Cyberseminar Transcript

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Session: Engaging Women Veterans in Research

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Molly: And we are approaching the top of the hour at this time, so I would like to introduce our speakers. Joining us first, we have Dr. Alison Hamilton. She is the associate director for Implementation Science and director for Qualitative Methods Group at the VA Center for Study of Innovation, Implementation, and Policy. That’s located at the VA Greater Los Angeles Healthcare System. She’s also an associate research anthropologist in the Department of Psychiatry and Biobehavioral Sciences at the University of California, Los Angeles. Speaking next we have Joya Chrystal. She’s at the HSR&D Center for the Study of Healthcare Innovation, Implementation, and Policy, also located at VA Greater Los Angeles. And finally we have Dr. Melissa Dichter joining us. She’s a core investigator and career, I’m sorry, and career development awardee for the VA HSR&D Center for Health Equity Research and Promotion at VA Philadelphia Medical Center. So with that, at this time, Dr. Hamilton, I would like to turn it over to you.

Dr. Alison Hamilton: Thank you so much, Molly. Good morning everyone. Good morning, good afternoon. Thank you so much for joining us. The three of us are really excited to talk with you today about the topic of Engaging Women Veterans in Research, and we do want to thank Molly and HSR&D for this opportunity to do a Cyberseminar for the Spotlight on Women’s Health.

So we just want to get a sense of who we have with us first. If we could quickly shift to a poll question just to get a sense of our audience.

Molly: Thank you. So for our attendees, as you can see up on your screen, we do have the first poll question. So as Alison mentioned, we’d like to get an idea of who is joining us. So which of the following describes you? And you can select all that apply. So we have Veteran, researcher, clinician/provider, administrator/manager, or policymaker. Go ahead and just click the circle, I'm sorry, click on your screen next to the response. And again, you can select more than one. Looks like we’ve got a very responsive audience today. Over three-quarters have already replied, so I'm going to go ahead and close out the poll and share those results. Nine percent selected Veteran, 69% researcher, 26% clinician or provider, 17% administrator or manager, and no policymakers joining us today. So thank you to those respondents, and I'll turn it back over to you now, Dr. Hamilton.

Dr. Alison Hamilton: Thank you. Okay, so Joya and I are going to get us started this morning. We’re going to talk about increasing engagement of women Veterans in research and specifically some results that we have from a study we conducted within the context of the Women’s Health Practice-Based Research Network. Sorry about that. Okay, I do want to thank HSR&D for our funding for the Women’s Health Research Network as well as Women’s Health Services, the Women’s Health Practice-Based Research Network, and of course all of the participants who provided wonderful information to us.

I also want to say a special thank you to the PBRN sites that participated. You see the five sites and the site leads and other colleagues who helped us tremendously at these sites. So we’re very grateful to them for their support of the study.

So briefly what we’re going to talk about this morning are a couple of things. First I just want to share with you the conceptual model of engagement that we’ve been using in the Women’s Health Research Network. A quick definition of engagement, we really draw on the PCORI, or Patient-Centered Outcomes Research Institute, definition of engagement which is 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. So we’re going to use that approach to engagement and specifically a community-engaged model of research. And what you’re going to hear about a little bit later from Melissa is one aspect of engagement more focused on recruitment. So we’re going to share with you our results related to increasing engagement of women Veterans in research. We covered a few other topics in the study, but we really wanted to focus on this topic for today. And we’re going to look at our participants’ perspectives on why women aren’t engaging in research and also what they suggest for how to increase women’s engagement in research.

Molly: Alison, I apologize for interrupting. Can you move the microphone just a little bit closer to your mouth please?

Dr. Alison Hamilton: Absolutely. Is this better?

Molly: It is. Thank you.

Dr. Alison Hamilton: Let me just turn, is that a little bit better too? Just turned it up.

Molly: Yeah, that improved it. Thank you so much.

Dr. Alison Hamilton: Okay, great. Thanks Molly. So what you see here is a model of community-engaged research that we adapted from Isler and Corbie-Smith. I won’t get into the weeds with everyone. But really the idea here is that we want to, in the Women’s Health Research Network, focus on multilevel engagement of stakeholders, and the stakeholders that we’re going to be talking about today are the three in the red square. That’s our focus for today, interviews that we conducted with women Veterans, providers, and leaders. We also conducted interviews with researchers, which I’ve shared in the previous Cyberseminar. But the idea more importantly with our conceptual model is that we want, as a foundation of the Women's Health Research Network, to have this multilevel stakeholder engagement, which we hope will, as you see in the dotted box, increase trust in research, respect, shared language, build relationships, foster shared decision-making, and foster more partnered activities. And I won't get into the rest of it, but I'm happy to talk about that more later if folks are interested.

