Increasing Engagement of Women Veterans in Health Research



Joya G. Chrystal, MSW, LCSW¹, Karen E. Dyer, PhD, MPH¹, Cynthia E. Gammage, BA¹, Ruth S. Klap, PhD^{1,2}, Diane V. Carney, MA³, Susan M. Frayne, MD, MPH^{3,4}, Elizabeth M. Yano, PhD, MSPH^{1,5}, and Alison B. Hamilton, PhD, MPH^{1,2}

¹VA HSR&D Center for the Study of Healthcare Innovation, Implementation and Policy (CSHIIP), VA Greater Los Angeles Healthcare System, Los Angeles, CA, USA; ²Department of Psychiatry and Biobehavioral Sciences, UCLA David Geffen School of Medicine, Los Angeles, CA, USA; ³VA HSR&D Center for Innovation to Implementation (Ci2i), VA Palo Alto Health Care System, Menlo Park, CA, USA; ⁴Division of Primary Care and Population Health, Stanford University School of Medicine, Stanford, CA, USA; ⁵Department of Health Policy and Management, UCLA Fielding School of Public Health, Los Angeles, CA, USA.

BACKGROUND: Meaningful engagement of patients in health research has the potential to increase research impact and foster patient trust in healthcare. For the past decade, the Veterans Health Administration (VA) has invested in increasing Veteran engagement in research.

OBJECTIVE: We sought the perspectives of women Veterans, VA women's health primary care providers (WH-PCPs), and administrators on barriers to and facilitators of health research engagement among women Veterans, the fastest growing subgroup of VA users.

DESIGN: Semi-structured qualitative telephone interviews were conducted from October 2016 to April 2018.

PARTICIPANTS: Women Veterans (*N*=31), WH-PCPs (*N*=22), and administrators (*N*=6) were enrolled across five VA Women's Health Practice-Based Research Network sites.

APPROACH: Interviews were audio-recorded and transcribed. Consensus-based coding was conducted by two expert analysts.

KEY RESULTS: All participants endorsed the importance of increasing patient engagement in women's health research. Women Veterans expressed altruistic motives as a personal determinant for research engagement, and interest in driving women's health research forward as a stakeholder or research partner. Challenges to engagement included lack of awareness about opportunities, distrust of research, competing priorities, and confidentiality concerns. Suggestions to increase engagement include utilizing VA's patient-facing portals of the electronic health record for outreach, facilitating "warm hand-offs" between researchers and clinic staff, developing an accessible research registry, and communicating the potential research impact for Veterans.

CONCLUSIONS: Participants expressed support for increasing women Veterans' engagement in women's health research and identified feasible ways to foster and

Prior Presentations

Portions of these findings were presented at the 35th Annual AcademyHealth Research Meeting held in Seattle, WA from June 24 to June 26, 2018, and the VA HSR&D/QUERI National Meeting held in Washington, D.C. from October 29 to October 31, 2019.

Received April 2, 2021 Accepted August 26, 2021 Published online March 29, 2022 implement engagement of women Veterans. Given the unique healthcare needs of women Veterans, engaging them in research could translate to improved care, especially for future generations. Knowledge about how to improve women Veterans' research engagement can inform future VA policy and practice for more meaningful interventions and infrastructure.

KEY WORDS: patient engagement; research engagement; Veterans; vulnerable populations; women's health.

J Gen Intern Med 37(Suppl 1):S42–S9 DOI: 10.1007/s11606-021-07126-4 © The Author(s) 2021. This article is an open access publication

BACKGROUND

The engagement of patients in research as equitable partners is an increasingly recognized tenet of health services research. Patient engagement in research is defined as "the active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognizing their experiences, values, and expertise."¹ Various patient engagement frameworks describe the context and function of patients as stakeholders; involvement occurs along a continuum of pathways whereby patients advise, inform, or partner in research.²⁻⁴ Despite the current momentum to equip health research with patient stakeholders, the concept of research engagement is less familiar to patient populations, and therefore met with its own unique challenges for adoption and inclusion within health research practice.5-7

Recent works have demonstrated the added value of engagement for healthcare organizations,⁸ stakeholders,^{9,10} and specific groups of patients such as Veterans,^{11,12} including successful implementation of engagement resources¹³ and the influence of engagement on policy.¹⁴ The Veterans Health Administration (VA) has committed to patient-centered care,¹⁵ building on findings that individuals who actively participate in their healthcare are more satisfied, and have better outcomes at reduced costs—i.e., the "triple aim" of healthcare systems.¹⁶ Promoting patient engagement in health research may be especially useful in improving quality of care among high-risk or under-represented populations, such as women Veterans.¹⁷

Women's increased enrollment in the military is reshaping the Veteran population. The fastest growing group of eligible VA healthcare users are now women.^{18,19} This trend has been accelerated by increased enrollment of women Veterans from recent wars in Iraq and Afghanistan.²⁰ Women's military experiences, and their responses to those experiences, are often distinct from men's; these distinctions can affect healthcare needs and outcomes. Given women Veterans' unique experiences and care needs, ²¹ participation in health research could result in findings that have the potential to directly (positively) impact their own healthcare.

