients’ health decisions,” (Patient-Centered Outcomes Research Institute, 2011–2020) (Bush et al., 2013; Haibach et al., 2020; Littman et al., 2018).

Our previous engagement projects confirmed that many veterans are unfamiliar with the research process and are uncomfortable embracing the role of research partner. Operation PCOR was designed based on veterans’ expressed concerns and recommendations elicited from our previous

engagement projects (Flynn et al., 2019; Krause-Parello, et al., 2019). Therefore, the overarching goal of this current project was two-fold:

1. To prepare veterans for their role as partners and important members of the research team
2. To create a vehicle to connect them to veteran-centered research opportunities

This project prepared veterans to communicate with a research team, make meaningful recommendations regarding research questions and approaches, and assist with the development of dissemination plans to reach and inform the veteran community. By demystifying and clarifying the main components of the research process, this project equipped veterans with the tools they need to be an informed member of the research team. It also provided them with a platform to navigate research opportunities and connect with researchers interested in conducting veteran-focused projects and studies.

Having a patient-centered approach to research is crucial to the advancement of efficacious and acceptable treatment options, particularly in response to the high prevalence of PTSD among veterans. Providing veterans the opportunity and capability to act as partners in research studies will shift PTSD research to be in alignment with the goals of patient-centered research, leading to more informed healthcare decisions. It is important for patients' voices to be heard and inform priorities in assessing the value of healthcare needs and options (Basch, 2012). Consequently, this project has the potential to lead to a cadre of formally trained veterans who understand the importance of their participation and partnership in PTSD-related PCOR and CER.

## PROJECT STRUCTURE AND PROCEDURES

Building on our prior work, the aims of this project were to:

1. Develop, implement, and evaluate a nationally accessible online training program—Operation PCOR—that prepares veterans to partner with research teams in the development of PTSD-related PCOR and CER.
2. In a convenience sample of 50 veterans:
  - Evaluate veteran learners' satisfaction with the training program in terms of relevancy of content, organization, and presentation.
  - Determine if participation in the online training program increased in veterans' willingness to participate in research.
3. Build a national infrastructure via a web-based platform in which veterans who have completed the

Operation PCOR training can connect with researchers focused on veteran-driven PCOR and CER.

This 2-year veteran-driven community engagement project was completed in September 2019. All project procedures were reviewed and approved by the appropriate university institutional review boards. We provided a clear description of the project on the Operation PCOR website stated the purpose of the project, the rights of the stakeholders to terminate their voluntary participation at any time, and access to the contact information of the project lead and evaluation responses were anonymous.

A National Advisory Board [NAB; ( $n = 8$ ) see [Table 1](#)] was formed and comprised of veterans, community stakeholders, researchers, and education experts who served as consultants to the project team.

The project team, comprised of the project lead, co-lead, and project manager, collaborated with the NAB to develop the Veteran-Driven Research Participation Training Program (VDRPTP). During regularly scheduled virtual meetings, learning objectives and curriculum for the VDRPTP were designed, reviewed, and revised based on recommendations from the NAB. The learning objectives and curriculum were then organized into four modules (see [Figure 1](#)). Each module began with an introduction, review of the module's learning objectives, overview of the topical outline of the module's content, and presentation of the module's content via a narrated slide deck. A brief quiz followed the presentation in order to evaluate the learner's mastery of the content. Modules concluded with a short questionnaire to determine the learner's satisfaction with the module's content, organization, and audio-visual presentation. Lastly, each learner was given the opportunity to make open-ended recommendations for content improvement. Each module was designed to be completed by a learner in approximately 15–20 minutes.

Members of the NAB leveraged their network within the veteran community and recommended four veterans who served as module narrators; each veteran narrator had research experience and each narrated one of the four modules. At the beginning of each module, the veteran narrator introduced themselves and the service branch in which they had served. The narrator presented module content using language and application examples, created by the NAB, relevant to a veteran audience. The veteran narrator also shared their personal experiences in research as well as why they believed it was important for veterans to learn about, participate as partners, and serve as advisors on research teams.

The production of the narrated videos and development of the VDRPTP website was directed by a technical expert. The virtual infrastructure for the VDRPTP was built, configured, and tested on an e-Learning

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**Table 1** NAB Members.



**Figure 1** Veteran-Driven Research Participation Training Program Modules.

platform that supported the use of automation software for navigation, creation of certificates of program completion, and which supported data capture from quizzes and evaluations. Closed captions for the audio files were then added to the modules so that content would be accessible and inclusive. Modules were developed so that the user could start, stop, and restart modules at their convenience. Upon completion of the four-module set, the learner was given the option to print a certificate of completion for their records.

### VDRPTP EVALUATION

Prior to the launch of the VDRPTP, a convenience sample (n = 15) drawn from the veteran community was invited by

members of the NAB to pilot, assess, and provide formative evaluation for improvement. Veteran volunteers were asked to review the modules and complete the satisfaction questions at the end of each module. They were also encouraged to take advantage of the opportunity to offer any comments or recommendations for revisions. Their responses were anonymous.

