# U.S. DEPARTMENT OF VETERANS AFFAIRS AIRBORNE HAZARDS AND OPEN BURN PIT REGISTRY

VETERANS/SERVICE MEMBERS FOCUS GROUP DISCUSSION GUIDE (90
MINUTES)
2019-2020

#### **RESEARCH OBJECTIVES**

- 1. Explore Veterans/service members perceptions of VA and the Airborne Hazards and Open Burn Pit Registry to understand the context/background of any future outreach.
- 2. Gather feedback from Veterans/service members on their awareness of and barriers/facilitators to registering.
- 3. Gather feedback from Veterans/service members on current and/or proposed messages, materials and distribution channels related to the Registry.

#### **SCHEDULE**

Date	Location	Venue	Type of Group	Local Time
TBD	Washington, District of Columbia	TBD	Engagers with the Registry	TBD
	Washington, District of Columbia		Engagers with the Registry	
	Washington, District of Columbia		Eligible but not engaged with the Registry	
	Oceanside, California		Engagers with the Registry	
	Oceanside, California		Engagers with the Registry	
	Oceanside, California		Eligible but not engaged with the Registry	

Fayetteville, North Carolina	Engagers with the Registry
Fayetteville, North Carolina	Engagers with the Registry
Fayetteville, North Carolina	Eligible but not engaged with the Registry
San Antonio, Texas	Engagers with the Registry
San Antonio, Texas	Engagers with the Registry
San Antonio, Texas	Eligible but not engaged with the Registry
Norfolk, Virginia	Engagers with the Registry
Norfolk, Virginia	Engagers with the Registry
Norfolk, Virginia	Eligible but not engaged with the Registry
Tacoma, Washington	Engagers with the Registry
Tacoma, Washington	Engagers with the Registry
Tacoma, Washington	Eligible but not engaged with the Registry

#### INTRODUCTION (10 MINUTES)

Thank you for joining us today. I'm [NAME] and I'll be moderating today's discussion.

We're gathering feedback from Veterans and Active Duty service members about the Department of Veterans Affairs (VA) Airborne Hazards and Open Burn Pit Registry. We appreciate you taking the time to speak with us today.

The Paperwork Reduction Act of 1995 requires me to notify you that this information collection is in accordance with the requirements of that Act under OMB Control Number [ENTER HERE]. The public reporting burden for this collection of information is estimated to average 1.5 hours per response. You may send comments regarding this burden estimate or any other aspects of this collection of information, including suggestions for reducing this burden, to the VA Clearance Officer (005E3), 810 Vermont Avenue, NW, Washington, DC 20420. Your participation has no effect on any benefits to which you are entitled.

As we move through the discussion, I'd like you to be open and honest. There are no wrong answers. It's okay to disagree with one another; I want to hear a range of opinions, so speak freely. Please remember to respect the opinions of others in the group and to stay on-topic. I am not a medical professional and we won't be sharing any of our private medical information today. If I've heard from a few people I may ask others to chime in or move on if needed so I can be sure to hear from as many people as possible.

This meeting is being recorded by my colleague, [NAME], but for our analysis only. As outlined in the Participant Agreement form that everyone signed, we are part of an independent third-party contractor team working with VA to conduct this research. Your personal identifying information will not be shared with VA.

Let's get started with a roll call and hear a little bit about each of you.

Tell us your first name (no last names please), what branch of the military you serve or served in and your favorite hobby. Please also let us know any first-hand experience you've had with open

burn pits during deployment, keeping in mind that we will not be sharing private medical information here.

(The moderator will briefly reintroduce herself in this format to give respondents an idea of what they should say. Then, the moderator will go around the circle, prompting each individual attendee to provide their introduction.)

Thank you all for those introductions.

Okay, I think we're ready to get started.

## PART 1: SOURCES OF HEALTH CARE INFORMATION AND PERCEPTIONS OF VA (15 MINS, 25 MINUTES ELAPSED AT END OF SECTION)

Our first topic of discussion will deal with where and how you get information on health care.