This qualitative study is the first to explore the concept of engagement in research from the perspectives of women Veteran patients, VA women's health primary care providers (WH-PCPs), and administrators. Women Veterans' high rate of attrition from VA care,^{22,23} combined with persistent organizational barriers to care,²⁴ highlight the need for VA infrastructure to leverage impactful research. Achieving more equitable healthcare, grounded in research, requires a deeper understanding of women's engagement challenges and recommendations from multilevel perspectives. This paper aims to (1) examine the perspectives of women Veterans' research engagement, specifically barriers to and facilitators of engagement, and (2) identify ways to foster increased research engagement among women Veterans.

METHODS

Study Design, Setting, and Sample

Qualitative, semi-structured telephone-based interviews were conducted with women Veterans, WH-PCPs, and administrators, across five geographically dispersed VA medical centers (VAMCs) between October 2016 and April 2018. All sites are members of the VA Women's Health Practice-Based Research Network (WH-PBRN), a national network of partnered VA facilities that supports the representation of women Veterans in VA research and quality improvement projects.²⁵ Members of the study team worked with WH-PBRN Site Leads to coordinate local study recruitment efforts. To recruit key VA stakeholders in Women's Health, WH-PBRN Site Leads provided study members with names and contact information for local WH-PCPs and site administrators (i.e., Women's Health Medical Directors, Women Veteran Program Managers). WH-PCPs and administrators were sent email invitations by a study team member, and those interested were scheduled for interviews accordingly. To recruit women Veterans, Site Leads distributed study flyers at local VAMC women's health clinics. Flyers described the study,

participation incentive, and study contact information. Women Veterans phoned the study team to express interest, and upon confirming their Veteran status, were consented, and enrolled over the phone.

Measures and Procedures

A semi-structured interview guide was developed and reviewed for comprehension. Interview questions were tailored for each sample group and sought perspectives on research experiences, and challenges to and facilitators of research engagement among women Veterans. A summary of interview guide questions is depicted in Table 1. All procedures were approved by the VA Central Institutional Review Board. Participants provided verbal consent to participation and audio-recording. Women Veterans were offered a \$25 gift card for participation, whereas no study incentives were offered to WH-PCPs and administrators. Telephone interviews lasted on average 30 minutes. Demographic information was collected from women Veterans following interviews. Interviews were audio-recorded and professionally transcribed verbatim.

Analysis

Deidentified transcripts were imported into ATLAS.ti (v7) for coding and analysis. Consensus-based coding was performed by two experienced qualitative analysts (JC, KD). In the first phase of coding, transcripts were reviewed, and thematic concepts were noted; this informed iterative development of a code list, which included *a priori* codes related to key topics of inquiry. Transcripts were coded using the constant comparative method,²⁶ with discrepancies resolved through discussion. The study PI (AH) oversaw the coding process and reviewed coded transcripts for quality and consistency. Coded segments were analyzed to identify emergent themes.

RESULTS

Participants

Table 2 depicts the VAMC region and gender characteristics of VA stakeholders in Women's Health (WH-PCPs and administrators). Women Veteran demographics are presented in Table 3. On average, women Veterans were 56 years of age, identified as single, and served during the Post-Vietnam era.

Table 1 Summary of interview guide

Question categories Experiences with/knowledge of research Attitudes/beliefs regarding engagement in research Preferred study role and level of engagement Practical issues (e.g., barriers, facilitators to participation) Interest in research engagement Engagement in women Veteran-related activities Views of women's health research priorities in VA

Perceived Importance of Women's Health Research

Women Veterans, WH-PCPs, and administrators overwhelmingly endorsed the importance of research for women Veterans' health and healthcare. WH-PCPs emphasized the importance of driving sex- and gender-specific research forward to increase understanding and awareness of women Veterans' unique healthcare needs. One WH-PCP stated: "I think it's important to develop gender-specific care... If the armed services are accepting more women, they need to be able to say, 'We welcome you and we have all of these wonderful resources for you through the VA.'" Some spoke about health research data (and related health treatments) as disproportionately focused on male civilian subjects: "We've been treating women as men, and we're not."

Women Veterans' Engagement Preferences and Experiences

None of the women Veterans reported having engaged in research as a patient stakeholder/partner previously. The vast majority were unfamiliar with the concept of patient research engagement, however expressed enthusiasm and interest for the inclusivity of patients to inform research beyond traditional subject roles. Moreover, most women Veterans reported little or no prior research experience. Half of women Veterans had never been invited to participate in health research (prior to the current study).

