

Veteran Engagement Initiative in VA Research:

Increasing the Voice of the Veteran in VA Research:
Recommendations from the Veteran Engagement Workgroup

VA HSR&D Cyberseminar

March 17, 2016

CyberSeminar Speakers

- **Susan Zickmund**, PhD, Chair, Veteran Engagement Workgroup, CHERP, Pittsburgh
- **David Atkins**, MD, MPH, Director, HSR&D
- **Sara Knight**, PhD, Conceptual Model Subgroup Co-Chair
- **Mark Helfand**, MD, MS, MPH, Health Experience Research Subgroup Chair
- **Alison Hamilton**, PhD, MPH, Engagement at the Project Level Subgroup Chair
- **Michael Ho**, MD, PHD, Engagement at the COIN Level Subgroup Chair

Origins of the Veteran Engagement Workgroup

- Created by HSR&D Director David Atkins
- The charge was to focus specifically on Veteran engagement rather than on various stakeholders



Rationale for Increasing Veteran Engagement

- The original topics to explore were:
 - Health Experience Research
 - Engagement at the proposal level
 - Engagement fostered through COINs
- A conceptual model subgroup was added to help guide a VA HSR&D-specific approach

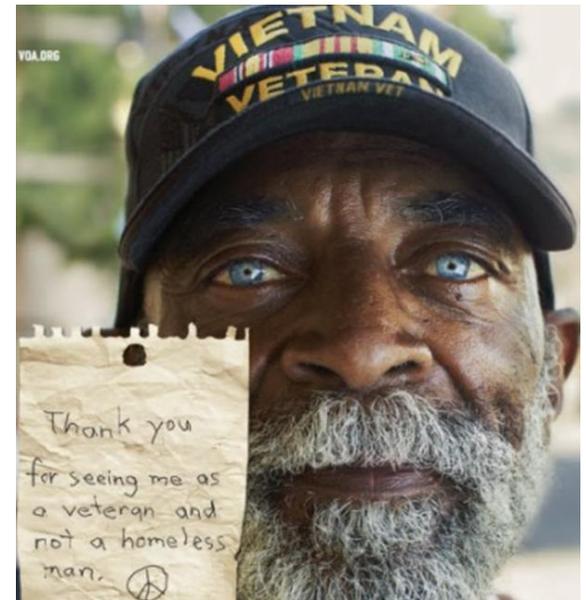
Dissemination Activities

- The first panel discussion of the Workgroup occurred at the 2015 VA HSR&D Conference
- Next the Veteran Engagement Workgroup Final Report was submitted in October 2015
- Two half-day conferences were convened in December 2015 featuring the engagement activities of Operational Partners as well as presenting the findings of the final report to COIN Directors

Introduction by David Atkins

Veteran Engagement – Why Now?

- Voice of the patient often missing from research.
- Solutions developed may not meet the needs of patients
- Patients and public feel disconnected from the goals of research
- Other organizations demonstrating potential value of more concerted attempts to engage patients



Veteran Engagement – Goals

- Veteran Engagement Workgroup created in January 2015 by HSR&D Director
- Goal was to review and recommend **ways to best incorporate Veteran input and engagement in research**

Goals:

- Improve design of patient-relevant research
- Increase uptake of research into practice
- Build Veteran support for research
- Restore trust in the VA



Veteran Engagement – General Conclusion

- Veterans are one of several important research stakeholders in VA research
 - Include providers, caregivers, managers, policy makers
 - Importance of Veteran perspective depends on nature of study
 - Area with most room to improve is in input from patients
- While understanding Veteran perspective is “the right thing to do,” as researchers we should document how it influences research process
 - How does it change the questions, designs and outcomes?
 - What does it cost to do this well (not a “checkbox”)?
 - Goal is not to prioritize research but to improve research

Conceptual Model Subgroup

Lead: Sara Knight (Co-chair)

Birmingham VA Medical Center (Birmingham & Tuscaloosa HSR&D Program)