As a result of this formative evaluation, it became apparent that most of the small groups of veteran volunteers began module 1 but did not continue to complete the remaining modules. Written feedback from participants on the satisfaction questionnaires indicated that the modules were too long and that the technical navigation through the modules was confusing and difficult. Based on this feedback, the content of the four modules was revised to be more concise, consistent, and engaging. Further, the

technical expert redesigned the site navigation to be more seamless and intuitive.

## PROJECT OUTCOMES

Following the initial, formative assessment and revisions, veterans ( $n = 50$ ) were asked to voluntarily engage in this project. To engage in this community engagement project, a link to the revised VDRPTP was electronically distributed to veterans via veteran organizations, veteran networks, and personal outreach by members of the NAB. Participants were anonymous and access to the VDRPTP was closed to new participants once the sample of 50 self-identified veterans was obtained. In recognition of veterans' historic concerns regarding lack of anonymity and perceived risks to privacy, no demographic data were collected. Participants were given the opportunity to receive a \$10 e-gift card in appreciation of their effort. The e-gift card was sent to an email address voluntarily provided by veteran stakeholders; the email address provided was not linked to participants' evaluation responses.

In accessing the VDRPTP, the first screen of the home page provided veteran stakeholders with an overview of the project, a description of process to ensure anonymity of their evaluation responses, and an overview of participant rights including the right to stop the evaluation of the training program at any time. Contact information for the project lead, in the event of questions, was also provided. Instructions on the home page invited participants to complete each of the four modules including the quiz and satisfaction feedback available at the completion of each module. Participants were instructed to complete the VDRPTP within a designated 2-week period. The technical design of the training program allowed participants to start, stop, and then return to the training program site at the point at which they exited.

The second screen of the VDRPTP asked the engaged stakeholders to complete the Research Attitudes Questionnaire (RAQ) (Kim et al., 2005) prior to progressing to Module 1. Serving as a post-evaluation, participants were asked to complete the RAQ again upon completion of the fourth and final Module. Each participant's pre- and post-evaluation responses were electronically paired for analysis. The RAQ is a 7-item summated rating scale developed to evaluate respondents' willingness to participate in biomedical research studies; the instrument also serves an indicator of the extent to which respondents are concerned regarding various elements of the research process. Higher scores indicate a higher willingness for research participation. Exploratory and confirmatory factor analysis demonstrated the questionnaire's validity as a one

factor measure of respondents' willingness to participate in research (Rubright et al., 2011)

Fifty veterans completed all elements of the training program as instructed and within the designated 2-week period. Anonymous evaluation responses were analyzed using IBM SPSS Statistics software version 26 to appraise the VDRPTP. A total of 96% (48/50) of the veterans who evaluated the training program modules reported being either very satisfied or satisfied with the overall training program. The majority of veterans 82% (41/50) rated the content as either excellent or above average.

## CHANGES IN RESEARCH PARTICIPATION WILLINGNESS

To appraise the VDRPTP, paired pre- and post-evaluation responses based on the RAQ were summed and examined for normality. Data were found to violate assumptions of normality and thus the Wilcoxon Signed Rank test was used to analyze the evaluation responses. Outcomes indicated a significant increase in total paired post-evaluation responses compared to pre-evaluation responses ( $n = 50$ ,  $z = -1.971$ ,  $p = .049$ ). To assess specific attitudes affected by the VDRPTP, pre- and post-evaluation responses on each of the seven elements were examined. The following items had significantly higher post-evaluation responses compared to those on the pre-evaluation responses:

- Participating in research is generally safe ( $z = -2.111$ ,  $p = .035$ ).
- If I volunteer for research, I know my personal information will be kept private ( $z = -3.207$ ,  $p = .001$ ).
- Society needs to devote more resources to research ( $z = -1.968$ ,  $p = .049$ ).

These evaluation responses indicated that veteran participants were satisfied with the VDRPTP and the content. Also, it appears that the VDRPTP may be moderately effective in increasing veteran participants' willingness to engage in research. Importantly, evaluation outcomes indicate that following completion of the VDRPTP, veterans' attitudes regarding the research team's protection of their safety and privacy improved.

## BUILDING A NATIONAL INFRASTRUCTURE TO CONNECT VETERANS AND RESEARCH TEAMS

In collaboration, the project team, members of the NAB, and the Florida Atlantic University (FAU) College of Nursing

Information Technology Team assisted in the development and launch of the *VetResearchHub*. This national web-based infrastructure provides a dedicated space where veterans can obtain no-cost access to information regarding current veteran-centered research projects that may be of interest to them. This site also provides veterans with the opportunity to network with research teams and to partner in research studies where they may have experience or added value in advancing veteran-focused PCOR or CER.