Women Veterans described factors that would be particularly helpful in their decision to engage in research: rationale for why the patient perspective is needed, clearly defined expectations and deliverables, relevant subject matter, and travel/time compensation details. Some expressed wanting to know personally relevant information about researchers in order to feel comfortable. For instance, a woman Veteran expressed a desire to know researchers' personal motivations: "[I'd like to know] a little about the experience of the researcher... Are they from families where they had Veterans?... What motivated you?... What has been your experience with female Veterans?"

Women Veterans expressed altruistic motivations in their desire to engage in health research. A woman Veteran described her desire to help as a form of advocacy: "It was the

 Table 2 VA Women's Health stakeholders (WH-PCPs and administrators)

	WH-PCPs (N=22)	Administrators (N=6)
VAMC region		
Great Lakes	13.6% (3)	16.7% (1)
South	9.1% (2)	33.3% (2)
Pacific Northwest	27.3% (6)	16.7% (1)
West	27.3% (6)	0.0% (0)
Midwest	22.7% (5)	33.3% (2)
Gender		
Male	4.5% (1)	33.3% (2)
Female	95.5% (21)	66.7% (4)

idea that you're helping the VA provide better care for the Veterans, particularly for female Veterans because there's not very many females in studies." Some said incentives were appreciated, but not a determining factor in their decision to participate. Other motivations included a desire to learn about a personally relevant topic, and interest in study outcomes following their participation; however, this feedback loop had not been closed for the minority who participated as research subjects.

Engagement Barriers and Facilitators

Table 4 depicts women Veterans', WH-PCPs', and administrators' converging and diverging perspectives on barriers to and facilitators of women Veterans' engagement.

Convergent Barriers

Four convergent themes emerged across all participant groups as barriers to engagement: (1) unawareness of opportunities, (2) distrust of research activities, (3) competing priorities, and (4) confidentiality concerns.

Table 3 Women Veteran demographics (N=31)

VAMC region	
Great Lakes	22.6% (7)
South	12.9% (4)
Pacific Northwest	22.6% (7)
West	19.3% (6)
Midwest	22.6% (7)
Age, years	
Mean (SD)	55.6 (13.0)
Range	25-86
Race/ethnicity	
White	45.2% (14)
African American	32.2% (10)
Other	9.7% (3)
Unknown	12.9% (4)
Relationship status	
Married, partnered	25.8% (8)
Single (including divorced, separated)	64.5% (20)
Unknown	9.7% (3)
Children	
Yes	41.9% (13)
No	48.4% (15)
Unknown	9.7% (3)
Number of children	
1	3.2% (1)
2	19.4% (6)
3	12.9% (4)
4	3.2% (1)
5	3.2% (1)
Military branch	
Army	29.0% (15)
Air Force	48.4% (9)
Navy	16.1% (5)
Coast Guard	3.2% (1)
Reserve/National Guard	3.2% (1)
Era of service	
During Vietnam Era	9.7% (3)
During Post-Vietnam Era	41.9% (13)
Between Persian Gulf War and 9/11	3.2% (1)
During September 11, 2001, to present	16.1% (5)
Extended service across multiple eras	19.4% (6)
Unknown	9.7% (3)
Years served in military	
Mean (SD)	8.14 (7.22)
Range	1.25-32.00

	Identified by women Veterans and WH- PCPs/administrators	Identified by women Veterans only	Identified by WH-PCPs/ administrators only
Barriers to women Veterans' engagement	 Unawareness of opportunities Distrust of research Competing priorities Confidentiality concerns 	Reluctance to discuss military experiencesBelief that participation will not yield change	Environmental concernsMental health distress
Facilitators of women Veterans' engagement	 Utilization of patient-facing portals of the electronic health record Warm hand-offs from provider/staff Accessible research registry Communicate potential research impact 	• Outreach (e.g., social media, Veteran events)	 Research ambassadors Provide Veterans with research findings Trauma-informed research

Table 4 Barriers to and facilitators of women Veterans' research engagement

Unawareness of Opportunities. Most of participants expressed that women are not aware of research opportunities. For instance, many women Veterans expressed the happenstance by which they learned about the current study (e.g., fellow woman Veteran passed along information, clerk provided a flyer). Some WH-PCPs were not clear whether research opportunities even existed within their VAMC, and surmised that women Veterans might be similarly unaware of such opportunities. An administrator shared that she would not know where to look for local research opportunities applicable to women Veterans: "Even working here, you know, it's such a hard system to navigate. It's such a maze."