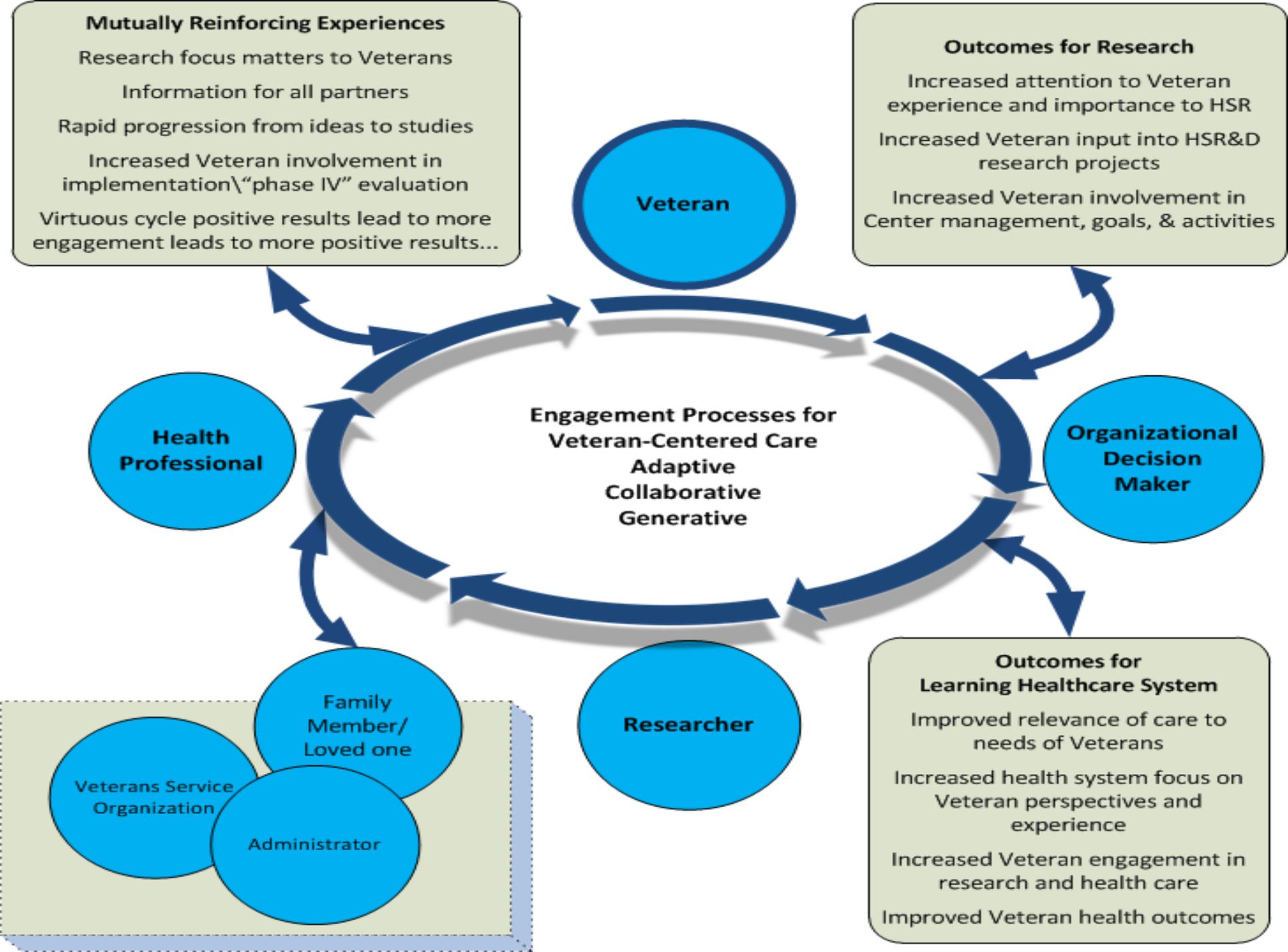
Conceptual Model Workgroup members: Jorie Butler, Alison Hamilton, Sarah Ono, Jeffrey Whittle, Susan Zickmund (Co-Chair)

Importance of Conceptual Models

- Provide a visual representation of important constructs, to lay out the broad landscape
- Make the relationships between constructs clear
- Provide directionality
- Specify desired outcomes

Need for a VA-Specific Conceptual Model

- Conceptual models are emerging to guide stakeholder engagement
- The VA is unique and, thus, requires a distinct approach
- No prior model depicts the constructs involved in Veteran engagement
- Having a conceptual model that informs decisions related to Veteran engagement places the field on stronger footing