So what we did for the study that we’re going to be sharing with you today is that we coordinated with the PBRN site leads you saw on the previous slide. And we recruited women Veterans via flyers, and we e-mailed providers and administrators to see if they were interested in participating. And we did phone interviews with all of these folks from October 2016 to March 2018. One question that we asked was about why women might not engage in research, and we also asked how to improve women's engagement in research. We also asked similar questions about providers, but that’s not the focus of today’s Cyberseminar. So there’s more to share as we go along analyzing this data. And we transcribed all the interviews, and then we developed codebooks [inaudible 07:02] participant groups and looked across groups for common themes.

So now it is my great pleasure to turn this over to Ms. Joya Chrystal who conducted the interviews and learned a lot and facilitated our connections with the site leads, so many thanks to Joya for her hard work on this, and she’s going to share some of our results.

Joya Chrystal: Thank you, Alison.

Molly: Thank you Alison. Joya, just before you get started, Alison, I hate to be a pain, but would you be willing to call in while Joya does her portion?

Dr. Alison Hamilton: Sure.

Molly: Thank you so much. Go ahead, Joya. Thanks.

Joya Chrystal: Great, thank you. So in our interviews, women Veterans, providers, and administrators shared really valuable and eye-opening reasons why women Veterans may not engage in research. Perhaps one of the most commonly cited reasons, that being unaware of research opportunities, was emphasized across all participant groups. It was not well understood where one might go to look for potential research opportunities. And in fact, for many women Veterans that we spoke to, their decision to participate in our study was also their first time enrolling in a study. Women Veterans, providers, and administrators emphasized distrust of researchers and the research agenda as a potential reason why women Veterans may lack engagement in research. For instance, one woman Veteran said, “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 something to help us when we’ve been struggling for such a long time.’ We’ve been let down so much.”

Additionally, participants emphasized competing priorities such as work or school demands, as well as caretaking responsibilities as a potential barrier to engagement. Many providers said it’s challenging enough for these busy women to keep their medical appointments, especially for younger generations of women Veterans who are balancing school and young families. Likewise, limited time was identified as a barrier to engagement by all three participant groups. And furthermore, women Veterans, especially those with those competing priorities, are less likely to engage in participation if research requires in-person or on-campus presence or if their participation is required during routine clinic business hours.

All participants emphasized confidentiality concerns as another reason why women Veterans may not engage in research. Along these same lines, fear of exposure related to sensitive subject matter may jeopardize benefits. So for instance there was a concern about sharing sensitive information related to her military service and that it might somehow be used against her.

Women Veterans mentioned intimidation as a potential reason for lack of engagement. However, interestingly, all women Veterans were overwhelmingly interested in working with researchers in collaboration to help drive research engagement. Not interested in speaking about the past. Some women Veterans emphasized how hard they work to leave the past in the past. In fact, one woman suggested that the prospect of agreeing to participate in a vague questionnaire or open-ended interview was, in fact, unappealing.

Women Veterans suggested lack of engagement may be rooted in the belief that participation will somehow not make an impact. So this is particularly important for us to consider as researchers in our recruitment efforts as we work toward engaging women who identify with this particular belief. And finally, women Veterans suggested there may be generational differences affecting their lack of research engagement. For instance, younger generations may feel more optimistic about research’s impact, whereas older generations may be influenced by lingering mistrust.

Providers and administrators emphasized concern over safety as well as avoidance of VA related to women’s lack of research engagement. One provider described her facility as physically uncomfortable for some Veterans, especially those with trauma histories. And one quote I have here is many of them have had a previous assault, whether it be physical or verbal, and they’re going to be less likely to come into a place that is mirroring their military time.

Providers and administrators suggested that research recruitment efforts were too obscure, and finally that there may be a cultural disconnect between researchers and the women Veteran population. For instance, an administrator suggested the need for researchers to connect and communicate with local Veterans to build trust and to harness that cultural competency in our engagement approach.

So next, moving on to increasing women Veteran engagement, thankfully our participants had a lot of helpful feedback to increase women Veteran engagement. Again, women Veterans as well as providers and administrators responded comparably in terms of engagement suggestions. All participant groups emphasized the use of My HealtheVet to publicize current research opportunities. In fact, many suggested that this resource made sense for a number of reasons. Patients who readily seek information on My HealtheVet may also be open to clicking on a link that will connect them to research opportunities. They also emphasized the importance of warm hand-offs from provider or staff to the Veteran as a way to simultaneously connect Veterans to research and to demonstrate endorsement of a study. Women Veterans in particular stressed the value of trusted endorsements in her decision to participate in a study. And again we see the theme of trust building as critical to engagement efforts.

