A Capacity-Building Toolkit

For Engaging Veterans In Patient-Centered Outcomes Research and Dissemination of Findings During the COVID-19 Pandemic

VETERANS ACTION LEAGUE 2.0 TOOLKIT

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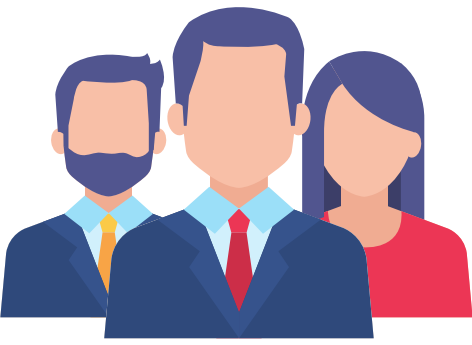Rutgers, The State University of New Jersey

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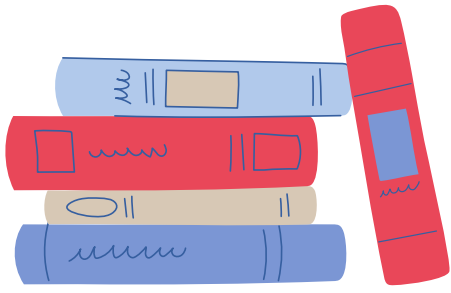
Ralph Prescuitti, U.S Army Veteran

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INTRODUCTION

Engaging the end users of health related research in order to advance the health and wellness of patients is often the primary objective of research, however, strategies to improve engagement of end-users to advance research often remains ambiguous among health care researchers and practitioners. Engagement of veterans to advance veteran-centered research that addresses service-related health issues is especially challenging given the history of mistrust and hesitancy in participating in the research process. This gap in knowledge has grown larger since the COVID-19 pandemic due to the initiation of social isolation and distancing measures, leaving many veterans unable and more resistant to partake in veteran-focused research. In order to address the need for effective and culturally congruent evidence-based approaches for military service members during times of social isolation and distancing due to the COVID-19 pandemic, a multi-state project funded by a Eugene Washington PCORI Engagement COVID-19 Enhancement Award, developed an opportunity for veterans to discuss and provide input on (1) their experiences and priorities for research related to their health, (2) existing barriers to engagement in the research enterprise, (3) recommendations for effective engagement techniques during the coronavirus for awardees/PCOR community to incorporate into decision-making settings, and (4) their preferences for how they would like to receive research findings and evidence-based practices. The recommendations and input of veterans engaged in this project comprise the foundation for the veteran-centered priorities, strategies, and related materials that are presented in this toolkit. The purpose of this Toolkit is to provide research teams, clinicians, policymakers, and other key stakeholders with the materials to guide and support their efforts in providing effective, evidence-based, veteran-centered research that meets the needs and challenges that are most important to the veteran population. This Toolkit also provides meaningful insight that may assist in addressing the existing gaps between the current delivery of service-related care and how military veterans would like to receive their care during times of social distancing and isolation.
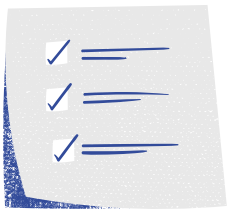
SECTION I

During the preparation phase of the VAL 2.0 enhancement award, COVID-19 pandemic expanded field note templates (FNT) were developed.

Each field note template was created one after the other and used to generate and guide dialogue during the Think Tank Meetings (TTM) specific to pain management, patient-centered outcomes research (PCOR)/comparative effectiveness research (CER), access to care and veteran healthcare utilization issues during the COVID-19 pandemic and distributed to the Collaborative Academic Research Members (CARM). A total of three COVID-19 pandemic field note templates were created. Each unit utilized one FNT for two TTMs. Overall, each FNT was utilized eight times to collect and guide dialogue at the TTMs.

The FNTs were used to generate and guide dialogue at the TTMs, and also to collect demographic information on those who attended. This information included total number of veterans, total number of stakeholders, type of veteran, and type of stakeholder. This information was gathered and placed in a table for further analysis by the Project Leads.

These field note templates can be adapted for use by other awardees in other populations and/or in times of social isolation and distancing.

