# How to Integrate Veteran Engagement from Research Plan to Publication

March 7, 2023 – Timely Topics of Interest HSR&D Cyberseminar Series

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Sarah Ono, PhD with Special Guest, Ray Facundo, MSW, Veteran VHA Office of Rural Health; Center to Improve Veteran Involvement in Care (CIVIC), Portland, OR; Oregon Health & Science University

Karen McNamara, PhD AAAS Science & Technology Policy Fellow, HSRD VACO, Washington, DC

Gala True, PhD SC MIRECC, Southeast Louisiana Veterans Health Care System and Associate Professor, LSU School of Medicine











- INTRODUCTION: Sarah Ono and Ray Facundo
- PROPOSAL: Karen McNamara
- PROJECT: Kenda Stewart Steffensmeier
- DISSEMINATION OF FINDINGS: Gala True
- Q&A



# Disclaimer

 The views expressed in this presentation are those of the presenter(s) and do not represent the Department of Veterans Affairs, the United States Government, or other affiliated institutions.

 This cyberseminar should be considered a brief guide, not a toolkit. Here's a <u>toolkit</u>.\*



U.S. Department of Veterans Affairs

Veterans Health Administration

\*Strengthening Excellence in Research through Veteran Engagement (SERVE) Toolkit 2.0

# Why Engage?

There is so much we don't know. If we listen, Veterans will share their knowledge.









Veterans should be involved in the research that advances the care they receive. Veteran Engagement allows us to work faster.

It's fun!

# Spectrum of Veteran Involvement in Research



Veterans are **research subjects** who may offer input through interviews, surveys, etc. Veterans are **partners** who may offer input at one or more times during multiple projects, but do not conduct the research.

Veterans are **members of the research team** who participate in all parts of the project from start to finish.



### Differentiating VE from Research Participation

Veterans and caregivers are participating as experts (consultants) providing their opinions, perspectives as individuals

**Relationship is ongoing** (regular, routine meetings with communication in between)

Mechanisms for Veteran engagement contribute to research capacity and infrastructure, potentially supporting all **projects at any stage** 

Veteran engagement promotes the goals of health equity and enhances capacity to address health disparities

# Investment Pays Off & More to Do

#### **Pre-Data Collection**

Outreach call:	0.5 hours	
Drive to Ray:	1.5 hours	
Convo & Consent:	2.0 hours	
Drive from Ray:	1.5 hours	
Follow up:	.25 hours	

#### **Total trust building: 5.75 hours**

Study activities:	
Fotal engagement:	

13.75 hours (est)

#### Post-Study Engagement:

30-40 hours (est)

8 hours (est)

- True G, Facundo R. (2012) *From War to Home: through the veteran's lens* [Cyberseminar]. Veterans Health Administration, VISN 4 Virtual PACT Collaborative.
- Facundo R, True G. (2013) From War to Home: an exhibition of OEF/OIF veterans' photos and stories. The Soldiers Project Annual Conference; Los Angeles, CA.
- Bean, N., True, G., Davidson, L., Facundo, R. (2014) Narrative Approaches (Journaling, Photovoice) in Teaching and Learning about Military Social Work. Military & Veteran Social Work Conference; St. Leo, FL
- True G, Facundo R. (2014) *The why and how of patient-centered care: learning from OEF/OIF veterans* [Cyberseminar]. VA Health Services Research & Development Cyberseminar Series.
- True, G., Davidson, L., Facundo, R., Ono, S. (2015) *Methods, Materials, and Ethics* of Community-Engaged and Participatory Action Research in VHA: Learning from Ongoing Veteran-Researcher Collaborations. Presentation at VA Health Services Research & Development / QUERI National Conference, Philadelphia, PA.
- Ray joins Gala's study team: 5,850 hrs (est)



Project Leaders for *From War to Home: The Impact of Invisible Injuries* opening exhibition, 2018 (Left to Right: Ray Facundo, Sarah Ono, Gala True)

