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WOUNDED WARRIOR PROJECT
STATEMENT FOR THE RECORD
SENATE COMMITTEE ON VETERANS' AFFAIRS
UNITED STATES SENATE

HEARING ON

"TOXIC EXPOSURE: EXAMINING THE VA's PRESUMPTIVE DISABILITY DECISION-MAKING PROCESS"

SEPTEMBER 25, 2019

Chairman Isakson, Ranking Member Tester and distinguished members of the Senate Committee on Veterans' Affairs – thank you for inviting Wounded Warrior Project (WWP) to submit the following testimony on "Toxic Exposure: Examining the VA's Presumptive Disability Decision-Making Process."

Wounded Warrior Project is transforming the way America's injured veterans are empowered, employed, and engaged in our communities. Since our inception in 2003, we have grown from a small group of friends and volunteers to an organization of nearly 700 employees spread across the country and overseas delivering over a dozen direct-service programs to warriors and families in need.

While we are primarily an organization that assists post-9/11 wounded, ill, and injured service members (and their families), the issue of toxic exposure is a cross-generational problem, and we are proud to advocate for all veterans affected. We understand that for thousands of men and women who served, environmental and chemical hazards have carried real and potential health risks. Accordingly, WWP has a strong interest in Congress' work on studying and addressing any harm to veterans that may have been caused by toxic exposure illnesses related to service.

A significant number of post-9/11 service members and veterans (like their Vietnam era counterparts), seem to be suffering from uncommon illnesses or unusually early onset of more familiar diseases like cancer. It appears that exposure to contaminants such as burn pits, toxic fragments, or other hazards typically seen on overseas deployments, are emerging as common threads among veterans who are sick, dying, or already deceased. We believe there is likely causation between deployments of the last 18 years and illnesses as noted above. While we are currently focused on deployment exposures, we are also aware of the challenges service members face regarding possible exposures stateside. Debates in scientific and medical communities have not reached consensus on the relationships between certain toxic exposures and presumed health outcomes which is why the issue must be further researched.

These concerns were the impetus behind recent WWP partnerships with the Tragedy Assistance Program for Survivors (TAPS), Burn Pits 360, and Vietnam Veterans of America (VVA) to bring forth public awareness and investigate the harmful effects of toxic exposures in the military. To date, WWP has invested

$620,000 in these partnerships to address the needs associated with toxic exposure. These funds help drive the mission to bring awareness and advocacy to service members, veterans, and survivors seeking access to the care they need and benefits they deserve.

To further raise awareness and improve collaboration across the community, WWP has led the formation of a new veteran and military toxic exposure working group called the Toxic Exposure in the American Military (TEAM) coalition. The TEAM coalition includes 15 Veteran Service Organizations (VSO) and Military Service Organizations (MSO) all addressing toxic exposure issues. Members of TEAM include, WWP, Burn Pits 360, Cease Fire Campaign, Hunter Seven, Iraq and Afghanistan Veterans of America, Military Officers Association of America, The American Legion, Tragedy Assistance Program for Survivors, Veteran Warriors, Vietnam Veterans of America, Enlisted Association of the National Guard of the United States, California Communities Against Toxics, National Veterans Legal Services Program, Vets First, and the Dixon Center. Additional organizations attend the monthly coalition meetings for broader input.

With the legacy of a decades-long struggle to deliver care and benefits to those who have or continue to suffer from the effects of Agent Orange, we strive to ensure that today's veterans struggling to receive health care are not fighting for treatment years from now. If we do not act, we may look back wondering if we should have done more sooner. Accordingly, our mission is focused on treating service members and veterans before they become critically ill through early identification and better research, which can be utilized to develop new forms of treatment.

