

Veterans Engagement Council Investigator and Staff Training

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Patient Engagement

- Critical part of the “learning healthcare system”
 - Better health outcomes
 - Improved quality and patient safety
 - Control healthcare costs
- Engagement defined as
 - Partnership
 - Shared decision-making

Background

Systematic Review commissioned by PCORI

<http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-89>

- Democratization of research process
- Arnstein Ladder of Participation



Tokenism: informing, consultation, placating

Non-participation: therapy, manipulation

<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 e experiences*. London: Zed Books, 1996:94-107.

Background

Tokenism

- **Informing & Consultation**

- Citizens hear and are heard
- Lack power to insure that their views will be heeded
- No follow-through, no muscle, no assurance of changing status quo

- **Placating**

- Ground rules allow citizens to advise
- Powerholders retain right to decide

Background

- Arnstein Ladder of Participation



Citizen Power: partnership, delegated power, citizen control (full managerial power)

Tokenism: informing, consultation, placating

Non-participation: therapy, manipulation

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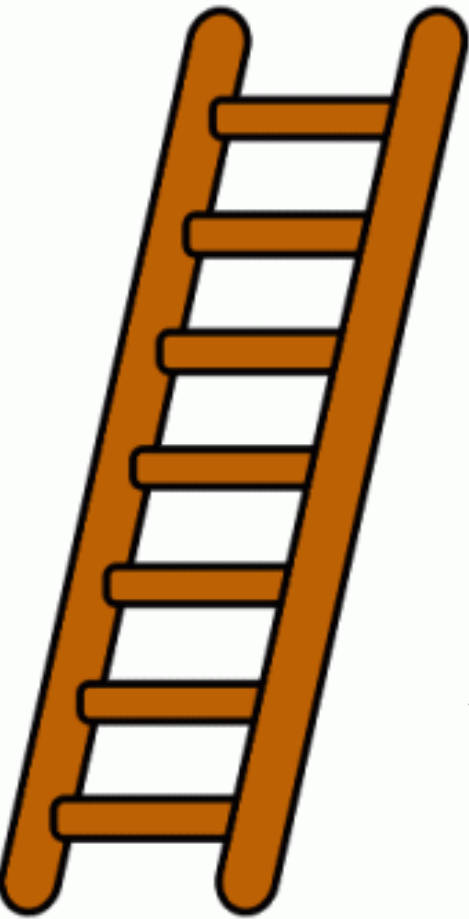
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Background

Citizen 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)



FACA & CINDRR

- Tampa ACOS, Dr. Campbell, connected us with legal council at Central Office
- We are using wording so that we do not fall under the impact of FACA
- Key Words: “share individual opinion, experiences, etc.”
- Words we don’t use: collaborate, partner
- See Member Description document

ONE MODEL FOR ENGAGEMENT

Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

OUTREACH	CONSULT	INVOLVE	COLLABORATE	SHARED LEADERSHIP
<ul style="list-style-type: none">• Some community involvement• Communication flows from one to the other, to inform• Provides community with information• Entities coexist	<ul style="list-style-type: none">• More community involvement• Communication flows to the community and then back; answer seeking• Gets information or feedback from the community• Entities share information	<ul style="list-style-type: none">• Better community involvement• Communication flows both ways, participatory form of communication• Involves more participation with community on issues• Entities cooperate with each other	<ul style="list-style-type: none">• Community involvement• Communication flow is bidirectional• Forms partnerships with community on each aspect of project from development to solution• Entities form bidirectional communication channels	<ul style="list-style-type: none">• Strong bidirectional relationship• Final decision making is at community level• Entities have formed strong partnership structures• Broader health outcomes affecting broader community; bidirectional trust

Reference: Modified by the authors from the international Association for Public Participation

Modified by the CTSA Consortium Community Engagement Key Function Committee Task Force Principles of Community Engagement from the International Association for Public Participation

What are the observed benefits of patient engagement?

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

What are the harms and barriers of patient 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

What are the harms and barriers of patient engagement?