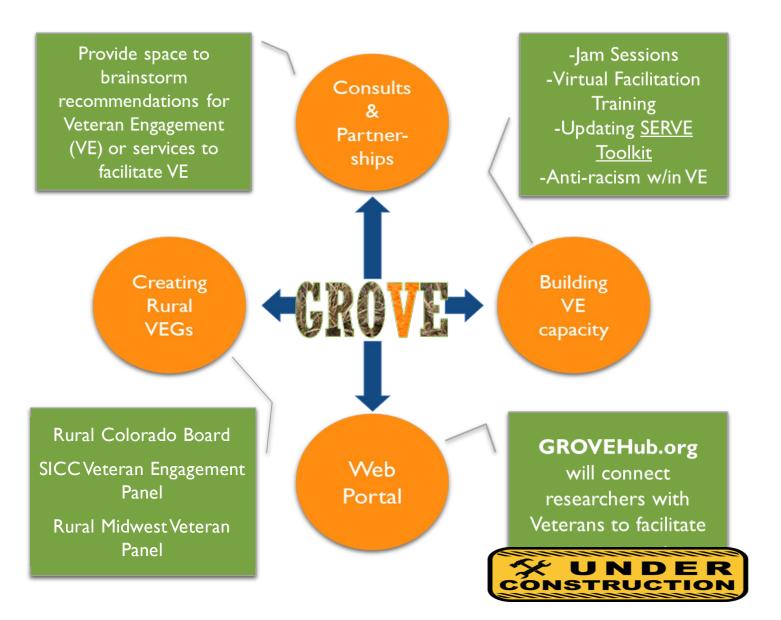
### Engagement to date: 13,703.75 hrs ...but who's counting?;)



More about Ray's Journey: Facundo, R. Veterans Helping Veterans: Reflections on 10 Years of Community Engagement. J GEN INTERN MED 37 (Suppl 1), 85-87 (2022). https://doi.org/10.1007/s11606-021-06986-0

### The Growing Rural Outreach through Veteran Engagement (GROVE) Center

- GROVE focuses on growing outreach among rural Veterans for ORH and HSR&D funded research & operations.
- In addition to innovating Veteran engagement practices, GROVE provides resources, consults, and training to researchers and Veteran engagement liaisons.
- To schedule a consult, contact Ray. <u>Raymond.Facundo@va.gov</u>



# PROPOSAL

How do you plan to engage Veterans?

HSR&D Merit Review Award (Parent I01) (va.gov)

To meet this goal, the VA health care system encourages **increased Veteran engagement at all levels of research**, using approaches based on **respect, trust, and reciprocity** between researchers and Veterans.

All proposals should include discussion of Veteran engagement. The appropriate level of engagement will vary with the nature of the project and the target of any interventions included. In cases where investigators determine that Veteran engagement is not applicable, the PD/PI must provide a clear rationale for that decision.

# How to do it? (from the RFA)

- Describe how Veterans and/or caregivers were involved in the proposal and their impact on the study plan
- Letters of support
- Describe plan to include diverse Veteran/caregiver input
- Budget for support staff
- Budget and describe plan for Veteran/caregiver compensation
- Dissemination plan

### Veteran Engagement Groups

### Ideas phase

- Define the problem.
- Ask Veterans their experience of the problem.
- What are we missing or not thinking about?

### IIR development postpilot and/or CDA

- Share pilot/CDA findings.
- Ask what surprises the group.
- Where do Veteran/caregivers see avenues for future research based?

### Share specific aims page

- Does it ring true to Veterans' experiences?
- Is there a problem that should be prioritized that is not currently one of the aims?
- Novel method?
- Ideas for recruitment?

### Veteran/Caregiver partners or consultants







Build on previous relationship with Veteran/caregiver.

Set up a GROVE consultation.

Contact Raymond.Facundo@va.gov Budgetary considerations.

# But my work is not Veteran facing...

e.g., VA admin data, clinician-targeted interventions, operationstargeted QI, chart review Think of downstream impact on Veterans/caregivers.

Ask about experience of care targeted for intervention, variables of interest.



All VA research ultimately impacts Veterans' health care either through treatment or policy. Veterans should be involved in the research that advances the care they receive.