- 1. When you are looking for general information about your health care options such as looking for a specialty doctor or facility where do you turn? (*Listen for: method of searching for information, publisher of the content*)
  - a. For those who answered "online," how do you begin your search? Where do you go first?
- 2. When you're looking specifically for health care information for symptoms or a condition you feel may be service-related, where do you turn?
- 3. Which of these sources of information on health care options we've just discussed do you find reliable or unreliable, trustworthy or untrustworthy? Why?
- 4. What typically motivates you to search for health care information (remember: no specific medical details, we're just speaking in general)?
- 5. **For Veterans who are enrolled in VA health care**: When you are looking for information specifically related to VA health care services and resources, where do you go?

- a. For those who answered "online," what specifically do you do? (probe: specific websites/sources, how participants conduct their searches, etc.)
- b. Are you familiar with online VA health care services such as My HealtheVet or VA mobile apps? (If so, probe briefly for information on how they use MHV or VA apps for health care information)
- c. (For those who did NOT answer "online", probe to understand why not, i.e.:

  Quicker or more reliable for them to make a phone call, they don't trust information found online, etc.)

#### 6. For Active Duty service members or Veterans NOT enrolled in VA health care: If,

while searching for health care information, you come across information from VA (such as a VA webpage or flyer), what would you think? (*Listen for: trust, applicability, etc*)

- a. Do you feel that health-related services provided by VA apply to you?
- b. Would you click on the search result or read further in the flyer/poster, etc. if you saw that it was put out by VA? Why or why not?

### PART 2: AWARENESS OF AND BARRIERS/FACILITATORS TO REGISTERING (30 MINUTES, 55 MINUTES ELAPSED AT END OF SECTION)

Thanks so much for that input. So now we're going to switch gears a bit and talk specifically about the Airborne Hazards and Open Burn Pit Registry, which I'll just call the "Registry" from here forward.

#### 7. Can I get a show of hands:

- a. Who had heard of VA's Airborne Hazards and Open Burn Pit Registry before being contacted for this focus group? [Non-engager groups only]
- b. Who had entered their basic information to check their eligibility for the Registry?

  [Non-engager groups only]
- c. Who had never heard of the Registry? [Non-engager groups only]
- d. Who has completed the online questionnaire AND done the optional medical exam?
- e. Who has completed the questionnaire and requested the medical exam?
- f. Who has completed the questionnaire but has not done the medical exam?

- g. Who has started but not completed the questionnaire? Why not?
- h. Who has entered their name into the system and is still in the eligibility check phase or hasn't begun the questionnaire for any reason?
- i. If anyone remains who hasn't raised their hand, ask him/her how far they made it in the registration process.
- 8. Do you remember how you first became aware of the Registry? *Probe to understand who came across information passively (where, in what form, etc.) vs. who actively sought out information, why (no medical details) and how that process unfolded.*

#### [Moderator will ask questions and probes based on the composition of each group.]

- 9. Great. What were you hoping or do you hope to achieve through registering?
- 10. And did you begin registration (or the eligibility check) right away, after you were made aware of the Registry?
  - a. If so, what motivated you to begin?
    - i. Did you already have the required logon credentials?
  - b. If not, did you see/hear about the Registry again after that? What motivated you to eventually begin registration?
    - i. Did you already have the required logon credentials?

#### **ENGAGED GROUPS:**

- 11. For those who started but have not yet completed the questionnaire or for those who paused between starting and completing it, can you remember why you stopped? Was there something in particular that you got hung up on?
  - a. About how long ago did you begin the questionnaire and stop?
  - b. Do you plan on going back and picking up the questionnaire where you left off?
  - c. Before today's discussion (or being contacted by our research team), had you heard about or thought of the Registry since taking a break from the questionnaire?
  - d. And, without getting into any private medical details, have you brought up open burn pits with a medical provider?

