

Measuring Processes and Impacts of Veteran-Engaged Research

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Veteran Engagement Initiative in VA Research Cyberseminar
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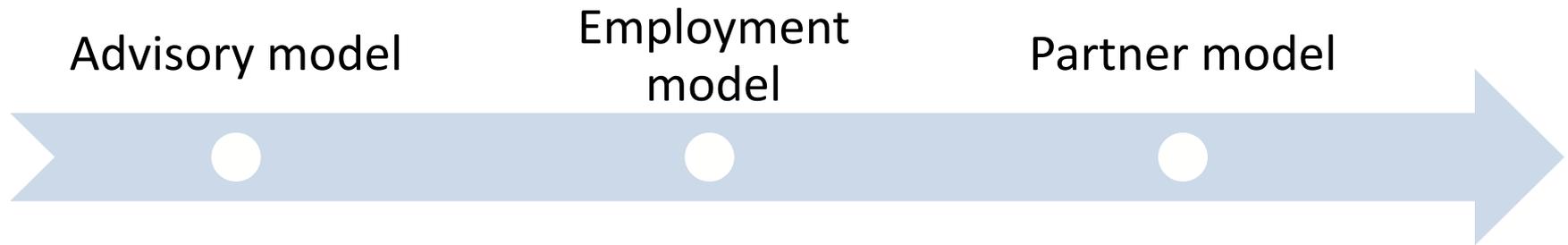
Special Thanks

- Dr. David Atkins, for spearheading the HSR&D Veteran engagement initiative
- Dr. Susan Zickmund, for her leadership of the Veteran Engagement Workgroup
- Veteran Engagement Workgroup members, for 1+ years of lively and productive dialogue
- Dr. Tana Luger, for her support in preparing this cyberseminar
- Our colleagues who have inspired, challenged, and informed us
- Our Veteran partners who are at the center of this work!

What Does Engagement Mean?

- “Participatory research is defined as systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change.” (Green)
- Encompasses individual patients and family members; communities and community-based organizations; service providers; healthcare organizations.
- Community-engaged research (CEnR)— framework or approach (not a single methodology); continuum of possible range of community involvement in research

CEnR Models and Examples



- Advisory model-- community members **play advisory role** on steering/advisory committee
- Employment model-- community members **hired as paid members** of research team
- Partner model-- community members are **partners or leaders** in all aspects of the research

Poll Question

Is your work community-engaged?

All of my work is community-engaged

Some of my work is community-engaged

My work isn't community-engaged yet, but I want to go in that direction

I might do community-engaged research eventually

I don't plan on doing community-engaged research

Context for this Cyberseminar: VA HSR&D Veteran Engagement Workgroup

- Convened by HSR&D Director Dr. David Atkins in January 2015
- Focus on how to increase Veteran engagement in VA HSR&D research
- Goals of increased Veteran engagement:
 - Improve design of patient-relevant research
 - Increase uptake of research into practice
 - Build Veteran support for research
 - Restore trust in the VA

Workgroup Activities & Products

- July 2015: VA HSR&D Conference Panel Presentation
- October 2015: Veteran Engagement Workgroup Final Report
- December 2015: Veteran Engagement Conference
- FY 16: Cyberseminar Series, planning for Veteran Engagement Learning Collaborative

Why Focus on Veteran Engagement Now?

- Because it's happening!
 - Need to measure processes and impacts to build evidence base and identify best practices
- Enhance research integrity
 - Increase accuracy of research
 - Ensure responsible conduct of research
- Foster trust in VA and in research
- Tailor engagement efforts to military/Veteran/VA contexts
- Contribute to development of CEnR as a field

What Are Guiding Principles of Engagement?

- Recognizes strengths, resources, diversity of community
- Foregrounds community-identified needs
- Honors various forms of knowledge & authority
- Emphasizes
 - transparency & reciprocity
 - sustained engagement & capacity-building
 - disseminating findings back to community

Agenda for Today's Cyberseminar

Today we will focus on:

1. Processes: What happens when Veterans are engaged in research, and how does engagement happen?
2. Impacts: What/who does Veteran engagement in research change, how and when does that change occur, and how do we assess the magnitude of the change?

Agenda for Today's Cyberseminar (cont.)

Today we will *not* address engagement-related constructs such as:

1. Patient engagement in health care
2. Patient activation

Measuring the Engagement *Context*: Where Engagement is Happening

Constructs (often at team/partnership level):

- Capacity for partnerships
- Alignment with CEnR principles and values
- History of collaboration
- Organizational readiness for patient engagement

Example: Guidelines for Participatory Research in Health

Green and colleagues

- Six domains assessing alignment with participatory research principles and values
 - Participants and nature of involvement
 - Origin of research question
 - Purpose of research
 - Process, context, and methodology
 - Opportunities to address multiple issues of interest
 - Nature of research outcomes

*Example:
Measuring Organizational Readiness
for patient Engagement (MORE)*

Oostendorp et al., 2015

- Pilot measure constructed through online Delphi survey
- 38 items assessing stakeholders, willingness to implement, and ability to implement patient engagement in healthcare
- Using in EMPOWER QUERI (with permission)

Measuring *Processes* of Engagement

Constructs:

- Task roles and communication
- Level/type of involvement in research components
- Influence and power dynamics
- Decision-making
- Problem-solving
- Dialogue, listening, respect, cooperation
- Leadership/governance
- Empowerment