Factors Influencing Veteran Engagement in Research

- **Environment**
 - VA priorities
 - Research funding
 - Research structures (e.g., center and project mechanisms)
 - Resource availability (e.g., information technology)

Factors Influencing Veteran Engagement in Research

- **Partner Characteristics**
 - Availability and interest
 - Research expertise and knowledge
 - Level of experience in community and research partnerships
 - Leadership experience

Factors Influencing Veteran Engagement in Research

- **Facilitators**

- Cues to action (e.g., events in the Veteran community)
- Collaborative tools
- Resources in the Veteran community
- Positive exemplars

Health Experiences Research *and* Engagement

Lead: Mark Helfand
Portland VA Medical Center (CIVIC)

Health Experiences Workgroup members: Debra D'Allesandro,
Mark Flower, Sara Knight, Carolyn Ray, Susan Zickmund

Incorporating Patient Voice into Research?

- Limited evidence-base on how to do this effectively
- Barriers to incorporating patient perspectives, values and preferences



Background

An essential component of patient-centered research is that it effectively incorporates the patient voice

BUT

Patient engagement in healthcare research “comes at a cost and can become tokenistic”¹

1. Domecq et al, “Patient Engagement in Research: a Systematic Review” *BMC Health Services Research* 2014; **14**:89

Relationship of HER and Engagement

- Health experience research can inform and advance patient engagement
- Health experience research is a form of engagement in itself



Repository

- *What does it do?*
 - incorporate Veterans' perspectives into the development of research questions and design of research studies, identify patient-important outcomes
 - inform and enhance other avenues of engagement
- *What is included?*
 - Many sources can contribute
- *IRB, other issues*

Healthexperiencesusa.org (DIPExUSA)

1. Bring the “widest possible range” of experiences of a condition or service to the table
2. Don't lose that experience research after a particular study ends



IRB/CIO Issues

- Data access is important for qualitative research
- Veterans' reasons for participation include helping other Veterans
- Veterans control the use of their (identifiable) images, voice, location

Veteran Engagement at the Project Level

Lead: Alison Hamilton

HSR&D Center for the Study of Healthcare Innovation, Implementation, & Policy

VA Greater Los Angeles Healthcare System

Proposal-Level Workgroup Members: David Arnett, Paul Arthur, Jorie Butler, Frank Parker, Gwen Sheppard, Miho Tanaka, Jeff Whittle, Susan Zickmund

Goal of Project-Level Subgroup

To develop guidelines and recommendations for HSR&D regarding Veteran engagement in research at the *project* level:

- Proposals
- Reviewer guidance
- Training on engagement
 - For investigators
 - For Veterans

Draft Guidance for Investigators in HSR&D Proposals

Planning Phase

Describe how Veterans have been involved in the following aspects of your proposal:

- Design
 - e.g., how have Veterans informed your research question(s)?
 - e.g., how was their input obtained?
 - e.g., how do you know your focus is important to Veterans?
- Development
 - e.g., how have Veterans informed your data collection instruments?

Draft Guidance (cont.)

Executing & Disseminating Phases

Describe how Veterans will be involved in the following:

- Execution/implementation
 - e.g., how will Veterans' perspectives/input be incorporated into the execution of your project?
- Dissemination
 - e.g., how will Veterans support production and dissemination of findings?

Additional Considerations

Across phases:

1. How will you foster core engagement principles* of reciprocal relationships, co-learning, partnership, trust, transparency, and honesty?
2. How have you identified/selected the Veterans who are engaging in your research?
3. Will Veterans receive any orientation or training for their role(s) in your research? (If so, describe)
4. Will Veterans be compensated for their contributions to your research? How was compensation determined and how will it be dispersed?

Subgroup Recommendations

- * Provide training to HSR&D investigators on Veteran engagement in research
 - Discuss measurement issues: how to measure process and impact of Veteran engagement
 - Address how engagement means doing research differently
 - Consider impact of engaged research on investigators' careers

*FY16 action item: Cyberseminar mini-series

Subgroup Recommendations (cont.)

For proposals:

- *Add a distinct “Veteran Engagement” section to RFAs (and/or consider revising RFA language to request Veteran engagement, or stakeholder engagement)

- *Provide training to SMRB reviewers on assessing the strengths and weaknesses of the engagement plan

- *FY16 action item: explore these recommendations and their implications

Subgroup Recommendations (cont.)