FIELD NOTE TEMPLATE#1

FIELD NOTE TEMPLATE #1

COLLABORATIVE ACADEMIC RESEARCH MEMBERS FIELD NOTE

SUMMARY: TO BE SUBMITTED FOLLOWING VAL UNIT MEETINGS

DATE OF VAL 2.0 UNIT MEETING:_____

TOTAL NUMBER OF VETERAN ATTENDEES: N=_____

Vietnam Veterans (n=_____

Korean War Veterans (n=_____

Gulf War Veterans (n=_____

Post 9/11 Veterans (n=_____

Total Number of Stakeholder attendees: N=_____ Total Number of male attendees: N=_____ Total Number of female attendees: N=_____

STATE:_____

TYPES OF STAKEHOLDERS PRESENT (e.g. family members, service providers, policymakers):

****

Summary of dialogue related to VAL COVID-19 enhancement project objectives:

1) Dialogue about the barriers/challenges in receiving pain-related healthcare information during a pandemic.

2) Dialogue about the trusted sources for pain-related healthcare information during COVID-19 (e.g. political officials, clinicians, news anchors, radio announcers, Facebook etc,?).

3) Discuss crucial research questions that are important to the veteran community when facing social isolation due to the COVID-19 pandemic.

4) Discuss specific factors that can accelerate and/or deaccelerate veterans' involvement in pain-related Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER).

5) Discuss recommendations that would help research teams to connect with veterans during times of social isolation.

6) Discuss the type of mediums most effective to keep veterans and the community up to date on COVID-19 health information.

FIELD NOTE TEMPLATE#2

FIELD NOTE TEMPLATE #2
COLLABORATIVE ACADEMIC RESEARCH MEMBERS FIELD NOTE
SUMMARY: TO BE SUBMITTED FOLLOWING VAL UNIT MEETINGS
DATE OF VAL 2.0 UNIT MEETING:_____
TOTAL NUMBER OF VETERAN ATTENDEES: N=_____ # Vietnam Veterans
(n=_____
Korean War Veterans (n=_____
Gulf War Veterans (n=_____
Post 9/11 Veterans (n=_____
Total Number of Stakeholder attendees: N=_____ Total Number of male attendees:
N=_____ Total Number of female attendees: N=_____
STATE:_____
 TYPES OF STAKEHOLDERS PRESENT (e.g. family members, service providers,
policymakers):
****
Summary of dialogue related to VAL COVID-19 enhancement project objectives:

1) Discuss the crucial research topics that are important to the veteran community

when making healthcare decisions during the COVID pandemic.

2) Discuss recommendations for veterans regarding the management of social and

chronic pain during times of epidemics/pandemics, or other kinds of widespread

infectious disease outbreaks.

3) Discuss how the COVID-19 pandemic can affect veterans' abilities to manage social

and chronic pain.

4) Generate new topics for a social and chronic research agenda.

5) Discuss ideas that research teams can use to help veterans engage in PCOR/CER

during COVID-19 and other infectious disease outbreaks.

FIELD NOTE TEMPLATE#3

FIELD NOTE TEMPLATE #3
COLLABORATIVE ACADEMIC RESEARCH MEMBERS FIELD NOTE
SUMMARY: TO BE SUBMITTED FOLLOWING VAL UNIT MEETINGS
DATE OF VAL 2.0 UNIT MEETING:_____
TOTAL NUMBER OF VETERAN ATTENDEES: N=_____ # Vietnam # Veterans
(n=_____
Korean War Veterans (n=_____
Gulf War Veterans (n=_____
Post 9/11 Veterans (n=_____
Total Number of Stakeholder attendees: N=_____ Total Number of male attendees:
N=_____ Total Number of female attendees: N=_____
STATE:_____
 TYPES OF STAKEHOLDERS PRESENT (e.g. family members, service providers,
policymakers):
****
Summary of dialogue related to VAL COVID-19 enhancement project objectives:

1) Discuss recommendations for veteran health organizations to improve veterans'

access to care during times of pandemics or quarantines?

2) Develop comparative effectiveness research (CER) questions that are important to

the veteran community as they face social isolation due to the COVID pandemic.

3) Discuss outlets research teams can use during times of necessary social isolation, in

order to make veterans' aware of research opportunities and share research findings.