- i. If so, did you feel that they were knowledgable about the Registry or open burn pits in general?
- ii. Was the provider a part of VA, a Tricare provider or someone else?
- **12.** For those of you who have started or completed the questionnaire (regardless of completing the medical exam or not), can you remember any particularly smooth or difficult parts of the questionnaire or process that stand out in your mind?
  - a. What did you like about the "smooth/easy" parts?
  - b. How did you make it through the more difficult parts?
  - c. Did you stop and go back to the questionnaire later? If so, about how many times?
  - d. About how long did it take you to complete from start to finish (including leaving and going back to it)?
  - **e.** If you could give a fellow Veteran or service member advice on completing the questionnaire (*probe for:* what to have handy in front of you, better or worse to take breaks, etc.) what would you tell him or her?
- 13. For those who have completed the questionnaire but NOT the medical exam (whether or not it was requested): Again, avoiding any private medical details, was there any particular reason that you decided not to do the optional medical exam?
  - a. (Only if anyone raised their hand for "e" during show of hands) For those who answered **yes** to the question about wanting to see a health care provider after completing the questionnaire...
    - i. If so, what happened (or did not happen) that kept you from having the medical exam?
  - b. And for everyone who has NOT completed the medical exam: Was it clear to you how to schedule the exam, who would conduct it, where you would have to go, etc.? (probe to see if their understanding is correct)
  - c. Was it clear to you that the exam cannot be scheduled with your regular **non-VA** primary care provider?
  - d. For Active Duty service members or Reservists: Did you have any concerns about getting the medical exam? (*Probe for concerns relating to health issues getting back to their Commanding Officer/DoD*)

- e. And, finally, without getting into any private medical details, have you brought up health conerns related to open burn pits or other airborne hazards with a medical provider?
  - i. If so, did you feel that they were knowledgable about the Registry or open burn pits in general?
  - ii. Did you speak to the provider about the Registry/open burn pits before or after beginning registration?
  - iii. Was the provider a part of VA or a Tricare provider?
- 14. **For those who have completed the questionnaire AND medical exam**: Avoiding any private medical details, what motivated you to opt-in to and schedule the exam?
  - a. What did you think of the process of scheduling and preparing for the exam? (*Probe to understand how they scheduled it- already enrolled in VA health care and went through their primary care provider or PACT, contacted their local Environmental Health Coordinator, etc.*)
  - b. Did you feel that the clinician who provided the exam was knowledgable about the Registry, your responses to the questionnaire, or open burn pits in general?
  - c. What were your overall impressions of the exam? (probe for impressions of the helpfulness, new information learned)
  - d. Did you feel that your questions or concerns were addressed?
  - e. Did you leave the exam with a clear idea of next steps? (*Listen for: engaging primary-care provider on topics from the exam, etc.*)
  - f. Would you recommend the exam for others signing up for the Registry? Why or why not?
    - i. What would you tell others who are not sure about getting the exam to help them decide?
- 15. Now that we've discussed your experiences with the Registry a bit and refreshed your memories, I want to ask again: What were you hoping or do you hope to achieve through registering?

- 7. Without getting into any private medical details, have you had any concerns related to airborne hazards or open burn pit exposures during deployment?
  - a. (If anyone answered yes) Again, without medical details- Had you ever spoken to a health care provider about your concerns?
  - b. If so, was this a VA health care provider? Tricare?

#### **ALL GROUPS:**

- 8. Have you heard about or discussed open burn pits with non-VA or non-DoD sources such as friends, colleagues or groups?
  - a. If so, where have these discussions occurred or who put out these communications (e.g.; VSOs, fellow Veterans/service members by word of mouth, family, etc.)?
  - b. If you can remember, what was the gist of what you've heard about open burn pits from these non-VA/non-DoD sources?
  - c. For those who had already heard of the VA Registry: Do you feel like the things you've heard about open burn pits outside of VA/DoD are consistent with or go against what you've heard from VA/DoD?
    - i. If you've heard things that are different what kinds of contradictory information have you heard and from whom?
    - ii. When you hear things that are different than what VA/DoD is telling you, who are you more inclined to believe? Why?
    - iii. When you hear things that are different, do you have a trusted source that you go to to figure out what to believe?

PART 3: CURRENT AND/OR PROPOSED MESSAGES, MATERIALS AND DISTRIBUTION CHANNELS (30 MINUTES, 85 MINUTES ELAPSED AT END OF SECTION).

Thank you so much for all of the great feedback so far. In this final part of the discussion, I'm going to be asking for your opinions on some materials I'll be showing you. Remember: There are no right or wrong answers; I'm not testing your knowledge, but rather understanding how you perceive VA's communications materials as we work to improve them.

