

A Capacity-Building Toolkit
For Engaging Veterans in Patient-Centered Outcomes
Research and Dissemination of Findings

*“Veterans Speak Out About Healthcare:
A Toolkit for Understanding Their Needs, Concerns, Research
Priorities, and Ways They Would Like to be Engaged in PCOR
and CER Activities”*

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INTRODUCTION

The engagement of consumers in health-related research is a widely accepted goal, yet effective engagement strategies remain elusive. This challenge is particularly evident among the nation's twenty-two million veterans. Despite a critical need for evidence-based approaches to service-related health issues, veterans are frequently reluctant to participate in the research enterprise.

To better understand this reluctance, a multi-state project funded by a Eugene Washington PCORI Engagement Award, created an opportunity for veterans to dialogue and identify (1) their needs and research priorities, (2) their barriers to research participation, (3) their recommendations for strategies that would engage them in research, and (4) their preferences for how they would like to receive research findings. Importantly, their recommendations comprise the basis for the veteran-centered priorities, strategies, and related checklists that are presented in this toolkit.

The toolkit is designed to assist research teams, clinicians, policymakers and other stakeholders in their efforts to give veterans an active voice in the research and outcomes that matter most to them. Importantly, the toolkit provides insights that may help to ***bridge the gap between how care is currently delivered and how veterans would like to receive their care.***

METHODS

To create a national platform for dialogue, *Veteran Action Leagues* were created in the six states with the largest veteran populations: California, Florida, New York, Ohio Pennsylvania, and Texas. Think Tank Meetings were led by a veteran unit leader with strong ties to the veteran community in their respective state; the veteran unit leader was assisted by a local university-based collaborative academic research member (CARM). In collaboration, the veteran unit leader and CARM in each state held nine Think Tank Meetings to dialogue with veterans and key community stakeholders over the two-year project period. Community stakeholders included veteran family members, friends, healthcare providers, and representatives from veteran advocacy organizations.

Across the six states, a total of 54 Think Tank Meetings were held and were attended by a total of 384 participants; 283 veterans and 101 stakeholders. Of the 384 participants, a total of 33% of attended more than one meeting resulting in 127 duplicated and 257 unduplicated Think Tank attendees who participated in dialogue.

Discussions at the Think Tank Meetings were led by the veteran unit leader; the Collaborative Academic Research Member recorded field notes including relevant quotes as exemplars. A field note template was developed specifically for this community engagement project to help guide the discussions and to provide a written summary of the dialogue generated at each meeting. The template included topic such as research priorities, barriers and facilitators to research participation, and preferences

for dissemination of findings. Field notes were validated with participants at the end of each Think Tank Meeting and sent to the project's lead research team for analyses via open and axial coding. The reoccurring themes were then reviewed and validated during a joint meeting, held in Denver, CO, of all VAL Unit Leaders and the Collaborative Academic Research Members.

SECTION I:

A Veteran-Centered Research Agenda

Patient-centered outcomes research (PCOR) involves studies that focus on outcomes that are most important to patients. Findings from PCOR investigations help patients evaluate their treatment options and to make informed healthcare decisions. Therefore, authentic PCOR is predicated on understanding the needs, concerns, and research priorities of the patient whom, for the purposes of this toolkit, is the U.S. veteran.

The following key concerns and research priorities presented in this Section were identified by veterans during the Think Tank Meetings.

Access to Care:

Veterans continue to report a wait time of 30 days or longer for an appointment with a Veterans Health Administration (VHA) provider. They also expressed multiple concerns regarding the efficiency with which the Veterans Choice Program is administered. A reoccurring theme across all six states was the recommendation that Veteran-Centered outcome studies are urgently needed that will compare the quality, efficiency and cost-effectiveness of differing models of care delivery, including access to local urgent care centers.

Care Coordination:

Another concern expressed by veterans in all six states was the need for improvements in care coordination within the VHA system and between the VHA and civilian providers. They suggested that an important veteran-centered research opportunity would include comparing the effectiveness of differing models of veteran-focused care coordination as well as the conduction of rigorous studies to investigate outcomes associated with differing levels of care coordinator caseloads.

Mental Health Services:

Veterans expressed concerns regarding treatment of veterans' mental health conditions. They also expressed concerns about what they perceived to be the use of polypharmacy in treating mental health issues. They recommended the funding and conduct of PCOR that tests interventions aimed at reducing polypharmacy. They also recommended comparative effectiveness studies that include traditional treatment options and complementary therapies.