Distrust of Research. Distrust was identified as a pervasive barrier to research engagement. A woman Veteran explained: "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." Some providers and administrators suggested that distrust of research may be correlated with former military experiences. A WH-PCP said: "There is distrust among female Veterans because of how they've been treated in the military system. Also, I guess I would feel the same way." Another provider perceived research engagement as potentially too vulnerable an experience for women Veterans with a history of trauma: "Many of them have had previous assault... They're going to be less likely to come into a place that is mirroring their military time." The climate of distrust was noted as particularly salient for African Americans Veterans. An administrator said: "I think our African American population is truly suspicious of us doing research... Because of the Tuskegee issues, the atrocities of that, those suspicions have carried on generationally." Another administrator made note of the various cultural complexities and biases that impact researchers: "There is a cultural bias against research among the African American community that is separate from the bias of a Veteran who has been in the system, that's separate from a female Veteran and whatever experiences she may have had in the system that makes her biased against research."

Competing Priorities. Participants suggested that women's limited time and responsibilities to employers, children, and

other dependents may take precedence. WH-PCPs recognized that adherence to medical care may already be a challenge for women Veterans compared to male Veterans; thus, they may be less likely to engage in voluntary commitments such as research. One WH-PCP said: "In general, women tend to put everybody first... A lot of taking care of their family, [which] leaves their health needs till last, but particularly for women Veterans." Expanding scheduling options for research participation (e.g., by adding evening/weekend hours) may not be enough; as one women Veteran noted, "There is probably not enough weekend availability for women because they also function as parents or single mothers."

Confidentiality Concerns. Women Veterans suggested there may be apprehension about data collection exposing something related to their military experience(s) that they would otherwise not want revealed (e.g., mental illness, military-related trauma). A woman Veteran shared: "They may be a little paranoid about confidentiality because they might have done things in their past that they don't want to be revealed." A few WH-PCPs and administrators theorized that women Veterans' apprehension might stem from the belief that research might uncover health information that would jeopardize their VA benefits. A WH-PCP explained: "I think they would fear [that it] would affect their disability somehow, that it might affect their disability benefits, so it might be a sense of what good is it going to bring?"

Divergent Barriers

Women Veterans suggested additional barriers not otherwise mentioned by WH-PCPs and administrators: (1) reluctance to discuss military experiences, and (2) belief that research participation will not yield change within VA. WH-PCPs and administrators identified two additional barriers to women Veterans' engagement in research: (1) environmental concerns, and (2) mental health distress.

Reluctance to Discuss Military Experiences. Women Veterans suggested that other women Veterans may feel disinterested in research that may prompt them to explore the past, therefore making research engagement at VA less desirable. A woman Veteran explained this potential barrier, hinting at the discomfort one might feel if pressed to relay details or memories from the military: "I think that it's hard for some women Veterans to be able to speak up due to some of the instances that does happen to them when they are in the service."

Belief that Participation Will Not Yield Change. Women Veterans expressed that they were not convinced that participating in research would result in actual change. For instance a woman Veteran said, "I think they [women Veterans] truly don't think anything will come of [research]," while another said, "Maybe they don't think it's going to change things."

Environmental Concerns. WH-PCPs and administrators suggested that some women Veterans may decline participation due to their discomfort with less controlled environments on VA campuses outside of women's clinics. For some women Veterans, particularly "those with [a history of] military sexual trauma," the prospect of volunteering time outside the Women's Health Clinic is not likely: "They feel more secure or less stressed in an area where it's women...just less anxious in an area where it's not full of men, male Veterans." Another provider said: "Many of our patients don't like being here, but the women especially don't like being here... They try to avoid it."

Mental Health Distress. According to WH-PCPs and administrators, mental health distress, particularly for those with anxiety and/or history of trauma, can impede women Veterans' ability to engage in research activities. For instance, a WH-PCP said that the post-traumatic stress disorder (PTSD) symptoms among some women "would get in the way of actually volunteering." Another provider discussed the unfortunate paradox of reaching this special population of women Veterans who "feel really alienated from the general larger system."

Convergent Facilitators

Four convergent themes emerged across all participant groups as facilitators of engagement: (1) electronic patient portal, (2) warm hand-off from provider-staff, (3) accessible research registry, and (4) communicate potential research impact.

Electronic Patient Portal. Participants recommended VA's patient-facing portals of the electronic health record as a potential resource for advertising research engagement opportunities since many Veterans already use it as part of their routine healthcare. For instance, a woman Veterans suggested: "Put a [research] link for women Veterans... Technology is there, we just have to be creative and put it into place." WH-PCPs had a similar

endorsement: "Seem[s] to be the fastest and easiest way to get their attention."