An idea that we thought was really interesting was the development of a recruitment repository, and we aren’t sure if this is possible within VA, but it is interesting to think about nonetheless. In its most basic form, this repository could function as a database of potential research participants who may be willing to be contacted for future study recruitment. And in that same spirit, another thought-provoking idea is that of a research registry. Again, all participant groups stressed the need for a study registry that is both up to date and user friendly. A registry like this might be an impactful resource to better connect and engage those interested to research. And since uncertainty about where one goes to find research opportunities was identified as a major barrier, we think the development of a registry could potentially address this obstacle. One provider said, “It is unclear what studies are active and where to refer patients.”

And finally a critical point acknowledged by women Veterans, providers, and administrators, we as researchers need to do a better job of communicating the details of our research work. In particular, participants underscored the importance of understanding a research study’s purpose, privacy, confidentiality measures, and of course the potential impact according to findings.

Women Veterans stressed the importance of word of mouth from other women Veterans. Again, they are more likely to engage if the research is endorsed from a trusted source. Also, women Veterans suggested utilizing social media outlets like Facebook and Twitter to target women Veterans, particularly for those women Veterans who are not active consumers of VA. And finally, women Veterans discussed the value in having researchers participate at women Veteran focused events in order to foster that relationship between research and women Veterans within the community.

Providers and administrators talked about the potential value of having something like research ambassadors available in different clinics. So for example, having a research team member physically located in a clinic space in order to service Veterans’ questions and to provide information about different research opportunities available to them may improve the potential for engagement.

As we heard in the previous slide, it is very important for us to make sure that if we want to increase Veteran engagement, and of course we do, we need to be conscientious about returning to our participants with research findings. We believe this step will promote a sense of trust in researchers and in research. One administrator said, “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.” This quote highlights the need for us as researchers to improve in this area, of course with appropriate IRB protocols in mind, providing our participants with findings and impacts bears weight on their willingness to engage in future research with us, of course.

And finally, our provider and administrator participants talked about the importance of engaging Veterans beyond the walls of the VA Medical Center. Both of these participant groups encouraged future efforts at community-based outpatient clinics, which are overlooked as a potential recruitment venue.

Okay, so some key take-home points, our take-home points about women Veterans engagement in research. First off, both women Veterans and providers agree that research specific to women is absolutely necessary given her unique medical needs and that research has the potential to translate to improved care of women, especially future generations of women. It was clear that many women Veterans felt empowered to participate in the research interview and regarded research participation in general as a form of advocacy for women Veterans.

Secondly, women Veterans and providers shared similar perspectives on why women don’t often participate in research. And finally, research opportunities for women Veterans need greater accessibility and transparency to providers and patients. For example, resources such as My HealtheVet, a searchable repository for active research opportunities, retaining contact information for future studies, and the importance of sharing results with our research participants are some potential avenues that may drive engagement forward. Thank you.

Dr. Alison Hamilton: Thank you so much, Joya. That was great. And now it is my great pleasure to turn the Cyberseminar over to Dr. Dichter. Thank you.

Dr. Melissa Dichter: Hello everyone. Thank you for being on today. I'm going to set this up so you can see these slides now. So thank you for Alison and Joya’s presentation about the importance of and barriers to and opportunities for engaging women Veterans in research activities. I'm going to share with you today some of our experiences and lessons learned from recruitment and participation of women Veterans in a particular VA HSR&D funded research study. This is our research team including our co-investigators on the study, PI, and these are our investigators and our staff who have participated in recruitment and data collection. We also have a robust study advisory board that is really important to the design and implementation of the study, including the development and implementation of recruitment strategies. And Linda Lipson is our wonderful program officer from VA HSR&D. So we will start again with a poll question. Molly will take over and administer that poll question.

Molly: Thank you. So for our attendees, we do have another poll question up on your screen at this time. This one is also select all that apply. Sorry, there seems to be an interesting character in there. What is your experience with recruiting research participants? You have experience recruiting participants, have experience recruiting women Veteran participants, or do not have experience recruiting participants. And it looks like about two-thirds of our audience have replied. We’ll give people a few more seconds. Okay, I'm going to go ahead and close this out and share those results. Seventy-one percent have experience recruiting participants, 46% experience recruiting women Veterans specifically, and 21% do not have experience recruiting participants. So thank you to those respondents, and I will turn it back to you, Dr. Dichter.