A Veteran-Centered Research Agenda

Building on concerns and research recommendations arising from the veteran Think Tank dialogue sessions, several sessions in each of the six states were dedicated to creating a comprehensive, veteran-centered research agenda. The agenda, synthesized from session field notes, was presented to participants for comment and validation at VAL Unit meetings, the VAL Unit Retreat, and Town Hall meetings. This veteran-driven, veteran-centered research agenda, reflecting outcomes deemed by veterans as most important to them, is presented below:

- Testing Models to Improve Access to Care
- Improving Veteran Care Coordination
- Polypharmacy – testing care models that reduce polypharmacy; health outcomes
- Comparative Effectiveness: Post-Traumatic Stress Disorder (PTSD) Treatments
- Impact of Pain on PTSD
- Comparative Effectiveness: Adjunctive Interventions for PTSD
- Suicide Prevention
- Opiate and Addiction Reduction – alternatives to pain management
- Comparative Effectiveness: Alternative Treatments for Migraines
- Sleep Disorders and Sleep Apnea – effect on veterans' health
- Comparative Effectiveness: Interventions for Sleep Disorders
- Improving Adherence to Exercise Programs
- Enhancing Compliance with Exposure Therapy or Cognitive Processing Therapy
- The Effects of Open Burning Pits on Veteran Health Outcomes
- The Effects of Training Practices with Repetitious Motion on Health Outcomes
- The Effects of Strength Training on Combat Readiness
- Messaging to Veterans – What is Effective and Not Effective

SECTION II: **Building Research Capacity: A Veteran-Centered Approach**

Although veteran participation in research is vital to the accomplishment of their research agenda, low research recruitment yields within the veteran community are well documented (Bayley, et al., 2014). Veterans who participated in the Think Tank Meetings were very specific about their barriers to engagement in research activities. These barriers included (1) mistrust and skepticism of the research process; (2) unfamiliarity with research in general and Comparative Effectiveness Research in particular; (3) concerns regarding adequate human subject protection; and (4) lack of awareness of opportunities for research participation or collaboration.

Key veteran-recommended strategies for engaging the veteran community in research activities included (1) appointing a veteran to the research team or study advisory board; (2) hiring a veteran to conduct recruitment and intake; use of group settings comprised primarily of veterans for data collection or other research activities; using social media to market research participation opportunities, and more.

Go to page 12 for a detailed checklist for veteran-centered research engagement strategies.

Disseminating Research Findings: A Veteran-Centered Approach

Veterans across all six states specifically recommended that research findings should be disseminated to the veteran community through organizations such as the American Legion, Veterans of Foreign Wars (VFW) as well as the many other veteran resource organizations listed in Section V. Resources for Veterans and Stakeholders. They also strongly recommended that veterans be involved in the research dissemination, and that the research team use a multi-media approach to dissemination.

Go to page 13 for a detailed and specific checklist for developing a veteran-centered dissemination plan.

SECTION III:

Veteran-Centered Delivery of Healthcare Information

Although the focus of this toolkit is to share veteran-recommended strategies for engaging the veteran community in research and dissemination activities, the receipt of basic healthcare information is vital if people are to make informed healthcare decisions (Bhuyan, et al. 2017; Martinez, et al., 2017; Osei-Frimpong, Wilson, & Lemke, 2018). Therefore, a veteran-centered approach to the delivery of healthcare information should reflect veterans' preferences in how they would like to receive healthcare information. As veterans across the six states discussed healthcare information, they generally focused their recommendations around two categories of healthcare information: Personal and General.

Veterans preferences regarding the delivery of personal healthcare information centered around an encounter with their provider that included the following requisite elements: 1) adequate time for clarification and an opportunity to ask questions; (2) the provider's use of language that is understandable to the lay community;(3) discussion on the various treatment options available and the relative effectiveness of each so that the veteran could make an informed healthcare decision; and (4) inclusion of personal healthcare information on prevention and health maintenance instead of information exclusively related to a disease or a service-related condition.

Regarding the delivery of general healthcare information, veterans essentially described and recommended a "one-stop shop" website, sponsored by a veteran advocacy organization, as their preferred delivery mechanism. They also recommended the use of social media in the dissemination of general health information.

Go to page 14 for a detailed checklist on developing a veteran-centered health information website.