Example: *HMORN Patient Engagement Workbook*

Madrid & Wright 2014

- Designed for research staff to walk through steps of engagement process
- See also VA HSR&D Cyberseminar, May 2015
- Similar research team “checklist”: PCORI’s *Pilot Projects Engagement Data Collection Tool*
- Process diaries as a project-specific tool

Example: Wilder Collaboration Factors Inventory

Mattessich, et al., 2001

- Free online tool to assess collaboration
- 20 “research-tested success factors,” e.g.,
 - Mutual respect, understanding, trust
 - Perceived benefits
 - Compromise
 - Mutual stake in process and outcome
 - Many layers of participation
 - Flexibility
 - Roles
 - Adaptability

Example: *Community Engagement in Research Index*

Khodyakov et al., 2013

- Measures individual perception of community partners' engagement in research
- Scores range from 4=low engagement to 12=high engagement

Thinking About Outcomes & Impacts of Engaged Research/CBPR

Sandoval et al., 2012

- 46 CBPR instruments with 224 individual measures
- Four components of pathways to change:
 1. Context (fewer measures)
 2. Group dynamics (most measures)
 3. Extent of community-centeredness in intervention and/or research design
 4. Impact of participatory processes on CBPR system change and health outcomes (fewer measures)

Measuring Proximal Outcomes of Engaged Research

Constructs:

- Health outcomes
- Uptake of innovations
- Study design
- Trust & collaboration

Example: Community Engagement to Address Depression Disparities

Wells et al., 2013

- Comparing approaches to implementation of depression Quality Improvement Toolkit
 - Community engagement planning (CEP) vs. standard technical assistance
 - Measures included mental HRQoL, physical activities, homelessness risk factors, service use
- CEP more effective than standard technical assistance on all measures

Example:
*Measuring Outcomes of a Veteran Research
Engagement Board*

Denver Center of Innovation

- Adapted Wilder Collaboration Factors Inventory to measure trust, shared decision-making, perceived benefits
 - Administered to Veterans and Investigators
- Investigator survey at 1 week, 6 months, 12 months post meeting
 - Measure whether and how Veteran recommendations led to change in study design or questions

Example:
Ways of Engaging-Engagement Activity Tool
(WE-ENACT)

PCORI 2014

- Learn about patient and stakeholder research engagement
 - Choosing study questions
 - Who to study
 - Outcomes
 - Progress
 - Sharing findings

Measuring Distal Impacts of Engagement

Constructs:

- System and capacity changes
- Long-term benefits of participating in engaged research
- Power relations/dynamics
- Trust over time
- Empowerment
- Sustainability of partnerships

Example: Developing and Measuring Typologies of Trust

Lucero et al., 2016:

- Mixed methods study of CBPR partnerships (N=450 survey respondents, 7 case studies)
- Community partner (CP) trust types: suspicion, functional, proxy, critical-reflective
 - At start, CPs reported proxy, suspicion, functional trust
 - Over time, most CPs reported shift to critical-reflective

Poll Question

Are you currently using measures of Veteran engagement in your projects? (check all that apply)

Yes, I'm measuring engagement processes

Yes, I'm measuring engagement outcomes

Yes, I'm measuring processes and outcomes

No, because my work doesn't focus on Veteran engagement

No, because I don't know what measures to use

Lessons Learned About Measuring Engagement

Khodyakov et al., 2013

- May need to combine open- and closed-ended items to ensure all survey items reflect the nature of research activities
- To capture possible variation in community engagement over the life cycle of a partnered project, follow-up questions may be added by asking participants to rate the change in their community partners' participation in each research activity
- May need to differentiate between research contributions of particular community partners

What Outcomes & Impacts Are Important But Difficult to Measure?

- Quality and type of outputs and dissemination activities
- Sustainability of project goals beyond funded time and during funding gaps
- System changes, impacts on policy
- New, unanticipated projects and activities
- Career development and satisfaction

Tailoring Your Measures

Need to consider the following about your research:

- Why Veterans will be engaged
- Which Veterans will be engaged
- When Veterans will be engaged
- How Veterans will be engaged
- Who will be engaging with Veterans, in what ways
- What will you expect of Veterans
- What will Veterans expect of you

Works Cited (See Handout)

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Veteran Engagement Initiative in VA Research Cyberseminar Series

Archived

3/17/16

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

http://www.hsrd.research.va.gov/for_researchers/cyber_seminars/archives/video_archive.cfm?SessionID=1125

4/19/16

Growing a Veteran Engagement Group (VEG): Examples from COINs

http://www.hsrd.research.va.gov/for_researchers/cyber_seminars/archives/video_archive.cfm?SessionID=1127

Upcoming

7/13/16 @ 10 am PT/11 am MT/12 pm CT/1 pm ET

Leveraging Health Experiences Research to Enhance Veteran Engagement

Sources of Support

True:

- PPO 10-255: Photovoice as an Educational Intervention to Improve Care of OEF/OIF Veterans
- IIR 14-399: Communicating Impact of TBI on Community Reintegration through Photovoice

Hamilton:

- QUE 15-272: EMPOWER QUERI
- SDR 10-012: Women's Health Research Network

Thank you!

Questions, Comments?

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**Measuring Processes and Impacts of Veteran-Engaged Research
VA HSR&D Cyberseminar (5.17.16)
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