Dr. Melissa Dichter: Okay, great. Thank you. That’s great. So we have a number of people who have experience with participant recruitment, and we know from our previous poll that many of you on the call today are researchers. So I will share with you some of our experiences of recruitment, particularly for our second of three aims of this particular study. And in this study, what we were interested in doing is recruiting women VA patients who had experienced past-year intimate partner violence. We had two VA study sites. We were looking to enroll at least 80 patients per site for a total of 160 patients, and we were enrolling participants to complete a structured interview in person with a member of the research staff on site at the VA at a baseline time period and a follow-up six to nine months following the baseline.

We had our initial recruitment strategy as most of you know. This is something that you put into the grant application several months, if not years, before you actually start your recruitment and your data collection. So in our initial recruitment strategy that we had outlined in our grant application and in our IRB protocol, we had determined that we would recruit participants through provider referral using a clinical reminder system and also have flyers available for patient self-referral.

So because we were interested in female identified patients who had experienced intimate partner violence in the past year, we wanted to take advantage of a screener for intimate partner violence that was in use universally for female patients at both of these study sites. And the screener was through a clinical reminder in the VA electronic health record system. So our plan was that we would add a button to the clinical reminder that if a patient screened positive, the provider would then say there’s a study you might be interested in, you might be eligible for. Is it okay for a member of the research team to contact you to tell you more about the study? And then we on the research side would have the information about the patients and their contact information so that we could contact them and tell them more about the study. This required and we succeeded in getting the clinics and the clinicians to agree to do this, and we felt it was important to have this provider referral system through the clinical reminder because we wanted to make sure that we had the women Veterans’ agreement before we contacted them.

In other studies, it is possible to identify patients through some characteristic that is identified in their health record. For example, we could have gone into the health records data and identified women with a documented positive screen for past-year intimate partner violence. But we felt that that sort of felt ethically inappropriate for us for the study population. We’ve done a lot of work with interviewing women who have experienced intimate partner violence and talking to them about the screening and the clinical process. And we anticipated that it wouldn’t feel right to many patients to contact them without their previous permission to say, oh, we see you’ve screened positive for past-year intimate partner violence. We want to tell you about the study. So we really wanted to make sure that the person clinically to whom they were disclosing this information would be getting their approval before we reached out to contact them. And then we also had flyers available so that patients could just contact us directly. And now I'll tell you about how and why our plans changed and what ended up ultimately working better than this initial strategy.

So as I said, our initial strategy was to have this provider referral through the clinical reminder system. The barriers that we encountered were that in one of the study sites, we had a local clinical reminders committee. And adding that button to the clinical reminder, even though the clinic had already agreed to this and IRB had already approved this, the clinical reminders committee, after months and months of back and forth, ultimately determined that they were not willing to approve this request to add this button to the clinical reminder. So we weren’t able to have that added so that the provider could click a button and directly send to the research team information that the patient approved our contacting them.

In the second study site, there was significant local staff turnover in the clinic that prevented the implementation of a modified reminder, so they had approval to modify the reminder, but there were just local implementation barriers. So we had to regroup and figure out another strategy. Without that clinical reminder button, we were still relying on provider referral, but we didn’t have that prompt to prompt the providers to remember to ask the patients for their approval, nor did we have a direct way for the providers to communicate that approval back to us in the study team. So that became a bit of a challenge. What it required is that providers would, if they remembered to ask the patient and if they got the patient’s approval, they could cosign the research team on a note or they could contact us directly with the information.

But we didn’t yield a lot of participants through that strategy, so we regrouped again and moved on to strategy number three, which involved in-clinic recruiting directly from the research team. So for this strategy, research team members took shifts in the clinic waiting room, and this was specifically in our Women’s Health Clinics at these two sites. And so we had research staff sitting in the waiting room and being available to introduce patients to the study, tell them about the study, and then if patients were potentially interested, we would collect their contact information and then contact them to follow up with more information. The benefit of this strategy is that it didn’t depend on the provider being involved in the recruitment process at all or telling the patients about the study or connecting us with the patient, so it really reduced or eliminated that burden on the provider. It allowed for that direct connection between the research team and potential participants, so research team members could directly tell people about the study. Providers didn’t have to be well informed about the study.

And then we had an added bonus that our eligibility criteria was women who had experienced past-year intimate partner violence. And so this allowed us to reach out to people who may have had this experience but weren’t necessarily screened or didn’t necessarily disclose as part of their clinical visit.

The challenges of this approach is that it was very time intensive for research staff taking shifts actually sitting in the waiting room. Also having this open waiting room area presented a challenge to having private conversations about sensitive topics, especially if patients were there in the waiting room with partners or others. We didn’t want to introduce the study to them at that time.