4) Discuss the consequences of social isolation on social and chronic pain

management.
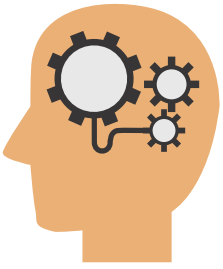
SECTION II

Florida Unit

- Establish trust by reading the consent form at the beginning of the meeting and emphasizing that the meeting is voluntary and information gleaned from the meeting will not contain any identifying information.
- Ensure that a veteran leads the meeting. Veterans prefer to talk to other veterans who understand the military experience and language.
- Hold the meeting on a virtual platform that is familiar to the veteran and CARM so the meeting will run smoothly and without many technical difficulties.
- Be nonjudgmental and create a space that encourages veterans and key stakeholders to share their experience and thoughts leading to a robust conversation.
- Provide time at the beginning of the meeting for introductions of the veteran leader, CARM, veteran participants, and community stakeholder participants. This is helpful for creating a safe space for dialogue.
- If possible, consider holding meetings in outdoor spaces and/or incorporating outdoor activities.

Georgia Unit

- Use telephone and email to recruit academic and community partners recognizing that they may be engaged in addressing pandemic-related issues.
- Tap organizations. During the pandemic, members of spiritual/religious organizations may be particularly receptive.
- Identify informal local veteran groups. The informal veteran groups consist of veterans helping veterans and rely heavily on word-of-mouth.
- Reach out to your personal connections to inform individual stakeholders and veterans about the opportunity to engage in research.
- Use technology. Video conferencing was an effective method for engaging in the study. However, not all veterans were comfortable or skilled with the technology. Therefore, some participants required individual coaching to make the connection.
- Early in the pandemic, social media (e.g., Facebook) was the source for information gathering prior to decision-making about healthcare. Later, as healthcare services were reopening, calls with healthcare providers, television announcements, and reports from fellow veterans became the source of trusted information related to healthcare decisions.

S E C T I O N   I I

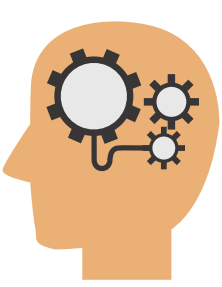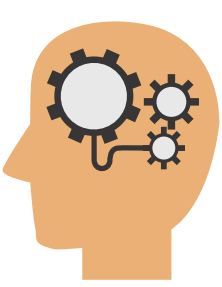Recommendations for effective engagement techniques during the coronavirus
for awardees/PCOR community to incorporate into decision-making settings

New Jersey

- Drop in "virtual social clubs", particularly for women only, would provide ongoing opportunity to interact, share information and experiences with other Veterans with like interests. These social informal meetings would mimic the social experiences Veterans lost during the pandemic when the VA stopped all live patient encounters.
- Scheduled Mobile Health Team outreach community "days" (e.g. every second Tuesday of the month) targeting vulnerable Veterans could reliably bring VA resources directly to those most in need of continuous live patient encounters during a pandemic. The Mobile Health Team could address individual Veteran's chronic pain and health and wellbeing at a micro level.
- Direct calls on scheduled "Open Telehealth days" (e.g. every second Tuesday of the month) targeting vulnerable Veterans could provide continuity of care with a Mobile Van outreach program. The Telehealth Team, in coordination with a Mobile Health Team, could provide follow up for individual Veteran's health and wellbeing issues, including chronic pain. Additionally, current information on resources available to Veterans within their communities could be disseminated.
- A well-advertised, web-based Community Resource Electronic Bulletin Board could be established where available Veteran live/virtual services and community resources can be located. Local Veterans Community organizations could post "flyers" about upcoming events. During a pandemic, these electronic bulletin boards connect Veterans communities that mimic VFW, American Legion, etc. community recreation centers.
- Monthly email newsletter to all regional Veterans to keep updated with information and resources. Local Veterans Community organizations could attach "flyers" about upcoming virtual social events during a pandemic. Veterans included in the email list serve would be able to submit emails responses to address health and wellness issues.