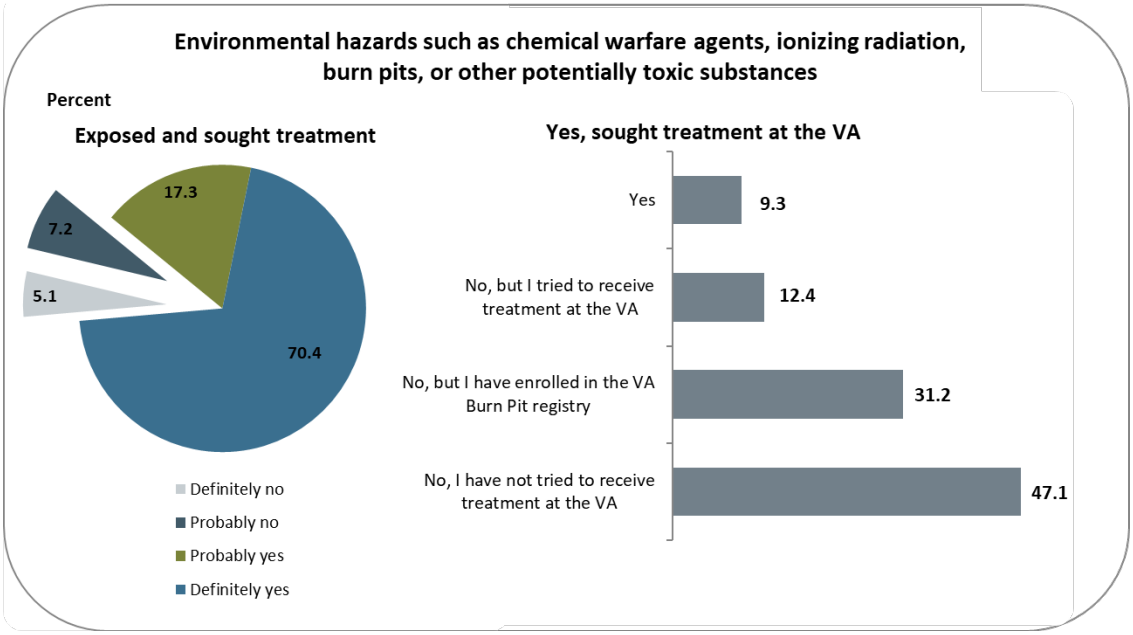
Through our testimony, we hope to highlight a host of issues we have seen regarding toxic exposure, and while the issues are broad – and the challenges great – we will be focusing on five key topic areas for this testimony that WWP considers to be the appropriate *first steps* needed to address the needs of the community. Additionally, our recommendations are informed by daily interaction with the young veterans we serve, guided through the work from the TEAM coalition, and from data captured using our Annual Wounded Warrior Alumni Survey, which is the largest and longest longitudinal survey of the post-9/11 veteran population with over 35,000 respondents and in its tenth iteration. The full results of this year's data will be released on October 29, in the Kennedy Caucus Room, but we are able to share data regarding toxic exposure for this testimony.

2019 WWP Warrior Survey Results on Toxic Exposure:

A new question in the 2019 Annual Wounded Warrior Alumni Survey asked post-9/11 wounded, ill, and injured service members about exposure to environmental hazards such as chemical warfare agents, ionizing radiation, burn pits, or other potentially toxic substances during their military service. A majority (70.4%) of Warriors reported certain exposure to hazardous chemicals or substances; however, only 9.3% said they had received treatment for their exposure at the VA. Slightly more than thirty percent (31.2%) are enrolled in VA's Airborne Hazards and Burn Pit Registry. Warriors who reported exposures were more likely to indicate poorer health. Additionally, 89.8 % of Warriors who reported their health as "Poor" or "Fair" indicated "Probably Yes" or Definitely Yes" to exposure of an environmental hazard during military service versus 81.9 % of

Warriors who rated their health as “Very good” or “Excellent” indicated “Probably Yes” or Definitely Yes” to exposure of an environmental hazard during military service.

Of those that indicated that they were exposed to environmental hazards such as chemical warfare agents, ionizing radiation, burn pits, or other potentially toxic substances during service, 9.3% stated they sought treatment at VA, 12.4% said that they did not receive treatment at VA for toxic exposure illnesses but tried, and 31.2% indicated that they have not tried to receive treatment at VA but have enrolled in VA’s Airborne Hazards and Burn Pit Registry. Although we do not clearly know why so few veterans seem to be receiving treatment at VA, our assumption is that access issues are driven by a lack of communication with veterans on this topic and the difficulty of establishing service connection for illnesses believed to be caused by toxic exposure. Whether successful in receiving VA treatment or not, it is noteworthy that nearly 22% of surveyed Warriors reported seeking such treatment.



As the conversation regarding prevention and treatment moves forward, it is important to look at the populations that legislative changes affect the most. We recommend reaching out to organizations who have original data on these populations to better understand how veterans might be affected and where lapses in care currently exist. *Please see the appendix for additional data on Toxic Exposure from our 2019 Warrior Alumni Survey.*

Below are Wounded Warrior Project’s recommendations for the Committee as it addresses the presumptive disability decision-making process.