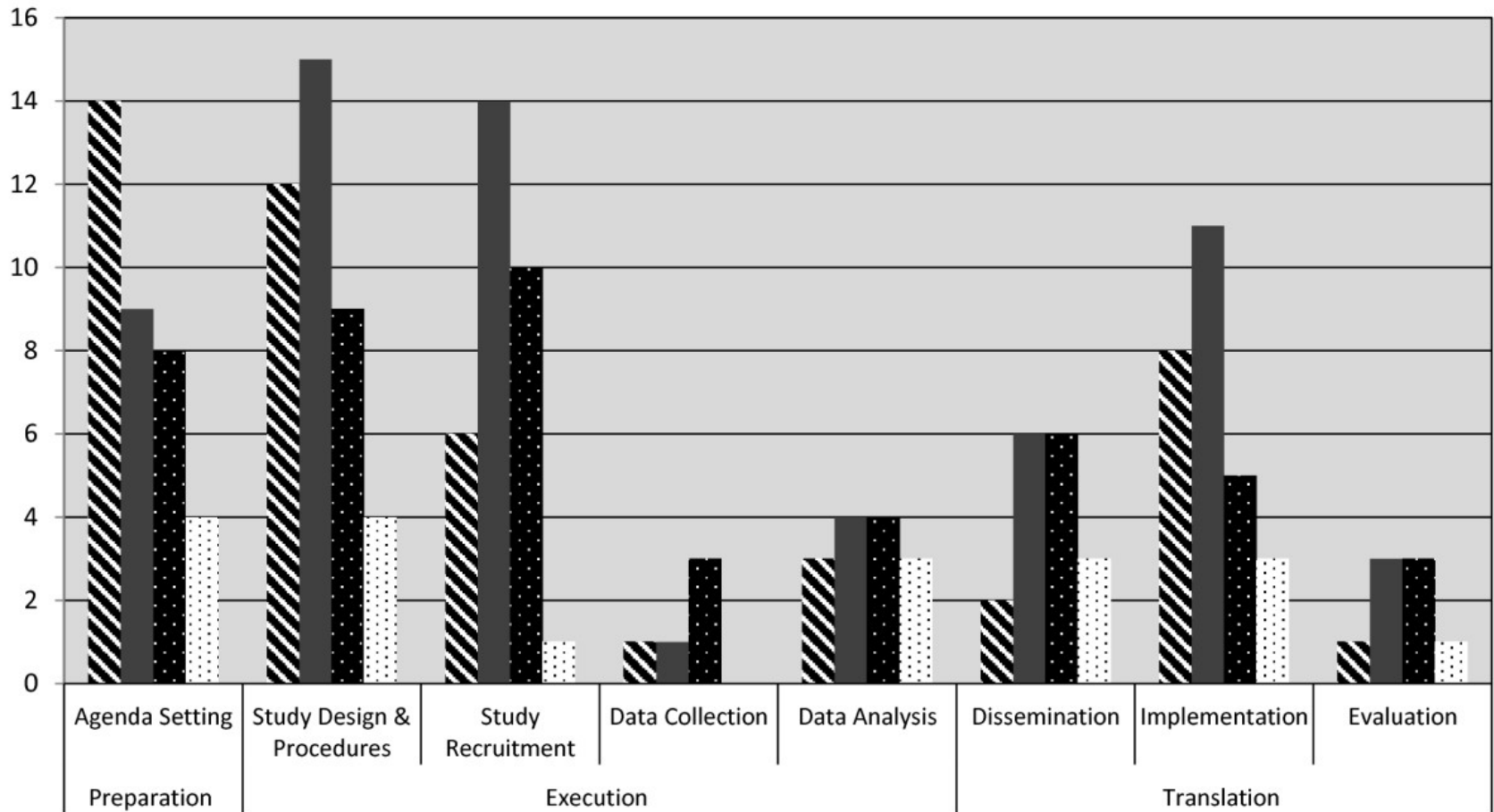
- Solutions
 - Time to build relationships
 - Foster mutual respect
 - Clear, explicit expectations documented in study protocols

Monthly Meetings

- 3 weeks prior to meeting
 - Investigator submits a 5-7 slide power point to Sandy/cc Valerie
 - Identifies 1-3 questions that they would like feedback on
 - Sandy/Valerie distribute to members 2 weeks before meeting date

How to engage them in designing and conducting research?