How do you implement your plan within the VA system?

My study's been funded, now what?

Regulatory Recruitment **Role clarity** Communication Compensation

### Federal Advisory Committee Act (FACA)

- Veteran engagement groups do not invoke FACA if:
  - Veterans speak only on their own behalf when providing advice or recommendations.
  - VA seeks only facts/information/experiences from a group.
  - An outside group not managed or controlled by VA providing unsolicited recommendations or advice to VA.

#### Best practice

- Clearly state the role of group members in documents such as MOUs.
- "Veteran/Caregiver Advisors provides individual viewpoints only. Their work does not implicate the Federal Advisory Committee Act."

### IRB and R&D

Consider if the VE group/consultant will:

- 1. Obtain informed consent
- 2. Collect, analyze, or review identifiable data.

If YES: include on IRB protocol and ensure they receive necessary VA privacy and CITI trainings.

If NO: There should be no R&D/IRB regulatory requirements

#### Best practice

 Meet with your local IRB early to identify necessary requirements, such as VA privacy and research training, WOC status. Recruitment: How do I find Veterans to work with?

### GROVEhub

**GROVE COMING SOON** 

- An online networking site to connect with Veteran partners
- In beta testing

# BV-

VSOs



- Contact Veteran Service Organizations
- Some states have Veteran Service Officers in each county

### Existing networks



- Develop relationships by presenting to existing VEPs
- Reach out to Veteran colleagues

# Role Clarity

- Define the *mission* of the project and how your
   Veteran partner helps fulfill that mission
- Establish clear boundaries and responsibilities for all study team members.

*Examples excerpted from:* GROVE Rural Midwest Veteran Panel, Gala True's study, "Preventing Firearm Suicides among Rural Veterans by Engaging Military Caregivers."

#### **RURAL MIDWEST VETERAN PANEL – MEMBER DESCRIPTION**



#### Position Title: Rural Midwest Veteran Panel Member

We are seeking rural Veterans or Veterans' caregivers who can use their military and other life experiences to help develop diverse projects aimed at supporting Veterans. Selected candidates will engage with researchers and other Panelists to inform all stages of project development, from generating ideas to sharing results.

#### **Position Objectives**

- 1) Develop a working relationship with researchers, Veterans, and caregivers on the Panel;
- Suggest broad directions for VA research to improve VA support of Veterans and their caregivers living in rural areas;
- 3) Evaluate specific projects to ensure they are relevant and useful to rural Veterans and caregivers, and to suggest changes to proposed methods and materials that may increase their chances of success;
- 4) Provide input on ways to share information outside the Panel, such as the results of research.



#### Preventing Firearm Suicides among Rural Veterans by Engaging Military Caregivers

We – the members of the VA study team – will be responsible for most activities related to the project including developing all materials and organizing and co-leading community meetings and discussion groups. If you agree to be a Caregiver Peer Champion, we will ask you to:

- Attend 3 Advisory Board meetings from January to September 2022 with the rest of the research team (12 hours, virtual) NOTE: If you are
  reading this after Jan 2022, we will catch you up on the first Advisory Board meeting.
  - This meeting will involve the discussion of our different roles, brainstorming ideas about caregiver roles in suicide prevention by firearm, tool development and data analysis discussions.
- Attend and co-lead 2-3 deliberative discussion forums (8-12 hours, virtual)
   O These discussions will provide the data to inform future interventions.
- Attend team meetings for discussion of study materials, data collection, <u>analysis</u> and interpretation of data, debriefing and networking, planning for dissemination of findings and future research ideas (up to 26 hours, virtual)
  - o These meetings will help us organize and act on the information we've collected from our outreach and forums.