Warm Hand-Off from Provider/Staff. Participants suggested including providers or clinic staff as a potential strategy to improve engagement. WH-PCPs acknowledged that clinic staff may already feel overburdened; however, endorsements to connect to research from a trusted source is key for women Veterans: "It's a familiar face presenting the research topic to the patient in a more comfortable setting, as opposed to a letter or phone call. [However] it would be difficult because I have yet to meet a primary care provider who is not overwhelmed." Furthermore, an administrator pointed out that WHC staff are more familiar with their women Veteran patients (including their mental health needs), and therefore "good candidates to help researchers [engage patients]."

Accessible Research Registry. Some WH-PCPs and administrators referenced the usefulness of a registry to minimize research barriers: "A broker who can scan that database and give researchers the names of potential subjects, can then (under IRB approval) be contacted." Another provider described the success of a local university that utilizes a registry: "It's an opportunity for patients, [and] potential future research volunteers that either has health conditions or are normal healthy controls to opt in." Although women Veterans did not mention the term "registry" or "repository" in their interviews, many suggested that the interviewer "keep my information on hand for future research opportunities."

Communicate Potential Research Impact. Participants emphasized the importance of being transparent about a study's purpose, privacy/confidentiality measures, and the potential impact or outcomes of the research. A WH-PCP underscored the importance of asserting that the goals of research would be to help other women Veterans: "...'If you wish to participate, you would be helping other women Veterans.' Usually, they are very amenable to taking part in it." Women Veterans emphasized the importance of researchers' communicating why their participation is needed, and how their involvement may result in helping other women Veterans.

Divergent Facilitators

Women Veterans emphasized the importance of outreach to facilitate inclusion and engagement of women Veterans. WH-PCPs and administrators identified three additional facilitators to women Veterans' engagement in research: (1) research ambassadors, (2) providing Veterans with research findings, and (3) trauma-informed research.

Outreach. Women Veterans suggested various avenues for outreach, including employing women Veterans to help disseminate information to other women Veterans. One woman explained: "We relate to one another. We trust one another, and we know that we are looking out for one another." Without endorsements from women Veterans, a study team will need to "try to build authentic and genuine relationships" with the cohort they are interested in. For instance, some suggested VA research–sponsored events in order to build community relationships, and raise awareness about VA's research mission. Some women suggested that research staff participate in local community events (e.g., VA Stand Downs), and to utilize social media forums to disseminate research opportunities.

Research Ambassadors. WH-PCPs and administrators suggested use of "research ambassadors" stationed in clinics or waiting rooms to help serve as a dedicated liaison to research. These ambassadors could function as informants (answer questions about research) as well as build rapport with the clinical community since research offices are often removed from clinical environments. For example, a WH-PCP suggested that the presence of research ambassadors would help to humanize research efforts and perhaps better engage women Veterans: "To have someone right there to talk with the patient can help with enrollment... They're able to meet with the patient."

Providing Veterans with Research Findings. WH-PCPs and administrators underscored the importance of connecting with participants following their involvement to provide study findings. An administrator explained that without researchers returning to inform others about their findings, the consequence may mean less research engagement in the future: "You never know what happened, where it went, what the aggregate results were. It goes off into space... 'No thanks.' 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, and I think the patients feel that way too."

Trauma-Informed Research. WH-PCPs and administrators emphasized the importance of integrating a trauma-informed lens when it comes to research engagement: "We need to do trauma-informed research to get at the heart of what we really need to do for them." In the same way clinicians engage in trauma-informed patient care, researchers must learn how to integrate trauma-informed practices into their research design and delivery. An administrator said, "Trauma-informed research, it's a very whole health type of perspective where we recognize exactly where they're coming from and we're able to design research projects that really speak to what's important to them or to recognize them culturally, or what it is that they experienced. I think they experienced some pretty horrible things."

DISCUSSION

Although the engagement of Veterans in both patient care and health research capacities is becoming a standard of practice within VA and across other healthcare institutions,^{9,27,28} the concept of engaging in research as a stakeholder/partner was unfamiliar to the women Veterans in this study—most of whom had limited or no experiences participating in research as subjects, let alone as stakeholder/partner.

Participants expressed several reasons for why women Veterans may not engage in research, namely not knowing about opportunities and distrust of research. Previous studies acknowledge such challenges: both a lack of opportunity,²⁹ and lack of trust between communities and research entities.^{30,31} Uncertainty about where to find research opportunities and its lack of visibility within the healthcare system may consequently create distance between researchers and women Veterans. Furthermore, the concept of trust (or lack thereof) is both ubiquitous and interrelated with other identified barriers including confidentiality and fear of exposure, which are particularly salient for Veteran populations.^{13,32} Trust is particularly complex because without it, a reciprocal relationship between women Veterans and researchers cannot exist. Krahe's study on perceived risk demonstrates that support for research decreases when consumers' trust in that environment decreases.³³ Researchers have a responsibility to acknowledge the importance of earned trust as a critical pathway to patients' research involvement.34