1. Establish Entitlement to Care for Veterans Suffering from Toxic Exposure Illnesses

While burn pit exposure numbers are alarming in their own right, these numbers pale in comparison to the population of service members who were exposed to other toxins for which there is no registry. Health outcome studies such as those performed by the National Academy of Medicine and the Committee on the Assessment of VA's Airborne Hazards and Open Burn Pit Registry have shown that "not only are the emissions released by burn pits a complex mixture of various chemicals and particulates that depend on factors such as the composition of the trash burned, accelerant used, temperature, ventilation, and the burn rate, but the composition and magnitude of air pollutants on military bases in theaters of operation are also affected by a variety of other anthropogenic and natural toxicants."[1]

This is why we believe that post-service preventative health checks and treatment for those suffering from toxic exposure illnesses are a priority. As with any large scale health concern, prevention and treatment go hand in hand. While the Department of Defense (DoD) is best suited to develop prevention measures to stop exposures to toxic substances, VA is best equipped to identify illnesses and the development of treatments related to those exposures. WWP recommends VA work with DoD using the Individual Longitudinal Exposure Record (ILER), and other evidence, to develop a "High Risk" database. This database should allow identified "High Risk" veterans the ability to receive a presumptive zero percent disability rating for toxic exposure. This zero percent rating would allow veterans access to needed healthcare within the VA medical system. We ask that VA start with treatment in conjunction with a study and data collection on those who are receiving treatment for illnesses. This study and data collection, in conjunction with ILER and VA's Airborne Hazards and Burn Pit Registry, should provide researchers the data needed to develop a list of illnesses that could be presumed to be related to toxic exposures. In doing so, this addresses two of WWP's primary concerns regarding toxic exposure: (1) early identification of toxic exposure illnesses and (2) life-saving treatment for those affected.

The difficulty in developing a "High Risk" database is defining those who could be considered "High Risk." We recommend by starting with deployed service members and veterans that have rare forms of cancer or other medical conditions that fall outside the norm for their age and background. The ILER system has the ability to pull clusters of individuals based off of common exposures and units. If a unit has an unusual amount of cancer rates, this would be an indication that the entire unit is at a higher than normal rate of risk. Once these clusters are identified, notification should be sent out by DoD and VA to inform the service members and veterans that they are considered to be at "High Risk." For those who receive treatment for illnesses through DoD and VA treatment centers, it is imperative that this data is fed back into the ILER system for tracking and research. By identifying "High Risk" cohorts, compiling data on their illnesses, and administering treatment, it may help compiling the data necessary to develop a list of presumptive illnesses.

[1] https://www.ncbi.nlm.nih.gov/books/NBK436096/

2. Allow Veterans and VSOs Access the ILER System

The Individual Longitudinal Exposure Record (ILER) is a web-based application developed over the past eight years between DoD and VA that can assist in determining the linkage between individuals and possible toxic exposures while serving in the military. DoD has been proactive in reaching out to the veteran and military communities to answer questions and identify concerns from VA and key stakeholders. The system is impressive and we sincerely appreciate the work that DoD has done to demonstrate the system to the community.

ILER can create a comprehensive exposure record for individual veterans by cross-referencing available DoD data. The system links individuals with known exposure events and incidents to compile a service member's possible exposure history. This system will be accessible to DoD clinicians, VA clinicians, VA claims adjudicators, and researchers. In theory, anyone with access to the database will have the ability to download a pdf file that contains a service members historical exposure, a possible connection between exposures and different medical complications, possible illnesses attributed to these exposures, high-risk indicators, and cross-reference other service members from a unit that might also be exposed. This system is useful to researchers attempting to find and isolate specific control groups and to service members and veterans undergoing treatment.

While this system has the potential to be life-saving, it is currently unavailable for use by anyone outside the DoD or VA. Allowing service members, veterans, and their health care providers the ability to identify possible exposure risk factors before or during treatment could mean the difference between life and death. We recommend that Congress consider directing DoD and VA develop an easy to use portal that allows individuals to download their ILER information. Currently, the process for a veteran to obtain his or her record is to file a Freedom of Information Act (FOIA) request with DoD. Alternatively, it is possible for a veteran to obtain permission from VA to release the information to a private health care provider, but not directly to the veteran. We find this unnecessary and counterproductive when this could be the difference between proving service connection or not receiving health care from VA. Additionally, while VA claims adjudicators have access to the system, Veteran Service Organization (VSO) claims representatives do not have access and are limited in their ability appropriately represent veterans.