Under consideration for FY17 and beyond (contingent on budget availability):

- * Pilot inclusion of Veterans on selected SMRB panels, with systematic evaluation of how the presence of Veterans changes the presentations, discussion, and decisions made on the panel
- * Develop and/or expand wide access to Veteran panels for HSR&D investigators, leaders, and administrators
 - Carefully consider composition of panels

Subgroup Recommendations (cont.)

Under consideration for FY17 and beyond
(contingent on budget availability):

- * Develop an RFA specific to Veteran engagement
- * Further develop training content and provide training for investigators, reviewers, Veterans
- * Organize special session at next HSR&D national meeting

Veteran Engagement at the HSR&D Center Level

Lead: Michael Ho

HSR&D Center of Innovation for Veteran-Centered and Value-Driven Care

Eastern Colorado Health Care System

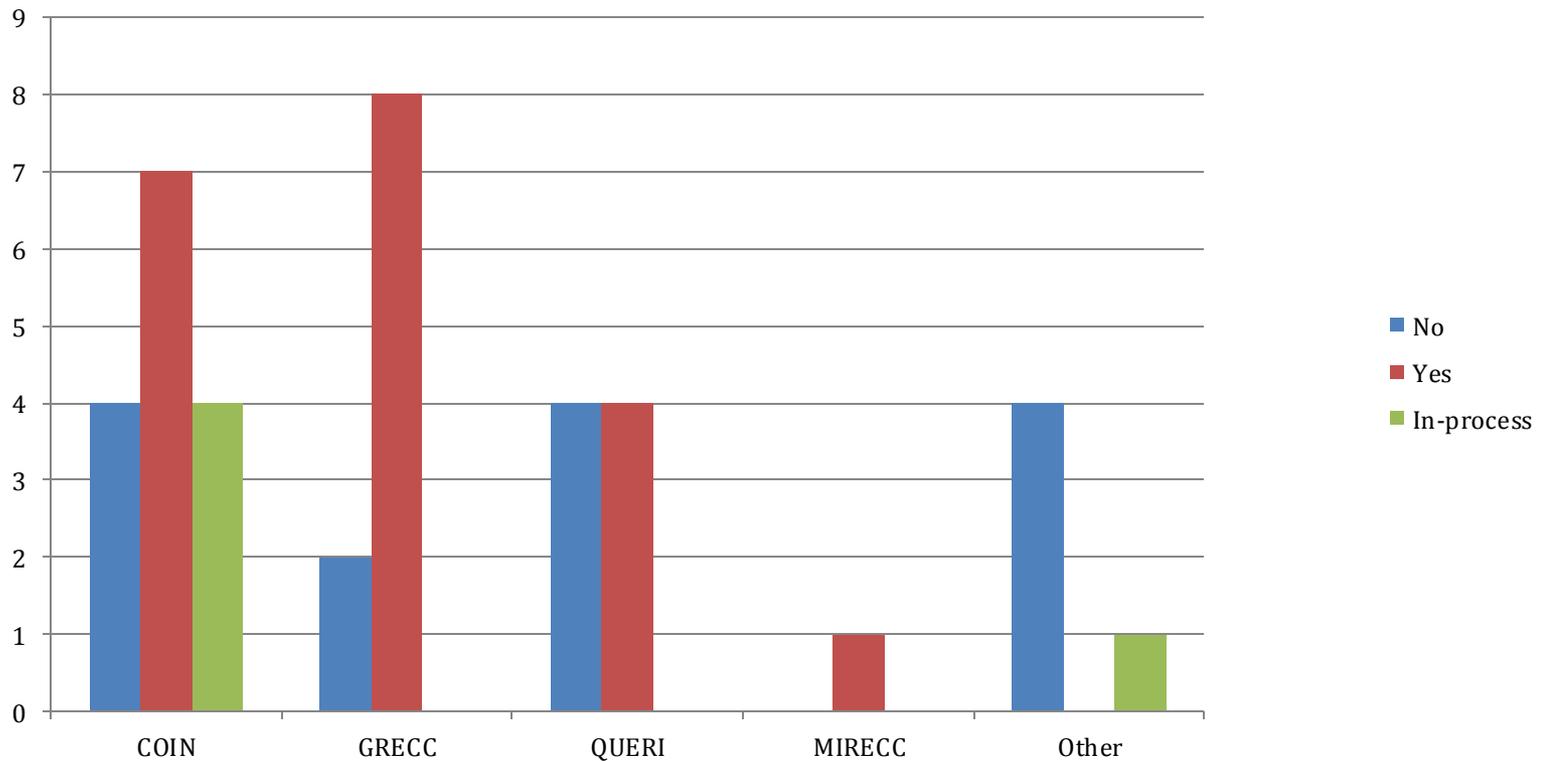
Center Engagement Workgroup members: Michael Ho, JoAnn Kirchner, Jennifer Gierisch, Bryan Gibson, Carmen Corsetti, Sarah Ono, Kelty Fehling, Ian Smith, Carolyn Ray