Participants offered suggestions to increase women Veterans' inclusion and engagement in research communities. These suggestions can extend to both recruitment strategies for subjects and strategies to increase engagement of stakeholders/partners. The adoption of existing technologies to increase the visibility of research opportunities was emphasized across all participants, and aligns with other research.^{35,36} For instance, utilization of patient-facing portals of the electronic health record to disseminate real-time availability of local or national research opportunities, the adoption of patient research registries,³⁷ and incorporating social media into recruitment methods have the potential to increase research visibility and to reduce the partnership gap between stakeholder/partners and researchers. Increasing participation and engagement hinges on researchers' ability to build and sustain trust in their relationships with women Veterans, and to challenge the expectation that researchers arrive with a predetermined need. Researchers may want to consider extending personally relevant information, such as the impetus for pursuing Veteran-engaged research; this can help to humanize research endeavors and build rapport. Anticipating women Veterans' concerns about confidentiality and educating patients about how responses will not jeopardize care, nor disability ratings, may help to demystify how VA research operates. Additionally, the provision of study findings at the conclusion of studies can demonstrate genuine regard and underscore value toward study participants.38

Both women Veterans and WH-PCPs suggested that women Veterans' mental health and trauma histories should be considered by researchers, raising important implications for the potential of adopting a trauma-informed approach to research engagement in VA. This is of particular importance to women Veterans given high reported rates of military sexual trauma (MST) history,³⁹ and recent recommendations for the inclusion of trauma-sensitive care for women Veterans.^{40,41} Improving the likelihood of engagement in research (from subject to stakeholder) may require the scientific community to consider the adoption of trauma-informed principles that go beyond standard IRB regulations and procedures.⁴² In the same way the VA has entered a paradigm shift in traumainformed care practices, research engagement efforts can benefit from sensitivity to the population with whom we seek partnership. Trauma-informed care delivery to patients has gained momentum as a best practice,^{43,44} but guidance is slow to take shape for trauma-informed principles related to research, despite the promise of such principles for mitigating challenges.

This study has limitations. First, the perspectives of women Veterans who utilize VA may differ from those who do not use VA. Second, women Veterans were recruited from VA health clinics in urban centers; perspectives in rural areas may differ. Additionally, findings are drawn from a small sample of women Veterans with diverse characteristics (e.g., age, military experience). MST histories were not sought, although these histories could influence results. Interviews were conducted with WH-PCPs and a small number of administrators, both of which lack demographic data, and do not necessarily reflect perspectives of PCPs outside of women's health. Lastly, exploration of barriers and facilitators may reflect the limited scope resulting from women Veterans' limited experience with research. Despite these limitations, this study is the first known exploration of research engagement from the perspectives of multilevel stakeholders; these perspectives combine to produce a dynamic exploration of barriers and facilitators related to research engagement.

Our exploration highlights the slow uptake of engagement as a practice, but also the demand for more inclusion across the spectrum of opportunities offered in health research. Our findings underscore the need for improved identification of engagement opportunities, as well as efforts to systematically, and culturally address multilevel barriers and facilitators to research engagement. Additionally, future research is needed to guide implementation methodologies for meaningful and ethical engagement practices. Efforts to mobilize diverse stakeholder populations (i.e., minorities, Veterans, women) ensure that health research is impactful and meaningful to the very population it aims to address.

Acknowledgements: The authors wish to thank Drs. Patricia Hayes and Sally Haskell of VA Office of Women's Health and the VA Women's Health Practice-Based Research Network (WH-PBRN) for supporting the team's efforts. Additionally, the authors thank the five WH-PBRN sites and respective Site Leads for recruitment assistance.

Corresponding Author: Joya G. Chrystal, MSW, LCSW; VA HSR&D Center for the Study of Healthcare Innovation, Implementation and Policy (CSHIIP), VA Greater Los Angeles Healthcare System, Los Angeles, CA, USA (e-mail: Joya.Chrystal@va.gov).

Funding This work was supported by the United States Department of Veterans Affairs Health Services Research and Development (VA HSR&D) SDR 10-012 (Women's Health Research Network; Multiple PIs: Yano, Frayne, Hamilton). Dr. Yano's effort was funded by a VA HSR&D Senior Research Career Scientist Award (RCS 05-195).

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons. org/licenses/by/4.0/.