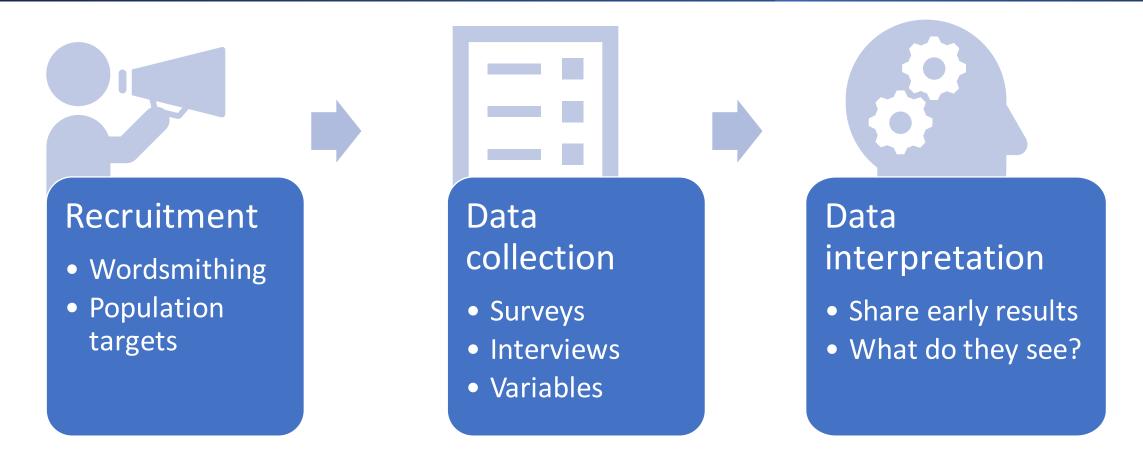
Compensation and Time: Up to 50 hours total obligation (\$50/hour x 50 = up to \$2,500 total compensation as a consultant)

The 50 hours of work will be spread out over the course of the first 9-12 months and will be approximate. We will pay you using a <u>ClinCard</u>, which is like a debit/credit card that we can load funds onto at regular intervals. We will share more information about the <u>ClinCard</u> and mail a card to you.

Please let us know if you have questions at any time!

Thank you, and we look forward to collaborating with you.

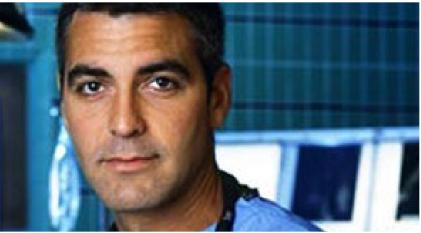
### Veteran Engagement Groups



\*\* Best Practice: Always report back to the Veteran Engagement Group how you incorporated their feedback. Like researchers, they want to know what they do makes a difference.









# Veteran/Caregiver as partner/consultant

- Study team member with subject matter expertise in military and/or patient experience of disease/treatment of interest
- Recruitment specialist in charge of wording recruitment materials
- Peer interviewer, PhotoVoice
- Co-analyst (ex. Listening guide analysis)

### Communication



Establish type and frequency of communication with Veteran partners.



Create and maintain a feedback loop.



Be flexible and open to new ways of communicating. Remember research may not be their "day job."



Say what you'll do and do what you say.

### Compensation

*Include Veteran compensation in your budget justification.* Include % effort for staff and facilitators, if applicable.

### How much and how often should Veterans be compensated?

• Most Veteran Engagement Groups compensate \$50 per two-hour meeting.

•

- Consider taxes. Compensating \$599/calendar year avoids a tax issue.
- Negotiate and communicate with<br/>your Veteran partners. Maybe<br/>money is not the most helpful form<br/>of compensation.
- Some Veterans have made themselves an LLC for tax purposes.
  - \$2500 is the current cap for compensating consultants.

Veterans will likely need to be vendorized (VA form 10009)

# DISSEMINATION OF FINDINGS

How do you engage your partners in developing dissemination products?

How do you get the word out to diverse audiences?



Describe engagement activities in **Methods** of manuscripts and/or include Veterans/Caregivers in **Acknowledgements** 

# Options for engaging Veterans/ Caregivers

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Facilitate ability of Veterans/Caregivers to present findings on their own at **conferences or school** 



Engage Veteran/Caregiver advisors or consultants as co-presenters or co-authors



Ask Veterans/Caregivers for **alternative dissemination venues** for findings (i.e., local or national VSOs and non-profits) Things to consider when Veterans/Caregivers have opportunities to present study findings on their own

- Where are the opportunitiesschool, work, professional conference?
- What data/story is an individual best able to share?
- Will they need your help & do you have time?
- How will you handle credits/acknowledgements?





