

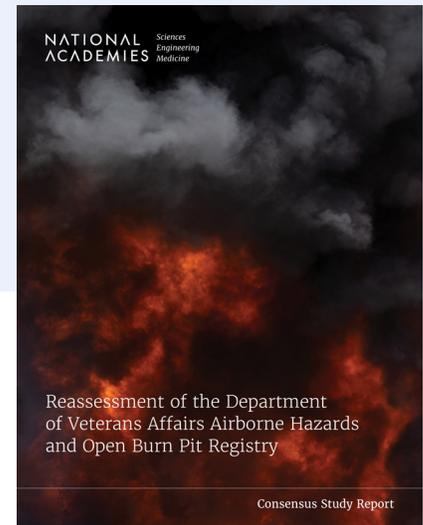
Reassessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry

Beginning with the 1990–1991 Gulf War, more than 3.7 million U.S. service members have been deployed to Southwest Asia, where they have been exposed to a number of airborne hazards, including oil-well fire smoke, emissions from open burn pits, airborne dust and sand, diesel exhaust, and poor-quality ambient air. Many service members, particularly those who served in Iraq and Afghanistan, have reported health problems they attribute to their exposure to emissions from open-air burn pits on military installations. The U.S. military has routinely used burn pits to dispose of waste, with more than 270 burn pits known to have been in operation in Southwest Asia. In 2013, Congress directed the Department of Veterans Affairs (VA) to establish and maintain the Airborne Hazards and Open Burn Pit (AH&OBP) Registry to “ascertain and monitor” the health effects of such exposures. As of July 1, 2022, more than 317,000 participants had completed the registry questionnaire, and more than 130,000 individuals had begun but not completed it.

AN ASSESSMENT OF THE REGISTRY

This report serves as a follow-up to the initial assessment of the AH&OBP Registry that was completed by an independent committee of the National Academies in 2017. This reassessment does not include any strength-of-the-evidence assessments of potential relationships between exposures to burn pits or airborne hazards and health effects. Rather, this report is an assessment of the ability of the registry to fulfill the five purposes that Congress and VA have specified for it:

- Etiologic (causal relationships) research on health effects associated with deployment exposures to airborne hazards;



- Population health surveillance to monitor the health of veterans exposed to airborne hazards while deployed;
- Improving clinical care for veterans who have health concerns related to their deployment exposures;
- Supporting VA processes, including benefits claims, and VA programs to help veterans with concerns about their deployment exposures; and
- Communications and outreach from VA to veterans, health care providers, and other stakeholders.

The committee’s findings lead it to conclude that the stated registry purposes of “research about potential health effects of airborne hazards exposures” and conducting population health surveillance are unattainable, that data collection to meet these purposes is not helpful, and that efforts to address these important functions could be pursued in other, more effective ways. The committee emphasizes that the AH&OBP Registry can be a unique and valuable resource for direct communications between veterans and VA and, indirectly, with health care providers, Congress, and other stakeholders. Therefore, the committee offers recommendations to optimize the registry’s use by refining its operations to concentrate on attainable goals and the two meaningful areas to which it can contribute: health care—especially for those enrolled in VA health care—and communications. AH&OBP Registry information could also be used to inform VA policies and procedures.

Recommendations:

The AH&OBP Registry should be ended in its current form as its stated purposes have largely been to support research and population health surveillance, neither of which it can do. The committee recommends that VA initiate a new phase for the registry that would build on key information from the first 7 years of registry operations and would be developed and implemented to optimize the registry to be a user-friendly, efficient, and effective resource to provide two-way communication between participants and VA. Implementing this new phase will require thoughtful and deliberate efforts and

careful alignment of the narrowed functions with the data collection process. Additionally, VA should ensure that this new phase provides information to enhance health care access and quality.

The current self-assessment questionnaire should be replaced with one that is shorter, more efficient, user friendly, and limited in scope to collect only information that can be used to support communication or health care.

VA should present AH&OBP Registry information in a manner that is helpful in informing the general public, Congress, and the media about participants’ collective concerns.