So we went on to a fourth strategy, and this strategy involved direct outreach via letters to patients. So for this strategy, we mailed letters to female patients who had a past-year visit at the particular VA facility, and we mailed these out in batches of one to two hundred every two to three weeks. So every two to three weeks we would take a batch of potentially eligible patients, female patients who had had a past-year visit and send them a letter saying that there was a study for which they might be interested and eligible and inviting them to contact us if they wanted to opt out of being contacted. They could also contact us to opt in or learn more about the study. And we let them know in the letter that if we did not otherwise hear from them within following a two-week period that we may reach out to them directly. So then we would follow up with a phone call to those patients who had not already contacted us.

The benefits of this strategy is that it was a much more flexible and efficient use of research staff time. So although there was considerable research staff time invested in doing the follow-up telephone calls and some time involved with putting together and sending out the mailings, it wasn’t sitting in the clinic waiting room waiting for patients to come in and approach us. There was also a bonus of having a much wider pool of potential participants because this didn’t depend on people who were actually coming into the clinic on the days that we happened to be sitting there, but we could reach out to a much wider pool.

It still remained labor intensive for research staff, and it required connections by mail and telephone, so whereas it didn’t require the patients to be coming into the medical center for a visit at the time of recruitment, it did require that we could reach patients by mail and telephone. And so if patients had moved or we didn’t have an adequate address or telephone number, then we would not be able to reach them through this method.

Throughout all these methods, however, the other methods remained open in terms of providers could still continue to refer patients to the study, and patients could also self-refer based on flyers posted in the clinic.

So I want to share with you the results that we found from our direct mail letter approach, and I'm able to share this with you because we had very deliberately tracked everything that happened in this process so that we could assess and report on how this went for us. So we mailed a total of 3,449 letters. Remember we mailed these out in batches of one to two hundred and kept doing new batches until we met our recruitment targets. Of those, a total of 116, so 37 in site one and 79 in site two, were returned to us. That means that the postal service returned the envelopes to us saying could not be delivered to intended recipient. So those 116 we know did not reach those patients. It’s possible that other letters also didn’t reach patients, but they were never returned to us, so we don’t know that. So we assume that the rest of them at 3,333 letters were received by the patients. Of those, a total of 105 contacted us to opt out before we would have a chance to contact them. That was 9 people in site one who called us in response to receiving the letter and said no thank you, please don’t contact me further. In site two, we had 96 who contacted to opt out. And the difference between those two sites is in site one they had to call us by telephone to opt out, and site two they could e-mail, send back through snail mail, or use the telephone to reach the research team.

So we had a remainder of 3,227 patients to whom we attempted to contact by telephone, and we reached about half of those. So the other people who we didn’t reach, it’s because it was the wrong number or the number was disconnected. In some cases we left a message and were never able to make contact with the patient, and the message was relatively vague about following up about a letter for a research study. And there were other instances when we did actually reach a patient by telephone, but they said it’s not a good time and call back later, and we never managed to really make that contact with them to talk to them about the study and screen them for eligibility for the study.

So we reached 1,589 women to screen them for eligibility for the study, and 90.7% of those whom we reached by telephone were either not eligible or not interested. In most cases, they were not eligible because they hadn’t experienced past-year intimate partner violence or didn’t disclose their experience of past-year intimate partner violence. In other cases, they simply weren’t interested in participating whether or not they were eligible. So that got us to our total of 148 people who were scheduled to participate in an interview for the research study, so it was 67 at site one and 81 at site two. Not all of those who were scheduled ended up completing the baseline interview. Some people didn’t show up for their appointments. We had an expected no-show rate.

So these are results of our ultimate sample composition by these different research strategies. We not only met, but we actually exceeded our recruitment target. So in site one we enrolled 89 participants and in site two we enrolled 83 participants, and our original targets were 80 for each site. But to get there, this extended our research timeline by eight months, so we had to go back and readdress our timeline and do a project modification to do this.

From our provider referral strategy, which was our initial strategy, though minus the clinical reminder button, that yielded six participants in site one and none in site two, so we didn’t have any provider referrals to the study for our second study site. The flyers or self-referral yielded another six in site one and just one participant in site two. The in-clinic recruiting where we had research staff sitting in the waiting room, we yielded 30 participants in site one and 20 in site two, so that was much more successful than the other strategies, but really the letters were what sort of drove our recruitment home for the study. So from our letters, we enrolled 47 participants in site one and 62 in site two. And we could have, if we had needed to exceed those numbers, we feel confident that we could have done so because we still had a larger pool of patients to whom we could have sent letters.