Workgroup Objectives

- Provide guidance on developing Veteran Advisory Groups for research centers
 - Assess how Centers are currently engaging Veterans in research at the Center level
 - Inform best practices for how to engage Veterans in research



Does your Research Center currently have a group, which includes Veterans serving as consultants on Center level research activities?



Step 1
Conceptualize Veteran
Engagement: Purpose
and Form

Recruitment

Interviewing/Selection

Veteran Board Orientation

Step 2
Identify Regulatory
Requirements at Local
Facility

Center Investigator
Orientation

Engage!

Example from Denver COIN: Conceptualization and Purpose

- **Goal:**
 - In order to promote patient-centered research and translation of VHA research findings into practice and community settings, the COIN and MIRECC will engage a group of Veteran stakeholders in the form of an ongoing Veteran advisory board. Involvement will span the research process from topic generation to dissemination and implementation of results
- **Preparation**
- **Regulatory Requirements**

Recruitment and Selection of Veterans

- Developed recruitment and interview documents
- Call for Veterans
- 12 candidates interviewed over 3 months
- Selection meeting



Member Demographics

- Gender: 8 Males, 1 Female
- Race/Ethnicity: 6 White, 3 African American
- Branch: 5 Army, 1 Air Force, 3 Navy (1 + Coast Guard)
- Education: 4 High School, 1 Associates, 1 Bachelor, 2 Masters, 1 PhD
- Era: 4 Vietnam, 2 Post Vietnam, 2 Desert Storm/Desert Shield, 1 OEF/OIF/OND
- Health conditions: PTSD, tobacco dependence, cardiovascular disease, diabetes, COPD, cataracts, suicidal ideation/behavior, TBI, spinal stenosis, sleep disorders

Orientation Sessions

- **COIN and MIRECC Investigators**
 - Concepts of Community Engagement and Partnership
 - Board Demographics
 - Research Review Process and Community Engagement Continuum
- **Veterans**
 - Board Cohesion
 - Research 101
 - Community Engagement
 - Research Review Process
 - Confidentiality, Intellectual Property, Media Interactions

How the Process Works

Contact with
project and
timeline

- Kelty.Fehling@va.gov
- 720-857-5126
- Ashley.Oconnor@va.gov;
720-857-5114
- Leah.Wendleton@va.gov
303-399-8020

Submit research
materials to be
reviewed

- Abstract in plain English
- Grant proposal/IRB protocol
- 5-7 slide presentation
- 2-3 specific questions

After submission
review
investigator
attends meeting

- Presents study verbally including 2-3 questions for Board
- Chair opens discussion
- Receives notes and summary with action items/recommendations
- Based on engagement with Board, letter of support issued detailing meeting interaction and impact