No. studies



▨ Focus Group ■ Interview ■ Survey ▫ Deliberation/Organizational participation

Day of Meeting

- 90 min to 2 hours
- Two research team members will attend
- 5 min introductions
- 20 minutes on presentation
- 50 minutes discussion
 - You are guiding discussion
 - Members will have already reviewed power point and have a general idea of your questions
- 10 minutes questionnaire

Day of Meeting

- Sandy and Valerie will be present.
 - Valerie will take notes
 - Sandy will monitor FACA rules
- Strong emphasis on group process

Measuring Process and Impact

- Processes: What happens when Veterans are engaged in research, and how does engagement happen?
- 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?

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

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

Measuring Process and Impact

What does HSR&D what: ART Report Template

1. # of COIN proposals reviewed by panel
 2. How VEC
 - impacted/changed research plans, or
 - informed development of a research project
 3. Describe activities related to Veteran Engagement and membership of the Veteran Panel with subsections on:
 - Function
 - Proposals or products reviewed
 - Insights
 - Dissemination
- con't

Measuring Process and Impact

4. How research findings/products were disseminated to Veteran Service Organizations or other Veterans groups, and specify whether these organizations included research findings in their internal publications or other communications

Measuring Process and Impact

1. PCORI WE-ENACT

- Degree and impact of engagement
- VEC member experience

2. Wilder Collaboration Factors Inventory

- Trust, shared decision-making, perceived benefits

<https://www.wilder.org/Wilder-Research/Research-Services/Documents/Wilder%20Collaboration%20Factors%20Inventory.pdf>

Modified PCORI Ways of Engaging-Engagement Activity Tool (WE-ENACT)

- Administered at each VEC meeting

WE-ENACT, modified

Every Meeting, **VEC Members** will

- 1.1 Count of how many of 11 parts of research engagement occurred
- 1.2 How members felt engaged and perceived impact of their engagement
- 1.3 What members learned
- 1.4 Effects of engagement of member
- 2.1 Rating of meeting experience
- 2.2 Optional comments

Metric at project level

Data can be summarized across 10-11 projects/year

WE-ENACT, modified

At every meeting, **investigators** will

- 1.1 Count of how many of 11 parts of research engagement occurred
- 1.2 Record suggestions made and changes resulting from the engagement
- 1.3 Insights

Metric at project level

Data can be summarized across 10-11 projects/year

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

Impacts of Engagement

Constructs:

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

Measuring Process and Impact

What does HSR&D what: ART Report Template

1. # of COIN proposals reviewed by panel ✓
 - Estimate 10-11
2. How VEC
 - impacted/changed research plans, or ✓
 - informed development of a research project
3. Describe activities related to Veteran Engagement and membership of the Veteran Panel with subsections on:
 - Function ✓
 - Proposals or products reviewed ✓
 - Insights ✓
 - Dissemination ✓ con't

Measuring Process and Impact

4. What does HSR&D what: ART Report Template

How research findings/products were disseminated to Veteran Service Organizations or other Veterans groups, and specify whether these organizations included research findings in their internal publications or other communications – **Dissemination Core or VEC?**

- VEC can tabulate data where VEC members checked “dissemination”

Discussion

FACA

- The Federal Advisory Committee Act became law in 1972 and is the legal foundation defining how federal advisory committees operate
- 2.b.6 the function of advisory committees should be advisory only
- 4.c Nothing in this Act shall be construed to apply to any local civic group whose primary function is that of rendering a public service with respect to a Federal program
- <https://www.gsa.gov/portal/mediaId/128410/fileName/FACA-Statute-2013.action>