So I want to talk through some lessons learned and some take-away points before we get into some Q&A and discussion here. In this study we found that direct research team outreach to the patients had real benefits for our study. It eliminated the workflow barriers that were dependent on relying on the clinical staffing and provider participation, and it allowed the research team to directly present the study information to the patients. We found that the patients were open to discussing their experiences of intimate partner violence in the research context and motivated to help others by contributing to the research. So by doing this direct outreach, we also found that we had lots of opportunities to hear anecdotally from our women patients about potentially participating in this research study. We had a number of patients who were not eligible but who said, “Thank you so much for doing this important work. I think this is really important.” People who said, “I haven’t experienced this in the past year, but I did experience it prior to that, and I would be happy to participate in a research study about it.”

The direct letters and outreach through mail and telephone have that added benefit of being able to reach people who weren’t necessarily coming into the medical center during our study timeframe. But because all of our data collection was in person at the medical center, these individuals were willing to come in for a research study visit, and most of them did so.

What we really learned from this study is that it’s really important to plan for the unexpected, to build flexibility into your timeline and processes, including time for IRB amendments, to always remember to expect that research recruitment is going to take longer than you originally anticipate, and to research what the options might be and to think creatively about how you might overcome some of these research barriers.

In thinking about this, while listening to Alison and Joya’s presentation, a couple of ideas came up for me as well. One is that Alison and Joya noted that women Veterans in particular may face some reluctance to participate in research studies and may be hesitant about that. We found that once we got to really being able to speak to women Veterans, many of them were quite happy to participate in the research study. A number of women did say that they weren’t interested in participating, and that could be related to some of the themes that Alison and Joya found. But another barrier they found is being unaware of the research opportunities. So again, doing that direct outreach really helped to be able to provide information about research opportunities to the women Veterans. And even though we had flyers posted, we had found in this and other studies that people may or may not see the flyers, but for many people, there will be a barrier to taking that next step to actually proactively reaching out in response to a flyer who may be willing to participate or learn more about a study if there is direct outreach from the research team.

However, all of these strategies really depend on the approval from all of our various stakeholders, and I'm thinking now that maybe we should have marketed this Cyberseminar more specifically to our IRB partners and administrators because that’s where we also see variations across VA facilities and some barriers that get imposed at that level. Joya and Alison talked about recruitment from outside of the VA setting, for example, and looking at community-based settings, and we sometimes face challenges there with our IRB and regulatory guidelines to being able to reach out to people in other settings beyond our VA walls.

I know that this direct outreach approach that worked for us in our two study settings doesn’t always work in all facilities. In some facilities the IRB does not approve researchers being able to directly reach out to participants and requires that the participants have to opt in rather than opt out of being contacted. So I think these are all ideas to think about and that as a community we might consider how this research from both of these presentations today can inform maybe the refinement or development of other protocols and IRB and regulatory processes for participation. I think that we find that women Veterans are often quite interested in participating in research and that if we can do things like also finding approved ways for recontacting participants to share research findings and to engage our clinical partners in more specific ways, that can help overcome some of the barriers to the recruitment and enrollment of women Veterans.

So this is just a summary of our take-aways and recommendations, and now I want to be sure to leave time for questions and discussions from the group.

Molly: Thank you very much. So for our attendees that joined us after the top of the hour, to submit a question or comment, please use the GoToWebinar control panel located on the right-hand side of your screen. Down towards the bottom is a question section. Just click the arrow next to the word questions. That will expand the dialogue box, and you can submit your question or comment there.

The first question we have came in for Joya. Does the point of providing Veterans with research findings include member checking to ensure we have the correct data?

Joya Chrystal: Molly, I'm sorry. Would you mind repeating the question?

Molly: Sure. Does the point of providing Veterans with research findings include member checking to ensure we have the correct data?

Dr. Alison Hamilton: Do you want me to take a stab at that, Joya?

Joya Chrystal: Yes, Alison, would you mind [inaudible 45:12]?

Dr. Alison Hamilton: No problem. It’s Alison speaking. I mean I think it could. I think that’s something that would definitely have to be built into one’s IRB protocol. And it may be a little bit different of a phase of the research process where you might want to engage in member checking during your analyses, during your analytic phase to make sure. For those who don’t do qualitative method member checking, it’s something that’s often used to, as it suggests, check with the people who participated in the research to see if they concur with your interpretation. It’s a very deliberate and intentional process that you, again, would need to make sure is part of what you have explained to the IRB in terms of how you’re contacting your participants and what you’re asking them to do. What we heard about in these interviews was a little bit further along the trajectory of the research process in the sense that what we heard a lot, and we’ve heard in other studies as well, is some frustration that once we’ve gotten what we need, so to speak, as researchers in the interviews or whatever the data collection approach is, then they never hear from us again. And they don’t know what we learned from the research, what the impact of the research was, and that they feel kind of left in the dark and potentially frustrated that they don’t know what the value and importance and impact of their participation was.