Evaluation of the Engagement Process

Post Meeting Survey-Veterans

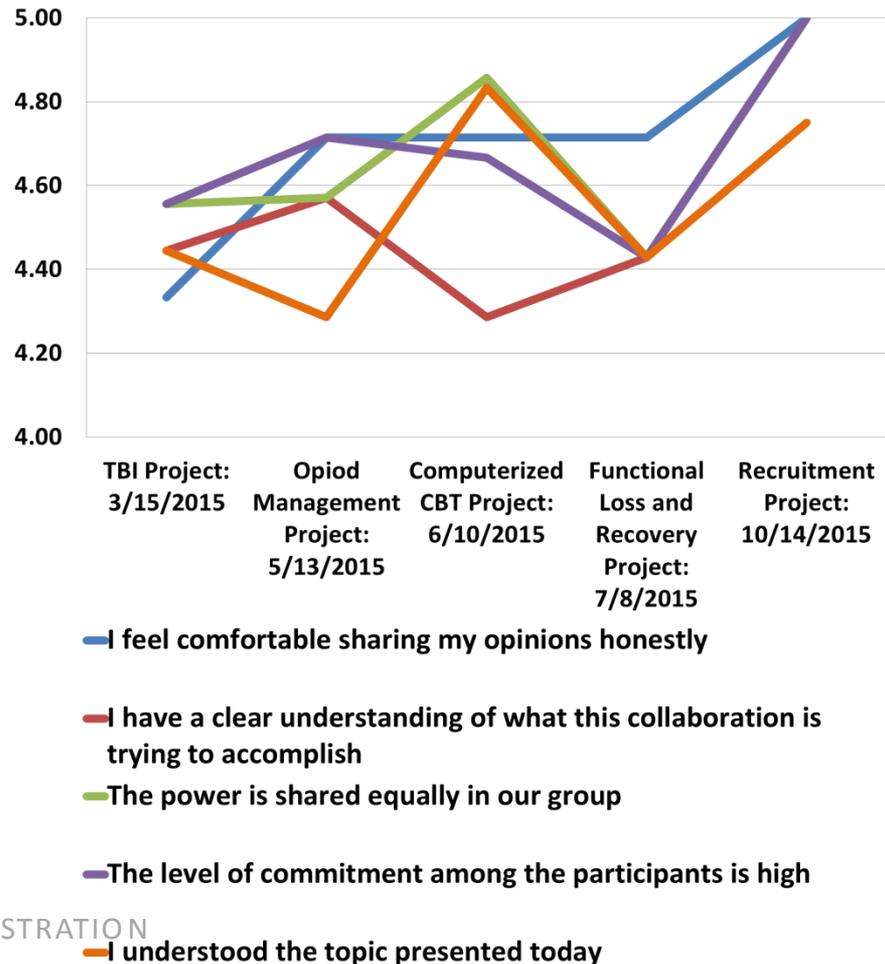
- Confidential surveys are distributed and collected after each meeting.
- Questions were modified from the Wilder Collaboration Factors Inventory and a survey currently being used to evaluate community engagement and power sharing in an ongoing community based participatory research (CBPR) project in the Denver area.

One Week Investigator Follow-Up Survey

- One week post meeting, investigators provided feedback and identified how they would make immediate changes to their projects based on board feedback.

Veteran Feedback About The Process

Veteran Engagement Board Survey



Investigator Feedback about the Process

- One Week Investigator Follow-Up Survey
 - Investigators have rated their interactions from “helpful” to “very helpful” to their research projects.
 - Several themes have emerged around the changes investigators are making based on suggestions from the Board:
 - Clarifying recruitment and enrollment procedures and documentation
 - Personalizing and simplifying intervention materials
 - Pursuing Board identified partnerships in the community to facilitate studies and center activities

HSRD Interest in Veteran Engagement Boards: COIN Supplemental Funding Request

Potential supplemental funding activities

- Center level Veteran engagement activities (e.g., establishing or further developing a Veterans engagement council or advisory panel, developing Veteran input for preparation of specific research project – see specific guidance at end of document)

In Closing



Poll Question

We are interested in creating a Veteran Engagement Learning Collaborative.

How likely would you be to join a Veteran Engagement Learning Collaborative?

- I would definitely join
- I would probably join
- I would join sessions occasionally
- I would not join

Upcoming Veteran Engagement Cyberseminars

4/19/16 at 2 pm ET

Growing a Veteran Engagement Group (VEG): Examples from COINs,
presented by Kelty Fehling and Sarah Ono

5/17/16 at 1 pm ET

Measuring Processes and Impacts of Veteran-Engaged Research,
presented by Alison Hamilton and Gala True

7/13/16 at 1 pm PT

Leveraging Health Experiences Research to Enhance Veteran Engagement,
presented by Erika Cottrell and Mark Helfand

Register here: <http://www.hsrd.research.va.gov/cyberseminars/catalog-upcoming.cfm>

Questions?