[NOTE: The first nine focus groups will review existing materials and language. The final nine focus groups will incorporate testing of updated materials and language. The questions themselves will follow the same format.]

Moderator will distribute and/or display on a large screen a visual aid: Fact Sheet "10 Things to Know About Burn Pits" (can be found in PDF format here:

https://www.publichealth.va.gov/docs/exposures/ten-things-to-know-fact-sheet.pdf)



- 16. Just off the top of your head, what is the very first thing you notice or that comes to mind (thoughts or feelings) when you see this 3-page fact sheet?
  - a. What stands out to you, whether in a positive way or negative?
- 17. **For those who have not seen this before:** Where would you expect to find a fact sheet like this?
- 18. Does anyone remember seeing this before today? If so, where?
- 19. Would you be likely to read through the entire thing (or did you read through it, for those who have seen it before?)?
- 20. If you came across a printed copy, would you take one with you (or save a digital copy to your computer/device)?

- 21. For those who have at least begun to sign-up with the Registry: Reading through this, do you feel like it accurately represents your experiences with the Registry? Why or why not?
- 22. What might you change about this fact sheet if you were asked to re-do it? This can be related to content, format/layout, amount of information or whatever you feel could be improved.
- 23. Let's look at #2 here in the lower right-hand side of the first page that refers to the research.

## 2. RESEARCH ON THE HEALTH EFFECTS OF BURN PIT EXPOSURES SPECIFIC TO VETERANS AND SERVICEMEMBERS IS LIMITED CURRENTLY.

At this time, there is conflicting and insufficient research to show that long-term health problems have resulted from burn pit exposure. VA continues to study the health of exposed Veterans. The registry is just one of several research projects currently underway.

The high level of fine dust and pollution common in Iraq and Afghanistan may pose a greater danger for respiratory illnesses than exposure to burn pits, according to a 2011 Institute of Medicine report.

- a. Without overthinking: What is your gut reaction to this section?
- b. Apart from on this fact sheet, does this information look/sound familiar to anyone, either from other VA materials or any other source?
- 24. And finally, I'd just like to draw your attention to #7 in the lower-right hand corner of the second page.

### 7. YOU CAN SIGN UP FOR THE BURN PIT REGISTRY IN THREE EASY STEPS.

Just head here: <u>veteran.mobilehealth.va.gov/</u> <u>AHBurnPitRegistry/#page/home</u>.

Step 1: Check your eligibility.

Step 2: Complete and submit the online questionnaire.

Step 3: Print and save your completed questionnaire for your records.

Veterans who are eligible for the registry are also eligible to obtain an optional no-cost, in-person medical evaluation (note this is not a disability examination).

- a. Reading this section, how important do you feel that an optional no-cost, in-person medical evaluation is for you?
  - i. (For those who haven't had the exam) What would you hope or expect to gain from this medical evaluation based on this fact sheet?
  - ii. Would you have any concerns or reservations about opting-in to this medical evaluation?
  - iii. And for Active Duty Service Members/Reservists: Does it seem like you are eligible for the medical evaluation from what's written here?

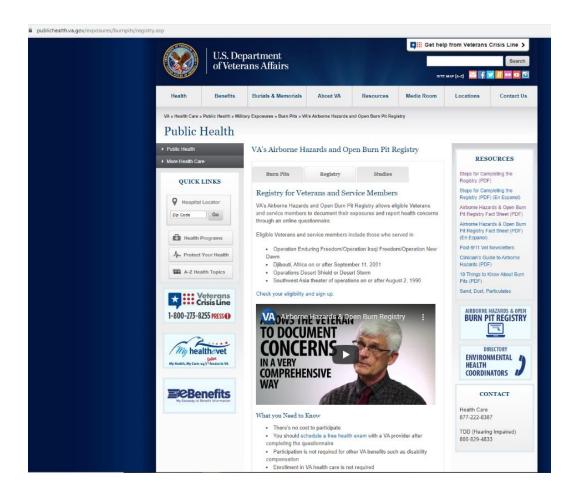
Thanks so much for all of that feedback. We're going to look at a video this time. The video is only four minutes long. If you could direct your attention to the screen... and then we'll talk about it and hear your thoughts. <a href="https://www.youtube.com/watch?v=Yrl63ipqZ5M">https://www.youtube.com/watch?v=Yrl63ipqZ5M</a>