REFERENCES

- Harrington RL, Hanna ML, Oehrlein EM, et al. Defining patient engagement in research: results of a systematic review and analysis: Report of the ISPOR Patient-Centered Special Interest Group. Value Health 2020;23(6):677-688.
- Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff (Millwood) 2013;32(2):223-231.
- Key KD, Furr-Holden D, Lewis EY, et al. The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress. Prog Community Health Partnersh 2019;13(4):427-434.
- Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. Annu Rev Public Health 2008;29:325-350.
- Gallivan J, Kovacs Burns KA, Bellows M, Eigenseher C. The many faces of patient engagement. J Participat Med 2012; 26:4:e32.
- Crockett LK, Shimmin C, Wittmeier KDM, Sibley KM. Engaging patients and the public in Health Research: experiences, perceptions and training needs among Manitoba health researchers. Res Involv Engagem 2019;5:28.
- Carroll SL, Embuldeniya G, Abelson J, McGillion M, Berkesse A, Healey JS. Questioning patient engagement: research scientists' perceptions of the challenges of patient engagement in a cardiovascular research network. Patient Prefer Adherence 2017;11:1573-1583.
- Forsythe LP, Frank LB, Tafari AT, et al. Unique review criteria and patient and stakeholder reviewers: analysis of PCORI's approach to research funding. Value Health 2018;21(10):1152-1160.
- Hamilton AB, Brunner J, Cain C, et al. Engaging multilevel stakeholders in an implementation trial of evidence-based quality improvement in VA women's health primary care. Transl Behav Med 2017;7(3):478-485.
- Norris JM, White DE, Nowell L, Mrklas K, Stelfox HT. How do stakeholders from multiple hierarchical levels of a large provincial health system define engagement? A qualitative study. Implement Sci 2017;12(1):98.
- Dugas M, Trottier M, Chipenda Dansokho S., et al. Involving members of vulnerable populations in the development of patient decision aids: a mixed methods sequential explanatory study. BMC Med Inform Decis Mak 2017;17:12.
- Littman AJ, True G, Ashmore E, Wellens T, Smith NL. How can we get Iraq- and Afghanistan-deployed US Veterans to participate in healthrelated research? Findings from a national focus group study. BMC Med Res Methodol 2018;18(1):88.

- Hyde J, Wendleton L, Fehling K, et al. Strengthening excellence in research through veteran engagement (SERVE): toolkit for veteran engagement in research (version 1). Veterans Health Administration, Health Services Research and Development. 2018. Retrieved from: https://www.hsrd.research.va.gov/for_researchers/serve/
- Woolf SH, Zimmerman E, Haley A, Krist AH. Authentic engagement of patients and communities can transform research, practice, and policy. Health Aff (Millwood) 2016;35(4):590-594.
- Bokhour BG, Fix GM, Mueller NM, et al. How can healthcare organizations implement patient-centered care? Examining a large-scale cultural transformation. BMC Health Serv Res 2018;18(1):168.
- Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. Health Aff (Millwood) 2008;27(3):759-769.
- 17. Hamilton AB, Chrystal JG, and Dichter, M. "Engaging women veterans in research." Presentation at VA Healthcare Services Research and Development (HSR&D) CyberSeminar as part of the Spotlight on Women's Health Series. 2018. Retrieved from: https://www.hsrd.research.va.gov/ for_researchers/cyber_seminars/archives/video_archive.cfm? SessionID=2476
- Women Veterans Report: The Past, Present, and Future of Women Veterans. National Center for Veterans Analysis and Statistics, Department of Veterans Affairs, Washington, DC. 2017. Retrieved from: https:// www.va.gov/vetdata/docs/specialreports/women_veterans_2015_final. pdf
- Frayne SM, Phibbs CS, Saechao F, et al. Sourcebook: Women Veterans in the Veterans Health Administration. Volume 4: Longitudinal Trends in Sociodemographics, Utilization, Health Profile, and Geographic Distribution. Women's Health Evaluation Initiative, Women's Health Services, Veterans Health Administration, Department of Veterans Affairs: Washington D.C. 2018. Retrieved from: https://www.womenshealth.va.gov/ WOMENSHEALITH/docs/WHS_Sourcebook, Vol-IV_508c.pdf
- 20. Epidemiology Program, Post-Deployment Health Group, Office of Patient Care Services, Veterans Health Administration, Department of Veterans Affairs. Analysis of VA Health Care Utilization among Operation Enduring Freedom, Operation Iraqi Freedom, and Operation New Dawn Veterans, from 1st Qtr FY 2002 through 3rd Qtr FY 2015. 2017. Washington, D.C. Retrieved from https://www.publichealth.va.gov/docs/epidemiology/ healthcare-utilization-report-fy2015-qtr3.pdf#
- Washington DL, Bean-Mayberry B, Riopelle D, Yano EM. Access to care for women veterans: delayed healthcare and unmet need. J Gen Intern Med 2011;26 (Suppl 2):655-661
- Hamilton AB, Frayne SM, Cordasco KM, Washington DL. Factors related to attrition from VA healthcare use: findings from the National Survey of Women Veterans. J Gen Intern Med 2013;28(Suppl 2):S510-S516.
- Friedman SA, Frayne SM, Berg E, et al. Travel time and attrition from VHA care among women veterans: how far is too far?. Med Care 2015;53(4 Suppl 1):S15-S22.
- Elnitsky CA, Andresen EM, Clark ME, McGarity S, Hall CG, Kerns RD. Access to the US Department of Veterans Affairs health system: selfreported barriers to care among returnees of Operations Enduring Freedom and Iraqi Freedom. BMC Health Serv Res 2013;13:498.
- Frayne SM, Carney DV, Bastian L, et al. The VA Women's Health Practice-Based Research Network: amplifying women veterans' voices in VA research. J Gen Intern Med 2013;28 (Suppl 2):S504-S509.
- Charmaz, K. Grounded Theory as an Emergent Method. In S. N. Hesse-Biber & P. Leavy (Eds.), Handbook of Emergent Methods. The Guilford Press; 2008: 155–170.
- Harrison JD, Auerbach AD, Anderson W, et al. Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. Health Expect 2019;22(3):307-316.
- Mallidou AA, Frisch N, Doyle-Waters MM, MacLeod MLP, Ward J, Atherton P. Patient-Oriented Research Competencies in Health (PORCH)