USE FOR ETIOLOGIC RESEARCH

To assess the registry’s ability to support etiologic research, the committee identified and applied six characteristics that an exposure registry to be used for such research should have. These include a sufficient sample size for precise estimation of causal effects; a representative sample of the population of interest; identification of an appropriate comparison population; an exposure assessment of adequate quality; a health outcome assessment of adequate quality; and identification of other contributing factors that might impact the association. The AH&OBP Registry does not have several of these characteristics, so its data are not appropriate for etiologic research on airborne hazards exposure and health outcomes. The registry has major design and data quality issues that cannot be overcome, and even substantial changes to the questionnaire would be insufficient to make the AH&OBP Registry appropriate for etiologic research.

Recommendation:

VA should support the conduct of epidemiologic studies to examine the associations between exposures to airborne hazards and open burn pits and health outcomes. The studies should be designed specifically to fulfill the characteristics needed for etiologic research.

USE FOR POPULATION HEALTH SURVEILLANCE

Although neither the registry-establishing legislation (PL 112-260) nor VA use the term “surveillance,” the

committee determined that this function is implied by the requirement that VA “monitor” veterans’ health. A population health surveillance system should meet four criteria: (1) have overarching goals to address the prevalence or incidence of a potentially harmful exposure or occurrence of a disease in a defined population; (2) conduct regular data collection, analysis, and interpretation to look for predefined signals; (3) disseminate results and information to key audiences; and (4) use the collected information to improve health.

The committee found that the AH&OBP Registry does not satisfy all four of the criteria necessary to conduct population health surveillance for veterans potentially exposed to burn pits or other airborne hazards in Southwest Asia. Given its fundamental design, refinements or improvements will not allow the registry to serve as a population health surveillance system. The committee also found that the registry is unable to simply monitor participants’ health because participation in the registry is a one-time self-assessment, and there are no longitudinal data on participants to indicate a change in health status.

USE TO IMPROVE CLINICAL CARE

Veterans are eligible to enroll in the Veterans Health Administration (VHA) for health care by qualifying for one of eight priority groups. AH&OBP Registry participation does not influence that eligibility even if the veteran has a health condition that may be related to airborne hazards or burn pits exposure. After submitting the registry questionnaire, a participant may request an optional, registry-associated health evaluation at a VA medical facility. Of the approximately 50 percent of participants who have requested a health evaluation, only about 10 percent (30,000) have received one. While the health evaluation may enhance a veteran’s knowledge of their health status, it does not improve their access to or continuity of health care.

Recommendations:

VA should expedite the receipt of the optional health evaluation for those registry participants who request one.

The Airborne Hazards and Open Burn Pit Registry Clinical Template for registry health evaluations

and the accompanying clinical guidance should be modified to ensure that the VA clinician conducting the evaluation discusses the registry participant’s military deployment and exposure history with them and documents the information in the participant’s electronic health record.

VA should simplify the scheduling of the registry’s optional health evaluation by having the VA environmental health coordinator proactively reach out to a veteran when notified of their interest via completion of the AH&OBP Registry questionnaire.

Following the health evaluation, VA should proactively schedule any necessary referrals with the appropriate VA providers for veterans enrolled in VHA to ensure that they receive the appropriate diagnoses and treatments. The committee recognizes that this proactive scheduling will not be possible for veterans who receive health care outside of VA.

INFORMING VA POLICIES AND PROCESSES

VA does not use the AH&OBP Registry for internal policy decisions beyond the standardization of registry procedures. Although improving the benefits claims process is one of VA’s goals for the registry, the Veterans Benefits Administration’s claims review process is completely separate from a veteran’s registry participation. Veterans may use the questionnaire responses and results of the health evaluation to support a disability claim, but the registry health evaluation does not replace the disability rating examination.

SUPPORTING COMMUNICATIONS AND OUTREACH

VA was required by PL 112-260 to “develop a public information campaign to inform eligible individuals about the open burn pit registry ... and periodically notify eligible individuals of significant developments in the study and treatment of conditions associated with exposure to toxic airborne chemicals and fumes caused by open burn pits.” VA has made some efforts to meet the mandate of informing eligible individuals about the registry, but it has not been consistently proactive about informing them about research developments, the treatment of conditions related to airborne hazards, or new programs and benefits.