We are also concerned that this system will be available to VA claims adjudicators with little understanding of how information will be interpreted. When individuals access the ILER database, there is a small disclaimer that states that lack of information found in the system does not indicate that a veteran was not exposed. It is our understanding that each military branch collects toxic exposure information differently. We would not want differences in data collection to lead to denial of benefits and healthcare. We must be careful to ensure that VA claims adjudicators do not inadvertently use the ILER system to deny claims if sufficient information does not exist within ILER regarding the veterans possible exposure. We would recommend Congress set clear guidelines on how VA can use the ILER system when processing a VA claim for possible exposure. Additionally, we look forward to working with the Veteran Benefits Administration (VBA) on learning how claims adjudicators are being trained to access the system and interpret the information.

Lastly, while DoD has done a great job reaching out to the community, it has been difficult to understand how VA will use the ILER system and whether VA has worked with VSOs regarding their implementation and usage plan. We encourage Congress to continue oversight of the ILER system and how VA is able to utilize this system.

3. Order Additional Research into Treatment and Causation

While working collaboratively with the TEAM coalition, WWP was able to identify common trends in existing research and delineate paths for future studies. The need for research can be broken down into two separate issue areas: (1) research into treatments and (2) research into causation. It is important to note the difference between research for treatment versus research for connection between exposure and illnesses. Research into treatment should encourage greater focus on genomics studies in order to ascertain the best treatments and expand predictive medicine for veterans. Research into causation should be focused on how different exposures relate to different illnesses.

Research for Treatment:

We recommend that VA perform a study on how to develop better treatment options for those affected by toxic exposure. Specifically, we would like VA to implement a national screening, treatment and research program within a Center of Excellence, preferably VA's Airborne Hazards and Burn Center of Excellence (AHBPCE), under the direction of the Deputy Under Secretary of Health for Policy and Services. One area of focus we would recommend looking into would be lung cancer screening and how to expand VA's ability to identify lung cancers. The incidence rate of lung cancer among veterans (137 per 100,000) is more than double that of civilian rates (54.9 per 100,000)[2] due primarily to higher smoking rates and exposure to known and suspected carcinogens during service.

Lung cancer develops slowly and rarely exhibits obvious symptoms until the late stages when survival rates drop to 5%[3]. Screening those at high risk with CT scans before symptoms appear can shift diagnosis to early stage. Since the National Cancer Institute's 50,000-person National Lung Screening Trial in 2010, multiple international screening randomized controlled trials – including the Belgian-Dutch NELSON trial[4], the MILD trial in Italy[5], decades of population screening in Japan[6], and the 20-year International Early Lung Cancer Action Program (I-ELCAP)[7] study, all show that between 50% and 80% of those diagnosed at early stage by CT screening will have long-term, recurrence-free survival.

Therefore, WWP recommends legislation authorizing the Deputy Under Secretary for Health for Policy and Services to develop and validate protocols and quality controls for simultaneous screening and management

[2] https://seer.cancer.gov/csr/1975_2016/browse_csr.php?sectionSEL=15&pageSEL=sect_15_table.05
[3] https://seer.cancer.gov/statfacts/html/lungb.html
[4] https://www.ascopost.com/issues/october-25-2018/nelson-trial/
[5] https://doi.org/10.1093/annonc/mdz117
[6] https://www.auntminnie.com/index.aspx?sec=sup&sub=cto&pag=dis&ItemID=124046
[7] https://www.ncbi.nlm.nih.gov/pubmed/30511179

of other findings, including, specifically, baseline and follow up CT scans to document and validate cohort and case-controlled studies of those exposed to burn pit emissions and other known and suspected carcinogens.

Research for connection between exposure and illnesses:

Wounded Warrior Project realizes that a barrier to care at VA, for health issues believed to be from toxic exposures, is proving an illness is related to service and as a result of toxic exposure. In order to fill gaps in research about the relationships between burn pits and other toxic exposures and specific illnesses, WWP recommends establishing a study by the National Academy of Medicine on burn pits and other contaminants that might have affected service members deployed Outside Continental United States (OCONUS). While the National Academy of Medicine has performed reports in the past, new conclusions can likely be drawn using the new ILER data. In the past, the National Academy of Medicine listed "Limited statistical power—Small sample size in many of the studies prevents the detection of associations[8]" as a reason for not being able to connect exposure and illness. Access to the ILER data should help address this problem. We recommend this report cover current ongoing research, identification of the negative effects of exposure from burn pits and other contaminants, an estimate of how many service members might have been affected, possible ways to develop a "High Risk" list using the ILER system, and what Congress, the federal government, and the VSO/MSO community can do to assist these service members and veterans.