So I definitely see them as potentially related and complementary efforts in terms of member checking and dissemination, but they might be different processes in terms of how you’d lay it out in a protocol. And you might not have the bandwidth in every project to do the member checking. But of course if you can, it’s always really, really interesting and informative and potentially can take you in new directions with your interpretation.

Molly: Thank you for that reply. We have a comment that came in. I’d like to say that this was very interesting and a helpful seminar, and it will help me greatly with my recruiting strategies. Thank you to that submitter.

The next question: Have you noticed a significant difference between the response rates and willingness to participate between male Veterans and female Veterans?

Dr. Alison Hamilton: Melissa, do you have thoughts on that?

Dr. Melissa Dichter: So I don’t because all of the studies that I have done at the VA have only included female participants. I do think we hear anecdotally often from the women that they are glad that there are studies that are specifically focusing on women Veterans and their experiences. But I don’t have data to say how that might be different from men.

Dr. Alison Hamilton: I mean it’s actually, this is Alison. It’s actually an interesting empirical question, and I don’t have an answer from my research either, per se. I mean I think one of the main considerations and one of the main efforts that we’ve been undertaking in the Practice-Based Research Network is to really ensure that women are being contacted for participation and research and being asked to partner in research efforts. And part of the issue has been that there are just so fewer women at any given facility than there are men, but I don’t know of efforts that have really looked at or compared efforts to recruit men and women to see if it’s more difficult to recruit one group or another, and I think it’s a fascinating question. I’ll keep thinking about it. I feel like there’s something I'm forgetting, but at the moment I'm thinking that we don’t necessarily have the answer to that really good question.

Molly: Thank you for those responses. When recruiting women Veterans, did you ask to keep their name on file to see if they are interested in participating in further research studies?

Dr. Melissa Dichter: This is Melissa. We did not ask for their permission to do that. I think one of the challenges there, again, is that it comes down to IRB approvals. And we’ve gotten the message that something like that in many cases would not be approved, that the IRB, at least in our experience at our site, does not want to give a blanket approval to be able to contact people again about future studies. We do find, though, that when we have women Veteran participants in studies, we often have women asking about possibilities of other studies. Are there any other studies that you have going on? Sometimes women themselves have asked could you contact me in the future if there is something else? I think a theme that we’re seeing coming up is that part of the challenge and a large part of the challenge in recruitment is not necessarily people saying I don’t want to participate, but their not even knowing about the opportunities for participation. And so one of the take-home points is finding these strategies for being able to do things like that, to have information that we can get to individuals about opportunities for participation.

Dr. Alison Hamilton: Yeah, I agree with those points, Melissa, and we’re trying in a lot of our studies to build in the possibility for consent to reach out for future research opportunities. We are asking in our provider studies if providers are willing for us to do that. So we successfully managed to get that into our IRB protocols, and we’re working on it for studies that involve women Veteran participants. So there’s two parts of it that we’re looking at. One is to see if they’re willing to be contacted for future studies, and two, to see if they are willing to be contacted with the results of the studies to really respond to that finding about needing more information about what happened as a result of the participation. So I think the way we’ve been approaching it is to try and to adapt whatever our approaches are to the specifications of the IRB but to put it out there, to put the opportunities out there for participants to consent to what they want to do and not to consent to what they don’t want to do.

Dr. Melissa Dichter : Yeah, I that’s really important. We’ve, sorry, just to say also we’ve heard from our Veteran Advisory Board that they’re also really interested in knowing about study findings and results, and that’s been something that we’ve also been trying to figure out is how we best then recontact folks for dissemination.

Molly: Thank you. This question is a follow-up to that, so you may have already answered it. So even if you put that question and a contact number in the consent form, the IRB would not approve it? What about a registry so you can contact them?

Dr. Alison Hamilton: So this is something, this is Alison, something that I’m really interested in learning more about and talking with our VACO partners about what’s possible. And I don’t know yet what’s possible. I'm very interested to find out. I know there are many others working in the Veteran engagement base that are thinking about this and working on it as well. So in some studies that I've done more so outside of the VA context, you have a locater form where we get different pieces of contact information if the person consents to being contacted again. I think something like that would probably be necessary if a registry were to be possible. But again, I don’t know sort of what the parameters are of what would be possible, but it’s something that a lot of us are really actively working on.

Molly: Thank you. That is the final pending question we have at this time, but we’ve got a few minutes. We can wait for more to come in while you ladies give any concluding comments you’d like to make. In no particular order, Alison, we can start with you.

