Engaging Women Veterans in Research

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HSR&D Cyberseminar: Spotlight on Women’s Health
June 6, 2018
Poll Question
Which of the following describe(s) you? (select all that apply)

Veteran
Researcher
Clinician/provider
Administrator/manager
Policy-maker
VA staff
Increasing Engagement of Women Veterans in Research: Findings from a Women’s Health Practice-Based Research Network Study

Alison Hamilton, PhD, MPH
Joya Chrystal, LCSW

HSR&D Cyberseminar: Spotlight on Women’s Health
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Dawn West-Rosado, LCSW

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Lisa Callegari, MD, MPH

Salt Lake City, UT
Lori Gawron, MD, MPH

St. Louis, MO
Eve Holzemer, DNP, ANP-BC
Today’s presentation

• Conceptual model of engagement
  – “meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results” (PCORI*)

• Increasing engagement of women Veterans in research
  – Reasons for lack of engagement
  – Suggestions for increasing engagement

*https://www.pcori.org/engagement/what-we-mean-engagement
Applying Tenets of Community Engagement to Advancing Impact of VA Women’s Health Research*

Aim #1 Consortium
- Education, training, mentorship, information sharing, dissemination

Aim #2 PBRN
- Infrastructure to support multisite research through multilevel engagement

Increased stakeholder-responsive research
- Increased stakeholder-driven/funded evaluation

Increased stakeholder/researcher partnerships

Improved intervention, implementation and high-impact research ($^2$

Today’s focus

* Adapted from Isler & Corbie-Smith (2012)
Methods

• Project team coordinated with PBRN Site Leads for local project initiation across five sites

• Women Veterans (n=31) recruited via flyers distributed in Women’s Health clinics and other recommended locations

• Providers (n=22) & administrators (n=6) recruited via email correspondence
  • List of potential names provided by Site Leads

• Phone-based interviews conducted from October 2016-April 2018
  • Questions about reasons for lack of engagement in research, how to improve engagement

• Interviews transcribed and summarized

• Codebook developed for each participant group
## Reasons for lack of women Veteran engagement

<table>
<thead>
<tr>
<th>Women Veterans</th>
<th>Primary Care Providers &amp; Administrators</th>
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<tbody>
<tr>
<td>Unaware of opportunities</td>
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<td>Distrust of research*</td>
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<td>Competing priorities (work, caretaking)</td>
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<td>Limited time</td>
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<td>Confidentiality concerns</td>
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<td>Fear of exposure, jeopardizing benefits</td>
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<tr>
<td>Intimidated by research</td>
<td>Safety concerns</td>
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<tr>
<td>Not interested in speaking about past</td>
<td>Avoidance of VA</td>
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<tr>
<td>Belief that participation will not influence anything</td>
<td>Research too obscure</td>
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<td>Generational differences</td>
<td>Cultural disconnect</td>
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*“We haven’t had anything that was helpful for us for so long. I think we have a mistrust when it comes to, ‘Oh, somebody’s finally trying to do so something to help us when we’ve been struggling for such a long time.’ ... We’ve been let down so much.” (Woman Veteran participant)
# Increasing women Veteran engagement

<table>
<thead>
<tr>
<th>Women Veterans</th>
<th>Primary Care Providers &amp; Administrators</th>
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<tbody>
<tr>
<td><strong>Use MyHealtheVet</strong></td>
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<td><strong>Warm hand-off from provider/staff to Veteran</strong></td>
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<td><strong>Develop recruitment repository</strong></td>
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<td><strong>Develop research registry</strong></td>
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<td><strong>Communicate details: purpose, privacy/confidentiality measures, potential impact</strong></td>
<td></td>
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<tr>
<td><strong>Word-of-mouth from other women Veterans</strong></td>
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<td><strong>Research ambassadors</strong></td>
<td></td>
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<td><strong>Social media (Facebook, Twitter)</strong></td>
<td></td>
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<tr>
<td><strong>Provide Veterans with research findings</strong></td>
<td></td>
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<tr>
<td><strong>Women Veteran-focused events</strong></td>
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<td><strong>Connect with community-based outpatient clinics</strong></td>
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*“It is unclear what studies are active and where to refer patients...” (Provider)

^“The next one comes down the pike and we say, “No, thanks.” You know, it’s an hour of my time and it didn’t result in any change. You didn’t even tell me what the results were. I think patients feel that way too.” (Administrator)
Key Take-Home Points

• Women Veterans and providers see research specific to women as necessary given unique medical needs; research could translate to improved care of women, especially for future generations
  • Some women Veterans see research participation as form of advocacy
• Women Veterans and providers shared similar perspectives on why women don’t often participate in research
• Research opportunities for women Veterans need be more accessible, transparent to providers and patients
  • My HealtheVet, searchable repository for active research opportunities, retaining contact information for future studies, importance of sharing results
Thank You!
Questions, Comments?