Additionally, new epidemiological data on the entire Post-9/11 cohort should be collected to understand exposures and current short and long-term health problems related to their military service. Wounded Warrior Project would also like to see an in-depth report on the DoD Periodic Occupational and Environmental Monitoring Summary (POEMS). These reports have a vast amount of data regarding environmental exposures in Afghanistan and Iraq. Conducting a report that can capture this data in a way that promotes informed legislative action is critical for future progress on this issue.

4. Update the Airborne Hazards and Burn Pit Registry

There are more than 165,000 veterans enrolled in VA's Airborne Hazards and Burn Pit Registry – all of whom served on or after 9/11, during operations Desert Shield and Desert Storm, or in the Southwest Asia theater of operations after August 2, 1990, and were deployed to a base or station where open burn pits were used or where possible exposures to toxic substances occurred. While VA's Airborne Hazards and Burn Pit Registry asks questions regarding exposures not related to burn pits, it can be unclear to veterans if exposure to other relevant containments is recorded in the registry due to the name. Our first recommendation would be to update the name to include or convey the idea that all forms of toxic exposures during deployments are captured.

While VA's Airborne Hazards and Burn Pit Registry is important, we are unaware of any analysis of the information being performed other than the 2016 study titled *Burn Pit Emissions Exposure and Respiratory and*

[8] https://www.nap.edu/download/13209

Cardiovascular Conditions Among Airborne Hazards and Open Burn Pit Registry Participants[9]. We recommend VA's Airborne Hazards and Burn Pits Center of Excellence conduct a comprehensive report on information that is being captured and any trends that have been identified.

Lastly, WWP recommends Congress pass H.R. 1001, the *Family Member Access to Burn Pit Registry Act*, which will direct the Secretary of Veterans Affairs to provide a process by which a family member of a deceased individual who is eligible for the Department of Veterans Affairs burn pit registry may register for such registry on behalf of the deceased individual. While we support H.R. 1001, we understand that it is important to keep datasets clean; however, we feel that it is still important to track this information. Therefore, allowing family members to add information to a file while keeping the original data safe from alteration still allows researches to identify trends, and expands the data to include those who are deceased. We feel this additional language should be considered if H.R. 1001 were to be addressed in the Senate. We also feel that feeding this information back into the ILER system and developing "High Risk" cohorts could save lives in the long run. A proactive approach VA and DoD can take is to track which veterans have passed away, from what type of illness, identifying clusters, and reaching out to other members of that unit.

5. Provide Training for Clinicians

Recently, WWP had a post-9/11 wounded warrior attend a medical examination for difficulty breathing, with the examination conducted by a VA contractor. During the medical assessment, the veteran reported that he was never asked about possible exposures to burn pits or other contaminants. Proper training and identification of possible "High Risk" veterans go hand in hand. WWP recommends VA develop a training module on questions VA providers and VA contractors should ask veterans at the beginning of an exam to help identify a possible "High Risk" veteran. This would include adding questions to the exam questionnaire, training to probe for additional information regarding types of exposures, and training to inform veterans of resources available to them. For instance, research has shown that there is a possible connection between chemicals that were inhaled by service members while deployed and a higher risk of chronic bronchitis or chronic obstructive pulmonary disease[10]. If VA clinicians are not trained on the types of symptoms that may be common to different toxic exposures, then there is a risk of misdiagnosis. Sometimes it can be as simple as asking "were you ever stationed near a burn pit?" to get both patient and provider to think more critically about toxic exposures.