The need for bidirectional communication is clear, not only for veterans to “speak” to VA about their deployment exposures and health concerns, but also to enhance VA efforts to notify them about new information on the diagnosis or treatment of specific conditions and provide guidance on obtaining VA health care. Notifications about deployment exposures and health outcomes could be one of the primary benefits of registry participation.

Recommendations:

VA should periodically assess whether its communications and outreach materials and activities provide value to registry participants and health care providers. This assessment may result in the expansion of the Health Outcomes Military Exposures communication strategy to capture feedback from potential or existing registry participants regarding their concerns or questions about the registry, their exposures to airborne hazards, and their health outcomes. A bidirectional communication strategy should include both written and verbal communications among VA experts, participants, and other interested stakeholders.

Communication channels other than the questionnaire that might be used include hardcopy mailed materials, virtual meetings, webinars, workshops, town halls, and a comment field on the registry’s website.

The AH&OBP Registry should serve as a roster of interested service members and veterans to provide a vehicle for them to express their concerns regarding exposure to burn pits and other airborne hazards and potential health outcomes.

CONCLUDING REMARKS

The committee emphasizes that the AH&OBP Registry can be a unique and valuable resource for direct communications between veterans and VA and, indirectly, with health care providers, Congress, and other stakeholders. The committee considers other sources and mechanisms in its report but finds that none of them allows for the self-identification of interests and concerns that are captured by the AH&OBP Registry. Therefore, the registry provides a function that must be preserved and enhanced by a new, more efficient, and impactful phase of the registry.

COMMITTEE TO REASSESS THE DEPARTMENT OF VETERANS AFFAIRS AIRBORNE HAZARDS AND OPEN BURN PIT REGISTRY DAVID A. SAVITZ (Chair), Professor of Epidemiology, Brown University School of Public Health; JOHN R. BALMES, Professor of Medicine Emeritus, University of California, San Francisco, and Professor of Environmental Health Sciences Emeritus, School of Public Health, University of California, Berkeley; MICHELLE L. BELL, Mary E. Pinchot Professor of Environmental Health, Yale University; MICHAEL J. DANIELS, Andrew Banks Family Endowed Chair, Professor, and Chair, Department of Statistics, University of Florida; MARIANTHI-ANNA KIOUMOURTZOGLOU, Associate Professor of Environmental Health Sciences, Columbia University Mailman School of Public Health; BHRAMAR MUKHERJEE, John D. Kalbfleisch Collegiate Professor of Biostatistics, Professor of Epidemiology, Professor of Global Public Health, and Research Professor, University of Michigan; FRANCES M. MURPHY, President and Chief Executive Officer, Sigma Health Consulting, LLC; KRISTEN M. OLSON, Leland J. and Dorothy H. Olson Professor of Sociology and Director, Bureau of Sociological Research, University of Nebraska–Lincoln; TYLER C. SMITH, Professor and Statistical Epidemiologist, National University

STUDY STAFF ANNE N. STYKA, Study Director, Senior Program Officer; ROBERTA WEDGE, Senior Program Officer (from August 2021); AASHAKA A. SHINDE, Research Associate (from October 2021); ALEXANDRA MCKAY, Senior Program Assistant (from March 2021); CARY HAVER, Senior Program Officer (through July 2021); ROSE MARIE MARTINEZ, Senior Board Director, Board on Population Health and Public Health Practice

CONSULTANTS CAITLIN CARTER, Westat; JOSEPH GASPER, Westat; CHRIS MANGLITZ, Westat

FOR MORE INFORMATION

The study was sponsored by the Department of Veterans Affairs. Any opinions, findings, conclusions, or recommendations expressed in this publication do not necessarily reflect the views of any organization or agency that provided support for the project.

To read the full report, please visit: <https://www.nationalacademies.org/burn-pit-registry>.

This Consensus Study Report is available from the National Academies Press | (800) 624-6242 | <https://www.nap.edu/catalog/26729>.

Health and Medicine Division

NATIONAL ACADEMIES Sciences
Engineering
Medicine