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Researching Intimate Partner Violence among VA Patients

Recruitment Strategies and Lessons Learned

Melissa Dichter
VA HSR&D Cyberseminar
June 6, 2018
Poll Question 2:
What is your experience with recruiting research participants?
(select all that apply)

- I have experience recruiting participants
- I have experience recruiting women
- Veteran participants
- I do not have experience recruiting participants
Intimate Partner Violence: Patient Characteristics, Service Use, and Experiences
VA HSR&D IIR 15-142

Aim 2: Identify patient health and safety following disclosure of past-year IPV, and associations with service use and safety-related empowerment.

- Structured interviews with female VHA patients at two sites – baseline and follow-up at 6-9 months
- Target enrollment: at least 80 patients per site (total 160)
Initial Recruitment Strategy

1) Provider referral via clinical reminder
2) Flyers for patient self-referral

*How and why plans changed... and what worked better*
Strategy I: Provider Referral through Clinical Reminder

Add study referral button to IPV screening clinical reminder – prompted by positive screen

- Approved by clinic, HSR&D, IRB
- Prompts clinician to refer to study – study team can directly receive referrals
- Alternative option to direct refer to research team or pt. self-referral

Barriers Encountered

- Site 1: Local clinical reminder committee denied request to modify reminder for study
- Site 2: Local clinic staff turnover prevented implementation of modified reminder
Strategy II: Provider Referral without Clinical Reminder Button

Provider referral without clinical reminder prompt or referral button

- Provider referral by co-signing research project manager on CPRS note or otherwise direct contact

Primary Challenge:

- Lack of prompt $\rightarrow$ required provider to remember to refer to the study (and process for doing so)
Strategy III: In-Clinic Recruiting

Research team direct recruitment in clinic waiting room
- Research team members took shifts in clinic waiting room with information to provide to interested patients
- Interested patients provided contact information and consent to contact

Benefits
- No dependence or burden on provider
- Direct connection between research team and potential participants
- Bonus: not dependent on screening and/or disclosure

Challenges
- Time-intensive for research staff
- Open waiting room area challenge to private conversations
Strategy IV: Direct Outreach via Letters

Letters mailed directly to potentially-eligible patients
- Letters mailed to female patients with past-year visit in batches of 100-200 every 2-3 weeks
- Introduction to study with invitation to “opt out”
- Follow-up call to all those not opting out

Benefits
- More flexible and efficient use of research staff time
- Bonus: Wider pool of potential participants (not dependent on clinic visits or in-person disclosure)

Challenges
- Labor intensive for research staff
- Requires connection by mail and telephone
## Results | Letters

<table>
<thead>
<tr>
<th>Category</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mailed</strong></td>
<td>1,199</td>
<td>2,250</td>
<td>3,449</td>
</tr>
<tr>
<td><strong>Returned</strong></td>
<td>37</td>
<td>79</td>
<td>116</td>
</tr>
<tr>
<td><strong>Opted Out</strong></td>
<td>9</td>
<td>96</td>
<td>105</td>
</tr>
<tr>
<td><strong>Not Reached</strong></td>
<td>546</td>
<td>1,092</td>
<td>1,638</td>
</tr>
<tr>
<td><strong>F/u contact attempted</strong></td>
<td>1,152</td>
<td>2,075</td>
<td>3,227</td>
</tr>
<tr>
<td><strong>Reached (assumed)</strong></td>
<td>1,162</td>
<td>2,171</td>
<td>3,333</td>
</tr>
<tr>
<td><strong>Reached for Screening</strong></td>
<td>606</td>
<td>983</td>
<td>1,589</td>
</tr>
<tr>
<td><strong>Scheduled</strong></td>
<td>67</td>
<td>81</td>
<td>148</td>
</tr>
<tr>
<td><strong>Not Eligible/Interested</strong></td>
<td>539</td>
<td>902</td>
<td>1,441</td>
</tr>
</tbody>
</table>
Results | Sample composition by strategy

Exceeded recruitment target (at least 80/site)
... but extended timeline by 8 months

Participants recruited via each strategy

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider referral</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Flyers/self-referral</td>
<td>6</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>In-clinic</td>
<td>30</td>
<td>20</td>
<td>50</td>
</tr>
<tr>
<td>Letters</td>
<td>47</td>
<td>62</td>
<td>109</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>89</strong></td>
<td><strong>83</strong></td>
<td><strong>172</strong></td>
</tr>
</tbody>
</table>
Lessons Learned

- Direct research team outreach to patients had benefits for this study
  - Eliminated clinical staffing and workflow barriers
  - Allowed research team to present study directly to patients

- Patients were open to discussing IPV experiences in research context
  - Patients motivated to help others by contributing to research

- Direct contact via letters reaches patients who may not be coming in for healthcare visits at that time – but willing to come in for research study visit

- Plan for the unexpected
  - Build flexibility into your timeline and processes (including time for IRB amendments!)
  - Expect it to take longer
  - Research options and think creatively
Take-Aways – Recommendations

*Plan for the unexpected*

- Build flexibility into your timeline and processes (including time for IRB amendments!)
- Expect it to take longer
- Research options and think creatively
Questions/Comments?

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