CONCLUSION

Wounded Warrior Project's mission is to honor and empower wounded, ill, and injured veterans, service members, and their families. We have seen increased health complications for a young population that should be generally healthy. We cannot ignore obvious correlation between certain toxic exposures and illnesses with no reasonable explanation for onset. We do not have the resources to adequately answer these questions alone

[9] https://www.ncbi.nlm.nih.gov/pubmed/27218278
[10] https://www.ncbi.nlm.nih.gov/pubmed/27218278

and rely on our partners, both in and out of Congress, to help understand why we have seen an increase in rare cancers and other illnesses. We believe it is in large part to toxic exposure. This is not only related to those deployed overseas but also encompass Per- and Polyfluoroalkyl Substances (PFAS) contaminants, Camp Lejeune water contamination, burn pits, and many other exposures. We will continue to advocate for all generations of Warriors who are dealing with medical complications due to toxic exposures and urge Congress to take action as each day that veterans are denied proper medical diagnosis and treatment is another day that could mean life or death.

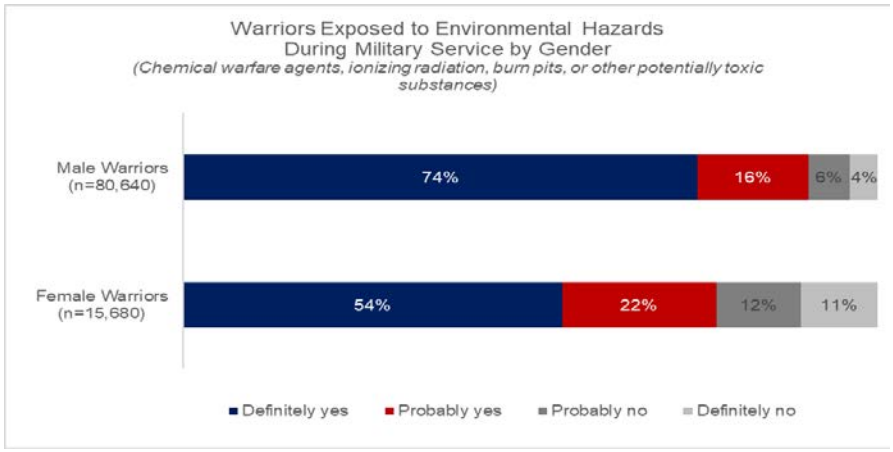
Wounded Warrior Project thanks the Senate Committee on Veterans' Affairs, its distinguished members, and all who have contributed to the discussions surrounding today's hearing. We share a sacred obligation to serve our nation's veterans, and WWP appreciates the Committee's effort to identify and address the issues that challenge our ability to carry out that obligation as effectively as possible. We are grateful for the invitation to submit this statement for the record and stand ready to assist when needed on these issues and any others that may arise.

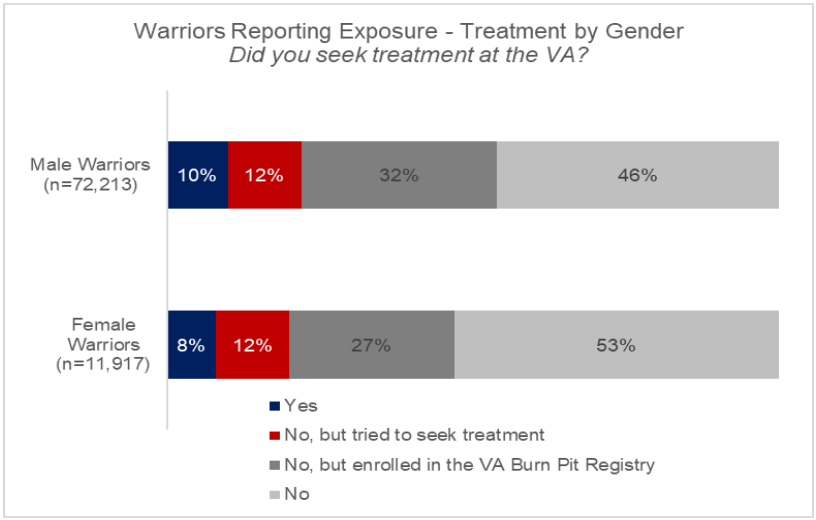
Appendix:

2019 Annual Warrior Survey
Toxic Exposure Information by Demographic Variables

A higher rate of male warriors indicated they had some exposure to environmental hazards such as chemical warfare agents, ionizing radiation, burn pits, or other potentially toxic substances during their military service, with 90% of male warriors reporting they were *definitely* or *probably* exposed versus 76% of female warriors.