SECTION II

Recommendations for effective engagement techniques during the coronavirus for awardees/PCOR community to incorporate into decision-making settings

New York

- To engage and retain veterans in research, researchers should strive to match veterans with topics of personal interest. Veterans have diverse interests, opinions, and experiences and study planning and recruitment methods should include concerted efforts to illicit the issues and healthcare areas potential veteran participants are concerned and passionate about in order to coordinate those interests with research participation.

- An important component of engaging veterans in research is to ensure that each veteran feels they have an opportunity (and encouragement) to be heard and to 'tell their story' before being expected to respond to or fulfill any study activities. This requires the research study method to incorporate time for moderators/coordinators to listen to the veteran first, allowing for the acknowledgement of the participants' unique perspectives and experiences.

- A common theme that emerged from Think Tank meetings is the compassion and comradery shared amongst the members of veteran community and the willingness to support other veterans. PCORI/CER activities should focus engagement tactics on study participants' potential to promote and impact the well-being of their fellow veterans.

- To engage veterans, it is useful to provide flexible methods of engaging participants in activities, particularly individuals that may be disenfranchised or reluctant to initially participant in research. A group setting and group conversation may adequately allow some participants to engage, however, more structured relationship building activities, sharing individual non-study experiences, or personal or study related presentations may serve other potential participants.

- While outlining and presenting the objectives and aspects of the particular PCOR/CER study, expanding engagement tactics should also make sure to interact and respond to the veterans in a holistic manner. Veterans may have concerns (e.g., transportation, family issues) unrelated to the research yet researchers should respond, as possible (perhaps with resources or information outside of study time), and portray an interest in the veteran participants' concerns beyond the specific research deliverables.

- Along with the bullet points above, it is recommended to ensure veteran participation at all levels of PCOR/CER activities, from advising on study development, recruitment, data collection, to dissemination of findings.

SECTION III

Florida Unit

Research Design

- Hold several focus group meetings with veterans and key stakeholders to create and reach a consensus on an effective research design.

Subject Recruitment

- Record a short video (up to 1 minute) with the veteran leader, CARM, and a volunteer veteran participant to promote the importance of working together for creation of a veteran-centered research agenda. Upload the video to social media for subject recruitment.
- Utilize different methods of communication, e.g., social media, texts, phone calls, emails, to promote subject recruitment, because all veterans do not have access to the internet and some may be more comfortable with one medium over another.

Research Activities

- Hold meetings outside to accommodate social distancing and schedule time to have fun prior to the meeting so it will be easier to discuss pertinent issues.

GA Unit

- Design the study with alternate methods of data collection in anticipation of pandemic-related guidelines limiting access to participants.
- Use multiple avenues for recruitment including: tv; radio; mass mailings; word-of-mouth; social media; and fliers in open local veteran owned businesses.
- During recruitment, include a discussion of potential changes in the research plan that might result from pandemic-related changes or regulations limiting access to participants.
- Seek veteran feedback along the way, during the research, not just at the end of the study.
- Incorporate goals for veterans and rewards to participants for small achievements during the research process.
- Include a plan to assess and address changes in physical and mental conditions.
- For meetings, consider using non-veteran organizations that would be a safe place for veterans given the available pandemic-related information at the time.

SECTION III

NJ Unit

- Invite more participants than are needed for the focus group to ensure a diverse group is present. This ensures the focus group meets the parameters of the grant and encourages a more robust conversation among participants.
- Get Veterans excited to be a part of something important by explaining the need for further research with Veterans populations to address relevant healthcare issues.
- Invite Veterans, with common interests (e.g. female Veterans) to participate in a conversation that discusses specific current issues negatively impacting their wellbeing.
- Be prepared for focus group meeting. Anticipate questions Veterans participating in the focus group may ask about the organization and grant purpose.
- During the focus group, keep the dialogue going among participants. Veteran Leader asks multiple participants their views on the same research question, to continue the conversation.

NY Unit

Research Design
- During times of social isolation, research design should include flexible and iterative methods to initiate and promote engagement such as team building activities and individual and group social outreach strategies.

Subject Recruitment
- During times of social isolation, subject recruitment strategies should include time and the opportunity for potential subjects to 'share' and 'be heard' regarding issues and difficulties related to isolation prior to being expected to respond or perform study related activities.