for patients, healthcare providers, decision-makers and researchers: protocol of a scoping review. Syst Rev 2018;7(1):101.

- Ford ME, Siminoff LA, Pickelsimer E, et al. Unequal burden of disease, unequal participation in clinical trials: solutions from African American and Latino community members. Health Soc Work 2013;38(1):29-38.
- Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. J Gen Intern Med 1999;14:537–546.
- Spears CR, Nolan BV, O'Neill JL, Arcury TA, Grzywacz JG, Feldman SR. Recruiting underserved populations to dermatologic research: a systematic review. Int J Dermatol 2011;50: 385–395.
- Kerasidou, Angeliki. Trust me, I'm a researcher!: The role of trust in biomedical research. Med Health Care Philos 2017;20(1):43–50.
- Krahe M, Milligan E, Reilly S. Personal health information in research: Perceived risk, trustworthiness and opinions from patients attending a tertiary healthcare facility. J Biomed Inform 2019;95:103222.
- Roche P, Shimmin C, Hickes S, et al. Valuing All Voices: refining a trauma-informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach. Res Involv Engagem 2020;6:42. Published 2020 Jul 19.
- Sankaré IC, Bross R, Brown AF, et al. Strategies to Build Trust and Recruit African American and Latino Community Residents for Health Research: A Cohort Study. Clin Transl Sci 2015;8(5):412-420.
- 36. Ambrosini A, Quinlivan R, Sansone VA, et al. "Be an ambassador for change that you would like to see": a call to action to all stakeholders for co-creation in healthcare and medical research to improve quality of life of people with a neuromuscular disease. Orphanet J Rare Dis 2019;14(1):126.
- Bush NE, Sheppard SC, Fantelli E, Bell KR, Reger MA. Recruitment and attrition issues in military clinical trials and health research studies. Mil Med 2013;178(11):1157-1163.
- Long CR, Stewart MK, Cunningham TV, Warmack TS, McElfish PA. Health research participants' preferences for receiving research results. Clin Trials 2016;13(6):582-591.
- 39. Military Sexual Trauma Support Team. (2019). Military Sexual Trauma Screening Report, Fiscal Year 2019. Washington, DC: Department of Veterans Affairs, Office of Mental Health and Suicide Prevention. Retrieved from: Facts and Statistics about Women Veterans - Women Veterans Health Care (va.gov)
- American Institutes for Research (AIR) and The National Center for Family Homelessness. (2013). Homelessness and Trauma in the Lives of Women. Retrieved from: https://www.air.org/sites/default/files/Women_Vets_Fact_Sheet_110813.pdf
- Bergman AA, Hamilton AB, Chrystal JG, Bean-Mayberry BA, Yano EM. Primary Care Providers' Perspectives on Providing Care to Women Veterans with Histories of Sexual Trauma. Womens Health Issues 2019;29(4):325-332.
- Campbell R, Goodman-Williams R, Javorka M. A Trauma-Informed Approach to Sexual Violence Research Ethics and Open Science. J Interpers Violence 2019;34(23-24):4765-4793.
- Yano EM, Hamilton AB. Accelerating delivery of trauma-sensitive care: Using multilevel stakeholder engagement to improve care for women veterans. Fam Syst Health 2017;35(3):373-375.
- Reeves E. A synthesis of the literature on trauma-informed care. Issues Ment Health Nurs 2015;36(9):698-709.

Publisher's Note: Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.