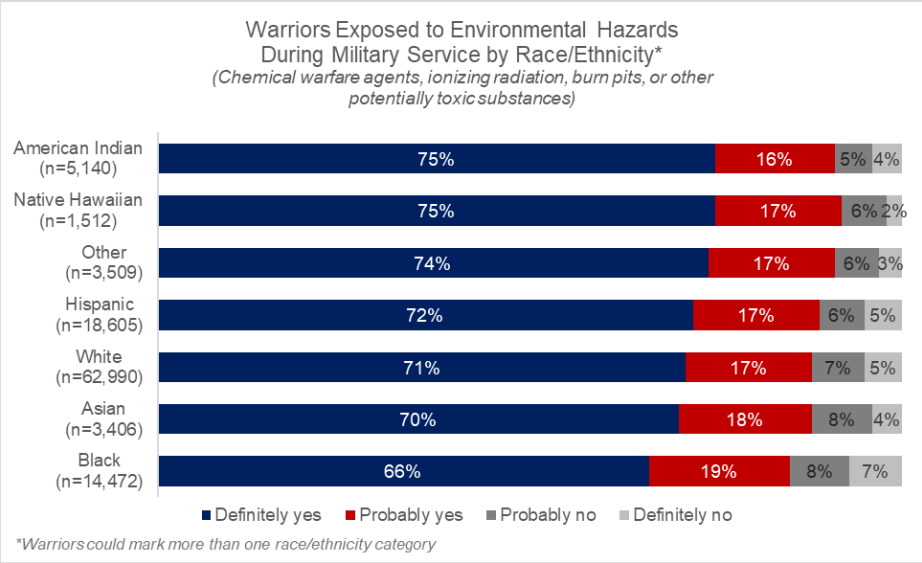
The treatment rates between male and female warriors were similar. Of those who indicated some exposure, 46% of male warriors had not received treatment or enrolled in the VA's Airborne Hazards and Burn Pit Registry, while 53% of female warriors had not received treatment or enrolled in the VA's Airborne Hazards and Burn Pit Registry.

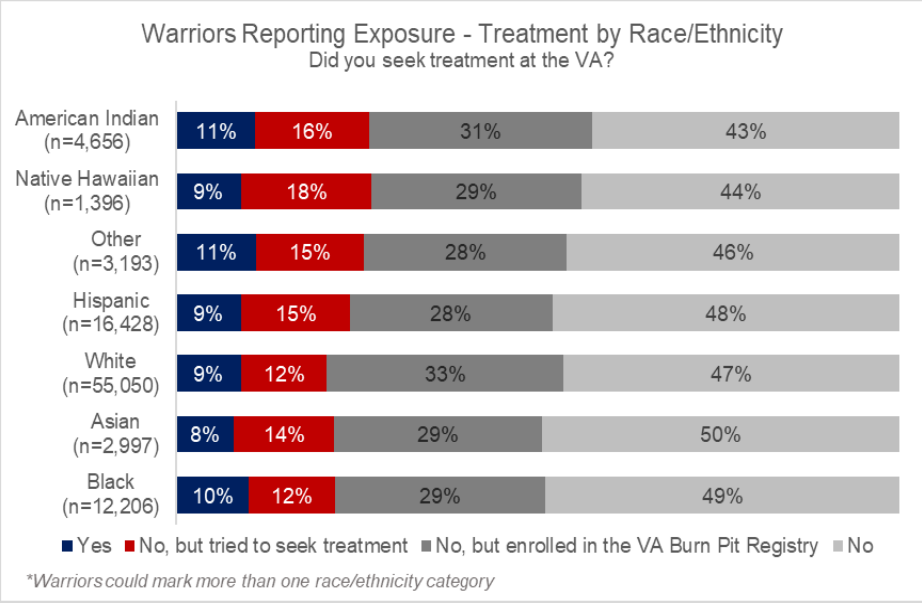




There was little variation among race or ethnicity for warriors reporting exposure to environmental hazards such as chemical warfare agents, ionizing radiation, burn pits, or other potentially toxic substances during their military service.