Figure 8. HSR&D workshop presenters.

Note. Four of the authors after presenting a workshop on Veteran–Researcher Collaboration at the 2015 VA Health Services Research and Development meeting (From left to right: Gala True, Lawrence Davidson, Ray Facundo, Sarah S. Ono).

Why should you engage Veterans/Caregivers as copresenters or co-authors?

- Aligns with values of engaged research
- Impact and credibility
- Integrity of findings
- Joy and connection

### THE WHY AND HOW OF PATIENT-CENTERED CARE: LEARNING FROM OEF/OIF VETERANS

#### Gala True, PhD

Center for Evaluation of Patient-Aligned Care Teams (CEPACT) Center for Health Equity Research and Promotion (CHERP) University of Pennsylvania School of Medicine

#### Ray Facundo, MSW

Director, Veterans Center at Portland State University Sergeant, U.S. Army, Operation Iraqi Freedom 2005-2006 & 2008-2009

Spotlight on Mental Health Centers of Excellence

Whole Health from the Perspective of VA Caregivers: Findings from a Photovoice Study

by David Meyer, Esq., MBA, CISSP ; Sharon Urbina, Seminar date: 12/11/2017 How will you know <u>who</u> to engage as co-presenters or co-authors?

- Some people show up and contribute consistently
- Others may have a particularly compelling story to share
- Veterans/Caregivers may be well-suited due to other advocacy or career roles

Be thoughtful and transparent about who you invite "Institutions Don't Hug People:" A Roadmap for Building Trust, Connectedness, and Purpose Through Photovoice Collaboration Journal of Humanistic Psychology 2021, Vol. 61(3) 365–404 © The Author(s) 2019 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/0022167819853344 journals.sagepub.com/home/jhp

Gala True<sup>1,2</sup>, Lawrence Davidson<sup>3</sup>, Ray Facundo<sup>1</sup>, David V. Meyer<sup>4</sup>, Sharon Urbina<sup>5</sup>, and Sarah S. Ono<sup>6,7</sup>

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

> Gala True, Ray Facundo, Carlos Urbina, Sawyer Sheldon, J. Duncan Southall, and Sarah S. Ono

How might you go about engaging Veterans & Caregivers as co-authors?

- If you identify an opportunity, ask collaborators early and set expectations and deadlines;
- Preliminary meeting -- present ideas about framing & format; gain structured input on results section;
- Present early draft of results (at least); gain structured input on results and discussion;
- Record and transcribe meetings, incorporate language into drafts

### Another approach to co-writing

The Future of Veteran Community Engagement: Perspectives on Engaging Veterans and Other Stakeholders in Research Agenda Setting



★ JOURNAL OF ★ VETERANS

#### RESEARCH

MARGEAUX ALANA CHAVEZ KAI RIVER BLEVINS CHRISTOPHER BROWN ANGELA J. GILES MONICA M. MATTHIEU MARETE WESTER JACQUELYN HEUER

BRIDGET HAHM O VIRGINIA TECH. JASON LIND O CHRISTINE MELILLO O CHRISTINA DILLAHUNT-ASPILLAGA O LISA OTTOMANELLI O KAREN BESTERMAN-DAHAN O

- 7 members of a 25-member multi-stakeholder panel (MSP) volunteered;
- Each MSP volunteer was paired with a writing partner from the research team;
- Used a writing prompt and gave one-month deadline for 250-500 words;
- Writing partners reflected on "big ideas in each narrative from the perspective of a curious reader rather than copy editing and grammar," asked questions to better understand the writers' goals, values, and points of view;
- Made suggestions for bringing those understandings to the forefront of the writing, MSP volunteers chose whether to edit their narratives before finalizing their writing for inclusion in the publication.

