

# Veterans Engagement Council Member Training

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# Member Description

**Position Summary:** A CINDRR Engagement Council member is a Veteran or a caregiver of a Veteran that brings their unique military background, health conditions, and health consumer perspective to the research arena. He or she engages as a stakeholder with CINDRR researchers spanning the research process from topic generation to dissemination of results.

# Member Description

**Position Objectives:** Provide individual viewpoints and provide individual viewpoints non-consensus advice to:

- Aid CINDRR researchers and support the CINDRR research mission
- Make CINDRR projects and research ideas more Veteran centric
- Increase the dissemination of research to Veteran communities:
  - Suggesting strategies to improve the share and utilization of information
  - Reviewing informational materials to ensure they are relevant and useful to consumers

# Monthly Meetings

- 2 weeks prior to meeting
  - You will receive a 5-7 slide power point presentation from the investigator
  - There will be 1-3 questions that the research team would like feedback on

# Day of Meeting

- 90 min to 2 hours
  - 5 min introductions
  - 20 minutes on presentation
  - 50 minutes discussion
  - 10 minutes questionnaire
- Sandy and Valerie will be present. Valerie will take notes and Sandy will monitor FACA rules
- Determine best time for meeting

# What are the observed benefits of Veteran engagement?

- Improves enrollment
- Decreases attrition
- Increased dissemination
- Dissemination
  - More meaningful
  - Understandable

# What are the harms and barriers of Veteran engagement?

- Frustration with time involved in training, transportation, and attendance
- Extra time to complete research
- Tokenism (false appearance of inclusiveness, devaluated patients' input)
- “Scope creep” - engaging patients in research may include irrelevant community concerns and issues, which would make the research unfeasible

# Solutions to harms and barriers of Veteran engagement

- Solutions
  - Time to build relationships
  - Foster mutual respect
  - Clear, explicit expectations documented in study protocols



# Engagement

Engagement defined as

- Partnership
- Shared decision-making



Citizen control, delegated power –  
partnership, delegated power, control,  
co-learning

Tokenism – informing, consultation, placating

Non-participation, manipulation

# Engagement

## Degrees of Subject Power

- Veteran control
- Delegated power
- Partnership

## Degrees of Tokenism

- Placation
- Consultation
- Informing

## Non-participation

- Therapy
- Manipulation

## Degrees of Tokenism

- Lack power to insure their voices will be heeded by powerful
- No follow through, No muscle, No change of status quo
- Subjects hear and have a voice

# Engagement

## Degrees of Subject Power

- Full managerial power
- Majority of decision-making seats
- Negotiate and engage in tradeoffs with investigators

And then there is **FACA** (Federal Advisory Committee Act)

# What is Group Process

- Trust
- Sharing
- Open communication
- Flexibility
- Adaptability
- Shared vision



# Measuring What the VEC Does

*Modified* PCORI Ways of Engaging Form (WE-ENACT)  
completed at the end of each session

- Degree and impact of engagement
- VEC member experience
- Trust, shared decision-making, perceived benefits

Confidential. We will collect one from everyone at the end of each session but you will NOT put your name on the form.

Comments?

Questions?

# References

- <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD004563.pub2/full>
- *Arnstein SR. A ladder of citizen participation. American Institute of Planners Journal 1969;35:216-24*
- *Cornwall A. Towards participatory practice: participatory rural appraisal (PAR) and the participatory process. In: De Koning K, Martin M editor(s). Participatory research in health: issues and experiences. London: Zed Books, 1996:94-107*
- <https://www.wilder.org/Wilder-Research/Research-Services/Documents/Wilder%20Collaboration%20Factors%20Inventory.pdf>