SECTION IV:
Tools and Checklists

A Veteran-Centered Research Agenda

- Testing Models to Improve Access to Care
- Improving Veteran Care Coordination
- Polypharmacy – testing care models that reduce polypharmacy; health outcomes
- Comparative Effectiveness: Post-Traumatic Stress Disorder (PTSD) Treatments
- Impact of Pain on PTSD
- Comparative Effectiveness: Adjunctive Interventions for PTSD
- Suicide Prevention
- Opiate and Addiction Reduction – alternatives to pain management
- Comparative Effectiveness: Alternative Treatments for Migraines
- Sleep Disorders and Sleep Apnea – effect on veterans' health
- Comparative Effectiveness: Interventions for Sleep Disorders
- Improving Adherence to Exercise Programs
- Enhancing Compliance with Exposure Therapy or Cognitive Processing Therapy
- The Effects of Open Burning Pits on Veteran Health Outcomes
- The Effects of Training Practices with Repetitious Motion on Health Outcomes
- The Effects of Strength Training on Combat Readiness
- Messaging to Veterans – What is Effective and Not Effective

Checklist for Veteran-Centered Research Engagement Strategies

Strategy	Yes	No	Required Action
RESEARCH DESIGN			
Research aims address a documented priority of the veteran community.			
Research design is informed by a veteran advisory council or advocacy group.			
A veteran is included as a member of the research team.			
Group sessions or networking opportunities with other veterans are built into the research design if possible.			
SUBJECT RECRUITMENT			
Veteran organizations agree to collaborate with recruitment and outreach efforts.			
Recruitment of veteran subjects is conducted by veterans.			
Strategies used to protect human subjects are clearly described during recruitment.			
The potential benefits of the research for the veteran community at large are clearly described during recruitment.			
The opportunity for veterans to “give back” to other veterans through research participation is discussed.			
RESEARCH ACTIVITIES			
All researcher-subject meetings / interfaces are held in a safe space such as space occupied by a veteran organization.			
Travel time for research participation is minimal.			
Mechanisms to provide participants with a summary of findings are ready for implementation.			

Checklist for Veteran-Centered Research Dissemination

Strategy	Yes	No	Required Action
Veterans are recruited to assist in developing dissemination strategies.			
Veterans assist in dissemination within veteran groups, advocacy organizations, and social groups.			
A research study website has been developed, findings are posted in lay language, and the link has been distributed by veteran organizations and through social media.			
A video has been created featuring veteran research participants who describe study findings in lay language. The video has been posted on YouTube and the link has been distributed by veteran organizations and through social media.			
A podcast has been created that describes findings in lay language. The link has been distributed through veteran organizations and social media.			
A manuscript, presenting findings in lay language, has been submitted to a magazine or journal preferred by veterans such as Military Officers Journal, Disabled American Veterans Journal, American Legion Magazine, or similar publication.			
A veteran-focused conference has been organized where findings will be presented. The conference has been marketed to the veteran community, providers, and other veteran stakeholders.			
Strategies have been developed to disseminate findings to providers in ways that inform evidence-based practice.			

Checklist for Developing a Veteran-Centered Healthcare Information Website

Strategy	Yes	No	Required Action
CENTRAL WEBSITE			
A one-stop shop for veterans that includes information on (1) general health promotion and disease prevention; (2) specific conditions of interest to the veteran community; (3) treatment options for those conditions.			
Includes state-specific web pages listing healthcare providers and veteran resources			
Contains downloadable PDF documents such as pamphlets, flyers, and newsletters containing general health education information focused on health promotion, disease prevention, and symptom management.			
Contains links to public access articles related to evidence-based treatment options, health promotion and prevention, and symptom management.			
Provides a list of volunteer veteran mentors willing to help other veterans navigate the Veterans Health Administration.			
WEBSITE ADMINISTRATION			
The website is developed, sponsored, and maintained by a non-provider organization (e.g. 501(c) 3)			
A veteran is a member of the site's administrative governance team.			
Access and utility of the website is marketed by a celebrity veteran via public service announcements, events, and social media.			
Website is linked to other forms of information delivery including social media and text messages.			

Section V. Resources for Veterans, Researchers, and Stakeholders

The following resources were recommended by veterans and stakeholders who participated in the Think Tank Meetings.

AmericaServes: <https://americaserves.org/>

This organization states that it is the country's first coordinated system of public, private, and non-profit organizations that work together to service veterans and their families. Check the website for locations across the U.S.

AMVETS: <http://amvets.org/amvets-in-action-programs/>

Offers free help filing VA claims, a Career Center, educational scholarships, advocacy activities on behalf of veterans, and other resources (nationwide).