(Moderator to repeat questions 16-22 above, tailoring to video instead of print)

#### If there's time:

Thanks so much for all of that feedback. We're going to look at one final thing which is a webpage. This is a static version, so we won't be able to click around, but I'd like to get your opinions on this page itself (<a href="https://www.publichealth.va.gov/exposures/burnpits/registry.asp">https://www.publichealth.va.gov/exposures/burnpits/registry.asp</a> "Registry" tab).



- 25. I'd like to get your first impressions of this page, imagining you had just landed on it when looking for or being directed to information on the Burn Pit Registry. [*Probe for aesthetics, organization, formatting, amount of information, etc.*]
  - a. Looking now at the content: Let's focus on this section, "What you Need to Know." Does anything that's written here jump out at you? [Probe for potential sources of confusion such as answers being based on recollection, not military records, the free health exam with VA provider, etc.]

#### What you Need to Know

- · There's no cost to participate
- You should schedule a free health exam with a VA provider after completing the questionnaire
- Participation is not required for other VA benefits such as disability compensation
- Enrollment in VA health care is not required
- Answers should be based on your recollection of service, not on your military records
- · Family members are not eligible to participate
- Your participation contributes to research on airborne hazards and health, which helps improve the quality of care for Veterans
- b. And still in this section, what comes to mind when you see that "Your participation contributes to research..."? [Probe for positive or negative reactions and feelings about the word "research" itself and what they think it entails, privacy concerns, etc.]
- c. Thanks for that. And finally, we can see that there are two videos on this page. For reference, the first is about 3 minutes long and the second is about 4.5 minutes long. Do you think you'd be inclined to watch one or both of these videos? [*Probe for why/why not, what they would hope to get from a video on this page...*]

#### PART 3 FINAL QUESTION FOR ALL GROUPS

26. So we've seen an example of a printed fact sheet and a video [and a website]. Are there other ways that you like or would prefer to receive this kind of information? [Probe for other formats/styles, delivery options such as email or postal]

#### CLOSING EXERCISES (10 MINUTES)

Thank you all so much. I really appreciate all of your feedback today as we enter the homestretch. So just one more topic of discussion.

27. As we've seen in these flyers and promotional materials and as we've talked a bit about, there are different reasons to sign up for the Registry. I'd like to hear YOUR reasons, either to join or not to join. [WHITE BOARD] I know that we all do things for lots of reasons, but if you had to choose YOUR #1 reason for signing-up with the Registry, what would it be- I'll go around and get everyone's answer individually and then we'll talk about them.

Great- thanks so much for that. (*Moderator will review results*.) Now let's talk a bit about these different priorities and which ones resonate with you, and also, any other motivators to sign-up with the Registry that were maybe second or third on your priorities. [Also listen for: Any reasons mentioned by others that some people don't feel are convincing or important- probe for reasoning.]

28. And finally, I'd like to just finish up with a little activity. We've covered a lot of ground today talking about open burn pits, VA's Registry and their communications having to do with the Registry. Now, to bring it all together, I'm going to pass around these cards. I want you to imagine that a military/Veteran friend of yours mentions the Burn Pit Registry. They ask you if you think it's worthwhile to sign up. I'd like you to fill in each part of this card with your answer on what you would *think*, what you might *feel* and what you would *say* to them out loud. These can be single words or short phrases. Whatever gets across what comes to your mind. [Moderator to invite free discussion of the activity, including any differences the participants notice in their thoughts, feelings or responses. Collect the cards for later analysis.]

(5)	Po l	I would think	
	I would	feel	
	$\supset$	I would say	

#### CLOSING (2 MINUTES, 90 MINUTES ELAPSED AT END OF SECTION)

Thanks so much for all your helpful feedback. We covered a lot of ground today and your input will be extremely useful to VA's Airborne Hazards and Burn Pit Registry Team. Before we leave today, does anyone have anything else to add or anything that occurred to them after we had already moved-on from a section or question?

Thank you for sharing your thoughts with us.