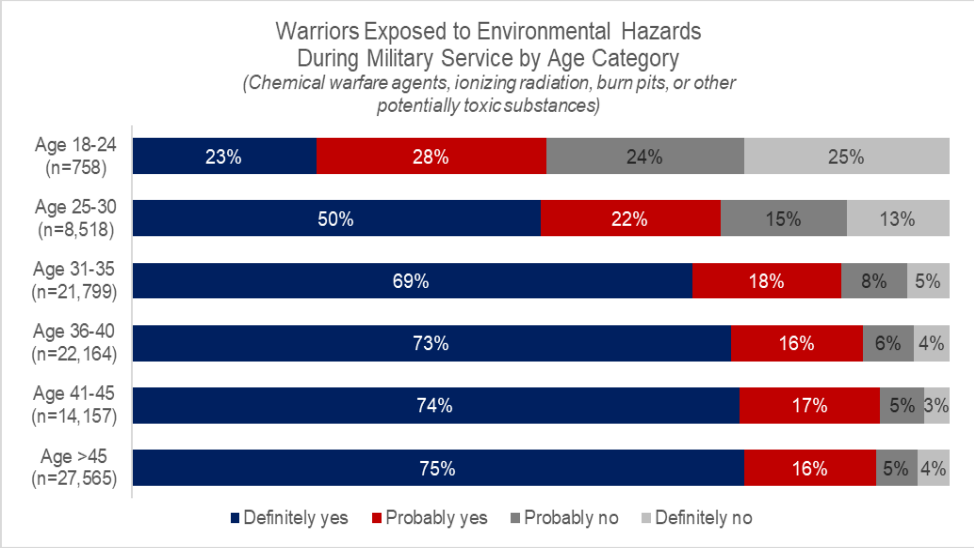
- The treatment rates among race or ethnicity were also similar.
- In the future, we will do significance testing to see if there are true differences.

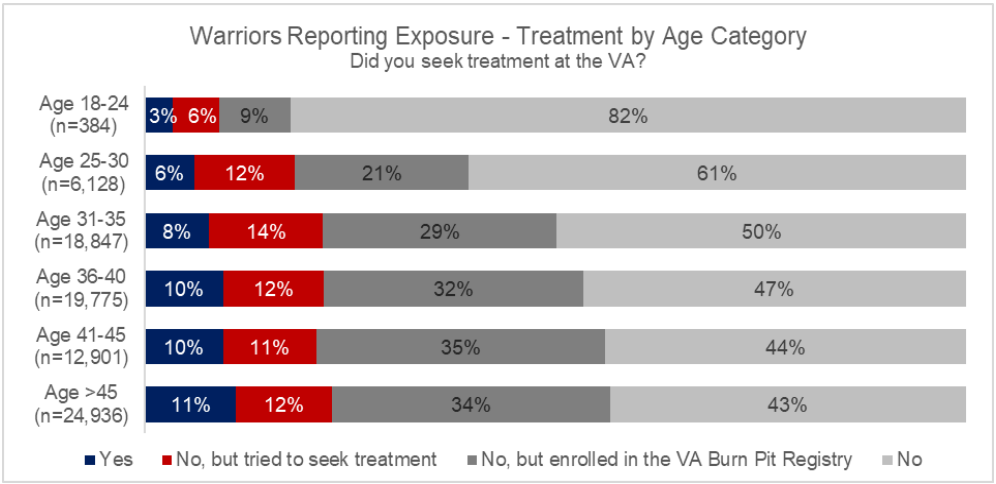




Older Warriors report higher rates of exposure to environmental hazards such as chemical warfare agents, ionizing radiation, burn pits, or other potentially toxic substances during their military service, with 92 percent of Warriors age 41-45 indicating *definitely* or *probably* yes, and 91 percent of Warriors age 45 and older indicating the same. For comparison, 51 percent of warriors age 18-24 indicated *definitely* or *probably* yes, and 72 percent of Warriors age 25-30 indicated the same.

- The treatment rates among age groups followed a similar trend. Of those who indicated some exposure, Older warriors had higher rates reporting treatment or enrollment in the VA's Airborne Hazards and Burn Pit Registry.





Perhaps not surprisingly, Warriors who reported being deployed 3 or more times reported higher rates of exposure to environmental hazards such as chemical warfare agents, ionizing radiation, burn pits, or other potentially toxic substances during their military service, with 93% of Warriors deployed three times indicating *definitely* or *probably* yes, and 94% of Warriors deployed more than three times indicating the same. For comparison, 85% of warriors deployed once indicated *definitely* or *probably* yes and 91% of Warriors deployed twice indicated the same.

- Despite the high rates of reported exposure among Warriors who deployed multiple times, these Warriors do not report high rates of treatment. A little over a third of Warriors within each deployment category have enrolled in the VA's Airborne Hazards and Burn Pit Registry (35% of Warriors deployed more than three times, 33% of Warriors deployed three times, 31% of Warriors deployed two times).