Research Activities
- During times of social isolation, research activities should be planned and presented with broad and diverse approaches to veteran participants' concerns- with potential responses to non-study related concerns around isolation (e.g., transportation) - and options for study participation (e.g., remote communication/participation).

SECTION IV

New CER questions/evidence needs based on COVID-19
Each unit creates questions based on their dialogue. Each unit creates 3 CER questions based on their unit meetings

FL Unit

1. What are the comparative benefits and risks of Cognitive Behavioral Therapy (CBT), Eye Movement Desensitization and Reprocessing (EMDR) and Mindfulness Interventions for veterans who live with social and chronic pain?
2. What are the comparative benefits and risks of Infrared Low-level Laser Therapy and Hyperbaric Oxygen Therapy for veterans who live with social and chronic pain?
3. What are the comparative benefits and risks of Medical Marijuana and Traditional Chinese Medicine (TCM) medication for veterans who live with social and chronic pain?

GA Unit

1. In community-dwelling veterans experiencing chronic pain and social isolation, how does prescribed opioid pain medication plus an intervention with touch involving a dog, horse, or human compared to prescribed opioid pain medication affect the severity of chronic pain and the amount of opioid use over a period of years?
2. In community-dwelling veterans experiencing chronic pain and social isolation, how does prescribed opioid pain medication plus engagement in purposeful activities of the veteran's choice, rather than arts and craft-type therapy, compared to prescribed opioid pain medication affect the severity of chronic pain and the amount of opioid use over a period of years?
3. In community-dwelling veterans experiencing chronic neuromuscular pain and social isolation, how does prescribed opioid pain medication plus a 3-part intervention with aroma therapy, followed by medical massage with myofascial release and, then, chiropractic adjustment compared to prescribed opioid pain medication affect the severity of chronic pain and the amount of opioid use over a period of years?

SECTION IV

NJ Unit

1. What are the comparative benefits and risks of telehealth welfare checks and mobile outreach programs for Veterans experiencing social isolation due to a pandemic?

2. What are the comparative benefits and risks of mobile health services and web-based health programs for Veterans needing chronic pain management during a pandemic?

3. What are the comparative benefits and risks of web-based female only group social events and mixed gender group social events for female Veterans experiencing mental duress (e.g. anxiety, depression) during a pandemic?

NY Unit

1. For veterans in treatment for chronic pain and depression and/or anxiety, do patients that begin primarily utilizing remote/tele-mental health adhere to chronic pain treatment over the next year compared to patients primarily utilizing in-person mental health care?

2. Are veterans with chronic pain that are beginning opioid pain medication therapy as likely in the next year to begin and adhere to alternative pain treatments (yoga, acupuncture, chiropractic treatment) as veterans beginning non-opioid analgesic medication therapy?

3. For veterans with chronic pain and taking pain medications, however seeking to cease medications, are patients that utilize individual psychotherapy, group therapy, or alternative pain treatments more likely to ween off and maintain no pain medications after 1 year?

CONCLUSION

This Toolkit was developed to be utilized as a resource for other awardees, potential awardees, and the research community. Throughout this Toolkit the Veteran Leads and Collaborative Academic Research Members of the FL, GA, NJ, and NY VAL Units came together to provide in-depth recommendations and revisions of existing engagement resources based off of their experiences and gained knowledge over the course of the VAL 2.0 Project.

The toolkit sections are strategically designed to lend thoughtful recommendations and guidance for individuals interested in a PCOR/CER project. Specifically, these recommendations are beneficial to those partaking in PCOR/CER within the veteran community or those whose decisions or policies directly impact this community. A key aspect of this project was thorough and consistent engagement. The VAL Unit Leads provided their opinions, techniques, and strategies utilized that were successful to fuel the depth and quality of information collected over the course of the project. These strategies and techniques were pivotal in providing robust dialogue in which reviewers found trending topics and findings that provided insightful outcomes. Overall, this Toolkit is comprised of individual sections that detail actions taken, adjustments made, and recommendations for improvement based off of first-hand experience from the veterans, key stakeholders, and Project Team. The authors of this Toolkit worked collectively to provide highly insightful information to promote success in engagement with the veteran community.

Acknowledgements

The Project Team would like to thank the veterans and community stakeholders who engaged in this project and provided the information to create this Toolkit.