### Where to co-present and co-author: experiences and examples

### 14<sup>th</sup> International Family Nursing Conference

The official meeting of the International Family Nursing Association

#### **Opening Keynote**



Investigator, South Central Mental Illness F Associate Professor of Community and Pop Louisiana State University School of Medic Dr. Gala True is an Investigator with the South Cent at the Southeast Louisiana Veterans Health Care Sys Population Medicine at Louisiana State University Sci anthropology, her research focuses on improving acc patient-centered and community-engaged research a action research methods to collaborate with Veterar barriers to post-deployment care and proposing solu from military service.

#### Sharon Urbina, Co-Presenter



Sharon Urbina is a caregiver to her husba years and sustained multiple traumatic bra is also a new mother, as she and Carlos r Elizabeth Dole Foundation, where she wo addressing unmet needs of military caregi to raise awareness in her community by t and caregiver events. Throughout her jou programs to advocate for her husband's h





Research2Practice Webinar Series by the Injury & Violence Preventio...

Colorado School of Public Health (ColoradoSPH)

The Armory Project: A Community-Partnered Approach to Providing Temporary, Out-of-Home Firearm Storage

Gala True, PhD, Dept of Veterans Affairs & LSU School of Medicine Caleb Morse, U.S. Army Veteran & Owner, Rustic Renegade

Colorado School of Public Health Injury & Violence Prevention Center Research2Practice Webinar November 16, 2022

1:02 / 1:00:2





# Alternate Venues and Audiences for Dissemination

- Veterans/Caregivers have access and authority that researchers do not
- Can lead to impact at local or national level
- Builds trust in VA, research, between people
- Personal stories are powerful!
- Ask your Veteran/Caregiver partner: who needs to hear these findings and how can we get the word out?
- Learn how to present information to diverse audiences
- Be prepared to step back

# Veteran/Caregiver partners or consultants

Co-present	Co-author	Empower	Advocate
Present work at conferences and on webinars Co-present to Veteran and Caregiver focused organizations	Strategies for writing with non-academic partners Friendly journals include JGIM, Journal of Veteran Studies, Progress in Community Health Partnerships, Journal of Humanistic Psychology	Veteran/Caregiver invites researcher to co-present to local or national group Veteran/Caregiver writes opinion piece, blog, presents as part of academic program	Reports to VA Program Offices, Service Line Leadership Legislation, Advocacy work

### Additional Examples

- Wendleton, L. R., Martin, L. A., Stewart Steffensmeier, K. R., LaChappelle, K., Fehling, K., Etingen, B., ... & Ono, S. S. (2019). Building sustainable models of veteran-engaged health services research. *Journal of Humanistic Psychology*, <u>https://doi.org/10.1177/0022167819845535</u>.
- Chavez, M. A., Blevins, K. R., Brown, C., Giles, A. J., Matthieu, M. M., Wester, M., Heuer, J., Hahm, B., Lind, J., Melillo, C., Dillahunt-Aspillaga, C., Slone, L. O., & Besterman-Dahan, K. (2022). The Future of Veteran Community Engagement: Perspectives on Engaging Veterans and Other Stakeholders in Research Agenda Setting. Journal of Veterans Studies, 8(2), pp. 21–35. DOI: <u>https://doi.org/10.21061/jvs.v8i2.360</u>
- Supplemental Issue: Patient and Veteran Engagement in Healthcare Research. Journal of General Internal Medicine. April 2022. <u>https://link.springer.com/journal/11606/volumes-and-issues/37-1/supplement</u>
- Franco, Z. E., Logan, C., Flower, M., Curry, B., Ruffalo, L., Brazauskas, R., & Whittle, J. (2016). Community veterans' decision to use VA services: A multimethod Veteran Health Partnership study. *Progress in community health partnerships: research, education, and action, 10*(1), 31-44. <u>10.1353/cpr.2016.0012</u>
- And many more...

### Reach Out

- Kenda Stewart Steffensmeier
   <u>kenda.steffensmeier@va.gov</u>
- Sarah Ono <u>sarah.ono@va.gov</u>
- Ray Facundo <u>raymond.facundo@va.gov</u>
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