Myhealthvet: <https://www.myhealth.va.gov/mhv-portal-web/home>

This resource offers veterans tips and tools to help veterans partner with their health care team, access medical record, and find useful resources (nationwide).

Military Officers Association of America: <http://www.moaa.org/>

The MOAA provides a variety of resources and programs including those focused on Pay and Benefits, Health, Transitions and Careers, and Retirement Planning to name a few. The MOAA currently serves Junior Officers, Mid-Grade Officers, and Senior Officers (nationwide).

Mission United (United Way): <https://www.unitedway.org/mission-united/veterans-and-families>

Mission United offers full case coordination for veterans and their families, including assistance with housing and employment. Check website for states in which services are available (selected states).

Patriot Guard Riders: <https://www.patriotguard.org/>

Shields families of fallen heroes from those that would disrupt the services of their loved ones (nationwide).

Pets for Vets: <https://www.petsforvets.com/>

Connects and matches veterans with rescue animals (in selected states).

PTSD Foundation of America: Camp Hope: <http://ptsdusa.org/>

Dedicated to combatting PTSD through pastoral counseling and peer mentoring, both on an individual basis, and in group settings. For Active duty, Reserves and National Guard personnel, veterans, and their families (selected states only – see website for locations).

Team Red, White, and Blue: <https://www.teamrwb.org/about-us/mission/>

Connects veterans to their community through physical and social activities (nationwide).

TAPS (Tragedy Assistance Program for Survivors): <https://www.taps.org/mission>
This organization provides emotional support for anyone dealing with the loss of a loved one while in service to their country. Also hosts a [TAPS 24/7 National Military Survivor Helpline](#) which is always available toll-free at 800-959-TAPS (8277). (nationwide).

The American Legion: <https://www.legion.org/>
This organization founded in 1919 states that it is the nation's largest wartime service organization. Resources include a Benefits Center, Career Center, Education Center, Troop and Family Support, a Health Center that provides information on veteran healthcare options, resources and support specific to women veterans, and USAA financial services (nationwide).

The 31 Heroes Project (One Team One Fight): <https://www.31heroes.org/home/>
Raises money for veteran-focused activities through athletic events and other fund-raising projects (nationwide).

Veterans of Foreign Wars: <https://www.vfw.org/>
Provides resources and/or assistance in the areas of Claims and Separation Benefits, Financial Grants, Educational Scholarships, Transition and Employment Services, as well as a Mental Wellness Campaign, political advocacy, and more (nationwide).

Veterans Health Administration / U.S. Department of Veterans Affairs:
<https://www.va.gov/health/>

Veteran and Military Service Organizations: <https://www.va.gov/vso/VSO-Directory.pdf>
A comprehensive list published by the Office of the Secretary, Veterans Affairs. Downloadable PDF format.

Vietnam Veterans of America: <https://vva.org/>
With a focus on Vietnam veterans, this organization offers claims assistance, financial planning, advocacy and a variety of outreach and assistance programs including those focused on PTSD, Homeless Veterans, Women Veterans, and more.

Wounded Warrior Project: <https://www.woundedwarriorproject.org/>
This multi-faceted project is VA-accredited and assists veterans to better understand the benefits to which they are entitled and to navigate the Department of Veterans Affairs (VA) and Department of Defense (DoD) to access their benefits. Among the many other resources offered by this Project are a Combat Stress Recovery program, a Peer Support program, a Family Support program, an Employment/Career Counseling program, and a Physical Health and Wellness program (nationwide).

California Resource

Warrior Built Foundation: <http://www.warriorbuilt.org/>

An organization that provides veterans with motivation and camaraderie while building spirits, souls, and machines.

Resources for New York Locations Only

Veteran Outreach Center: <https://veteransoutreachcenter.org/>

Provides a wide array of resources and services for veterans including housing, employment, benefit counseling, legal counseling, and treatment and wellness programs.

Resources for Texas Locations Only

22kill: <http://www.22kill.com/>

22KILL provides traditional and non-traditional therapies for service members and their families for those suffering from hidden wounds. The organization offers free to low-cost counseling services provided by a mental health professional. Additionally, through empowerment, services help individuals find a sense of purpose after service (selected locations in Texas only – check website for locations).

TXServes: <https://northtexas.americaserves.org/>
<https://sanantonio.americaserves.org/>

Offers access to providers and services including housing, employment, financial services, and recreation to name a few.

VetTRIIP: <http://www.vettriip.org/>

Group of providers in selected Texas communities who provide innovative approaches to managing PTSD, other stress disorders, and chronic pain.

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