The *VetResearchHub* is housed on the Canines Providing Assistance to Wounded Warriors (C-P.A.W.W.) webpage at FAU (<https://nursing.fau.edu/outreach/c-pawww/vetresearch.php>). The FAU staff are responsible for maintaining the *VetResearchHub* and populating it with up-to-date research opportunities from across the nation. The *VetResearchHub* also contains a link providing easy access to the VDRPTP.

## IMPLICATIONS FOR CLINICAL PRACTICE, PUBLIC POLICY, OR FUTURE RESEARCH

Engaging patients and consumers in healthcare research has the potential to create meaningful interventions, yet there is a well-recognized reluctance among veterans to participate in patient-centered research. This reluctance stems from an unfamiliarity and distrust of the research process (Flynn & Krause-Parello, 2019). Evaluation of this project suggests that participation in the VDRPTP may reduce veterans' concerns about safety and privacy when participating in research. Given the considerable challenges of successfully engaging and treating PTSD in the veteran population, the outcomes of this project demonstrate veterans' willingness to engage as partners in research studies when they are informed of the importance of research as well as the processes associated with human subject protection during the research enterprise.

One goal of this project sought to address one of the challenges in conducting PTSD research in veteran populations—the demystification of participation in veteran-focused PTSD research. The project demonstrated the potential contribution of education and training in the engagement of veterans in research activities. Through educational activities such as the VDRPTP, veterans may be better informed of not only the opportunities, but also the important voice they provide in PCOR and CER.

Additionally, this project developed and launched a web-based mechanism—*VetResearchHub*—designed to connect veterans and research teams from across the nation. Follow-up research and evaluation is needed to determine the extent to which the *Hub* is used by veterans and research teams alike. Also important is determining users' satisfaction and recommendations

for improvement particularly as information technology evolves.

Like all projects this project is not without limitations. Although engagement for project participation was targeted to veterans, demographic data, verification of military service, and discharge information were not collected for reasons previously specified (e.g., to protect anonymity); therefore, we cannot be assured that all those who assisted in evaluating the training modules were veterans.

## CONCLUSION

As a result of this project, the development of the VDRPTP, and the *VetResearchHub*, the outcomes show an important and promising first step toward reducing existing barriers between veterans and research teams. Our previous projects support that although deterred by skepticism and misunderstandings, many veterans want input into the selection and design of studies that they feel are relevant to them. The provision of free, accessible, web-based education about the research process, designed for non-researchers and veterans, combined with a networking infrastructure such as *VetResearchHub*, may ultimately support the advancement of veteran-focused PTSD-related PCOR and CER. Below are stakeholder responses to the question “what I've learned from my participation in this program is.”

### DR. M. DANET LAPIZ-BLUHM (KEY STAKEHOLDER/ RESEARCHER PERSPECTIVE)

What I've learned from my participation in this program is that Operation PCOR's NAB afforded many learning opportunities about working with and for veterans, development of a community basic research course, and strategies for nationwide collaborative endeavor to engage vulnerable communities in patient-centered outcomes research (PCOR). Operation PCOR was an endeavor to promote research participation among veterans to address their prioritized issues such as PTSD. The NAB consisted of academics who are engaged in veteran-specific research. In every step of the development of the research course, veterans had input as to the relevance of the content. This input ensured that the product is relevant and acceptable to the population of interest: veterans. The development of the basic research course provided opportunity to learn how to simplify complex research processes and distill them into simple understandable terms that can be understood by the community. It also provided opportunity to learn various information technology (IT) strategies in the delivery of an online course. The NAB was a team consisting of nurses,

psychologist, researchers, and veterans. Working with the NAB provided opportunity to work interprofessionally as a team at a national level and provided a roadmap in how to engage various key stakeholders in PCOR. In summation, participation in the Operation PCOR was truly a worthwhile learning experience! I am truly grateful to Dr. Cheryl Krause-Parello for inviting me to be part of a wonderful team!

### MR. RALPH PRESCIUTTI (VETERAN PERSPECTIVE)

What I've learned from my participation in this program is that the veterans were eager to participate in our project with the hope that it would help others. I also want to share my experience as one of the military veterans working on this project. I had previously co-lead a small group of veterans in round table discussions regarding their experiences with veterans' healthcare. The VetResearchHub is giving a voice to all veterans and allowing them to find and engage in research that helps with issues like PTSD, depression, substance abuse, and survivor's guilt. This project allows the veterans to engage in the research process and advance at their own pace. Along the way they realize that they are becoming part of their solution and less of their problem. I call that success!

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### DISCLAIMER

The views, statements, and opinions presented in this article are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee, nor do they represent an endorsement by or the policy or position of the U.S. Department of Veterans Affairs or the U.S. Government.

### COMPETING INTERESTS

The authors have no competing interests to declare.

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