Dr. Alison Hamilton: Well, actually one of my comments is geared toward Melissa. I wanted to have a whole conversation with you, Melissa, because it was really interesting to me that one of the things that we found in talking with Veterans and providers and administrators was the importance of the warm hand-off from providers and staff to women Veterans. And it was interesting in your study that that yielded no participants. So I didn’t know, sorry I'm asking a question, Molly, instead of wrapping up, but I didn’t know if you had any observations about maybe it was the subject matter of the research or that was just an interesting kind of point of divergence between a suggestion that was made pretty consistently in our interviews but one that didn’t really pan out so much in your study.

Dr. Melissa Dichter: Yeah, I think it does depend in part on what the study is about. This was an interview study, not an intervention study, and so I think you could have very different findings if you have a study where you’re offering a particular intervention for something. And the provider comes across a patient who might benefit from that intervention is one thing. But I think we can do a better job of partnering with our clinician partners for research purposes. Our clinicians, especially our primary care clinicians and women’s health clinicians, they’re so busy and they have so many things going on. I think we would have gotten a better yield if we had had that button on the clinical reminder because that would have been much easier for them, and that’s what they preferred. But I think if we can maybe better empower that relationship to do that warm hand-off to studies, I don’t think the clinicians are opposed to it. I think it’s just another burden and challenge for them often.

Dr. Alison Hamilton: Yeah, it’s really, really interesting, and I hope that the audience found it useful to kind of hear these different vantage points on increasing engagement and participation, and just, again, thank CIDER and HSR&D for the opportunity to share this work. It’s really great to hear about your work, Melissa. And of course I think I speak for all of us in thanking the Women’s Health Practice-Based Research Network and Susan Frayne and Diane Carney for really facilitating the work that we’ve been doing in the Women’s Health Research Network. But, Melissa, any parting thoughts from you?

Dr. Melissa Dichter: Just thank you again everyone for being on this webinar today and for the important work that the PBRN is doing in particular and the Women’s Health Research Network and Consortium. And I think we all welcome just the kind of networking and reaching out and sharing ideas within the VA research community, so please feel free to contact us with any follow-up or questions or brainstorming or ideas moving forward.

Molly: Thank you. We do have a couple last-minute questions that came in and a few minutes if you ladies are willing to get those in. First one: Have you tried using social media for recruitment like Facebook, Twitter, organizational pages, or other social media sites?

Dr. Alison Hamilton: We haven’t, but we’re looking into that. And it’s definitely been a really excellent suggestion from Center for the Study of Women Veterans, or Center for Women Veterans, sorry, and Kayla Williams, the director of that center. It’s something we should look into, and I think the key will be to do it in a way that meets the IRB requirements. But it’s really a strong direction that we want to go in.

Molly: Thank you.

Dr. Melissa Dichter: This is Melissa. I have not, just to say I have not recruited through social media, but it is another good option.

Molly: Thank you. We just have one last comment. Many of the women who have participated in my research have expressed a desire to hear the results as you were describing. When you say that it is something that you are figuring out, do you mean with regard to the IRB approval? I wonder what would be acceptable to report back to participants or if there would be ethical issues around providing results of one study.

Dr. Alison Hamilton: So one of the things that we’re looking into is just the format for sharing results, like for example, there are a few studies that have looked at like a trifold brochure with, of course, just aggregated results across the study, so sort of key points, key things that were learned from the study, sending that out to participants. That’s one thing that’s actively going on in a few different studies. We’re looking at the possibility of creating an infographic in one of our studies to send back to our participants with just things that we learned and the direction that the research is taking as a result of what we learned. So I think, and there are many examples from the broader engagement community. PCORI examples, other types of examples outside of VA of really, really creative ways that studies and investigators have gone about getting results back to their participants, town hall meetings, things like that. So there are some really active ways to do that just depending on how accessible your participants are and the ways that they’ve agreed to be contacted. So I think this has also been a topic in some of the Veteran engagement, different platforms that we’ve had over the past couple years. So we can just keep working on trying to pull that information together and making sure that it gets to our HSR&D community. And hopefully people will add in their ideas and efforts in this area as well.

Molly: Well, thank you all very much for coming on and lending your expertise to the field. We do have a few remaining comments, but I will allow, they are pretty specific, so I will allow those women or ask those submitters to please contact you all offline to discuss them further.

With that, I want to thank our attendees for joining us, and I'm going to close out the session in just a moment. Please wait while the feedback survey populates on your screen. It’s just a few questions that we’d like to ask and get your responses on. And we do look closely at those, so please take the time to answer those few questions. Once again I'd like to thank our presenters, and this does conclude today’s HSR&D Cyberseminar. Have a great day everyone.

[ END OF AUDIO ]