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

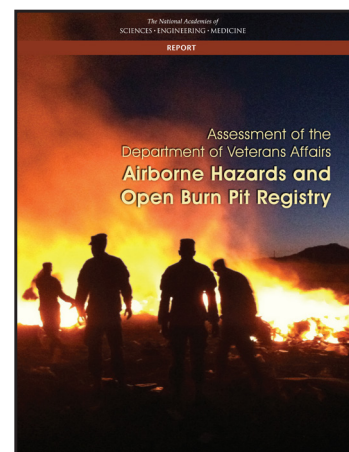
Military operations in war zones have long relied on open-air “burn pits” as a means of incinerating refuse. Concerns over possible adverse effects from this activity have grown over the past several years, and in 2013, Congress directed the U.S. Department of Veterans Affairs (VA) to establish and maintain an environmental health registry for deployed service members who may have been exposed to toxic chemicals and fumes generated by open burn pits and other airborne hazards. Congress also requested an independent scientific review of issues related to the establishment and conduct of this registry and use of its data.

Thus, the National Academies of Sciences, Engineering, and Medicine was asked by VA to convene an ad hoc committee to analyze the initial months of data collected by the registry and offer recommendations on ways to improve the registry questionnaire and best use the information it collects. The resulting report, *Assessment of the Department of Veterans Affairs Airborne Hazards and Open Burn Pit Registry*, fulfills the congressional mandate and provides conclusions and recommendations addressing other more specific questions on the registry posed by VA.

THE AIRBORNE HAZARDS AND OPEN BURN PIT (AH&OBP) REGISTRY

Registries are a relatively quick and inexpensive means of collecting and maintaining data on a group of people with a shared health condition or exposure. However, those that rely on voluntary participation and self-reported data have several intrinsic limitations. These include potential biases in the collected data that result from selective participation, misclassification of exposures or diseases, faulty recall, and other sources of inaccuracy. Such issues make them an intrinsically poor source of information on exposures, health outcomes, and possible associations among these events.

The questionnaire that VA developed to collect information from AH&OBP registrants is subject to these limitations, which are exacerbated by flaws in the registry’s structure and operation as well as in the questions that are asked and the way they are asked. The cumulative effect of the flaws is evidenced by the high percentage (about 40 percent) of respondents who initiated but did not complete the questionnaire and the number of questions that had large nonresponse rates. It’s important to understand, though, that even a well-designed and executed registry would have little value as a scientific tool for health-effects research compared to a well-designed epidemiologic study.



The best use of the registry and data it collects is to make it a means for the eligible population to document their concerns over health problems that may have resulted from their service, to bring those concerns to the attention of VA and their health care providers, and supply VA with a list of persons who are interested in burn pit exposure issues.

As such, the best use of the registry and data it collects is to make it a means for the eligible population to document their concerns over health problems that may have resulted from their service, to bring those concerns to the attention of VA and their health care providers, and supply VA with a list of persons who are interested in burn pit exposure issues. Registry data might also possibly be used to stimulate research using more sophisticated analysis means such as an epidemiologic study.

If VA were to use the registry for those purposes, the committee provides specific recommendations to improve the questionnaire as well as the data collection, administration, and management efforts.

The full text of the committee's recommendations is on page 3 of this Report Highlights. To read the full report, please visit nationalacademies.org/BurnPitRegistry.

THE COMMITTEE'S ANALYSIS OF REGISTRY DATA

The committee was limited to analyses that could be conducted using data that did not contain any personally identifiable information concerning the questionnaire respondents. This affected the types of analyses that it could conduct and the confidence of its conclusions regarding the process of data acquisition and the validity of the information reported on exposure and health outcomes. The information that was made available was derived from data collected over the registry's first 13 months. It comprised data on approximately 46,400 people, representing 1.0 percent of eligible Gulf War veterans and 1.7 percent of eligible post-9/11 veterans: a small, self-selected proportion of the registry's eligible population.

On the basis of its evaluation of the data, the committee concluded that the exposure data are of insufficient quality or reliability to make them useful in anything other than the most general assessments of exposure potential. There may be some circumstances where supplementing these data with other information might yield results that would suggest that some individuals or groups experienced greater or lesser exposures to specific pollutants. These results might in turn stimulate more detailed assessments of health outcomes in particular populations.

The committee focused its health outcomes analyses on data related to the symptoms, conditions, and diseases associated with the respiratory and the cardiovascular systems. In general, it found that the observed prevalences of respiratory and cardiovascular outcomes appear consistent with what would be expected in a population that is predominantly male, aged 25–60, and for whom about one-third report a current or former history of smoking. An examination of multiple indices of exposure to burn pit emissions and other hazards associated with deployment showed that registry participants who reported more exposures of all types also tended to report more health problems of all types. However, the committee's analyses suggest that such results may be a consequence of the population's selection and the limitations of the self-reported exposure and disease data and cannot be taken at face value. The committee wishes to emphasize that it would have reached this same determination had the analyses found no associations or weak associations between the exposures and health outcomes. A more rigorous and appropriate study design, such as a well-designed epidemiologic study, is needed to examine the relationship between the exposures encountered during deployment and health outcomes.

CONCLUSION

Attributes inherent to registries that rely on voluntary participation and self-reported information make them fundamentally unsuitable for addressing the question of whether burn pit exposures have caused health problems. Addressing the issues identified by the committee would, though, improve the AH&OBP Registry's utility as a means of generating a roster of concerned individuals and creating a record of self-reported exposures and health concerns.

All parties—service members, veterans, and their families; VA; Congress; and other concerned people—would benefit from having a realistic understanding of the strengths and limitations of registry data so that they can make best use of them and, if desired, conduct the kind of investigations that might yield salient health information and improve health care for those affected.

RECOMMENDATIONS

The committee recommends that...

...VA eliminate the questionnaire sections addressing locations of previous residences (Section 4), non-military work history (5) and home environment, community, and hobbies (6), which collect data that might only be useful in epidemiologic studies of the population.

...once VA clarifies the intent and purpose of the registry, it develop a specific plan for more seamlessly integrating relevant VA and DoD data sources with the registry's data with the goals of reducing future participant burden, increasing data quality by restructuring questions to minimize recall and other biases, and improving the usefulness of the registry database as an information source for health care professionals and researchers.

...alternative means of completing the questionnaire, such as a mail-in form or via a computer-assisted phone interview, be offered in order to ensure that the subset of eligible persons who do not use or are not facile with the Internet have the opportunity to participate in the registry.

...VA involve external survey experts experienced in Web-based instruments in any restructuring of the registry questionnaire.

...VA evaluate whether and how registrants who did not complete the questionnaire differ from those who did, analyze the determinants of non-completion, and use this information to formulate strategies to encourage registrants to finish and submit their responses and improve the completion rate for future participants.

...other means for evaluating the potential health effects associated with airborne hazards and open burn pit exposures be developed, such as a well-designed epidemiologic study.

...VA's messaging be explicit about the limitations on the ability of the AH&OBP registry to generate valid information that can be used to improve VA health and benefits programs or to inform treatment of individuals potentially exposed to burn pits or other airborne hazards in theater in order to ensure that participants and others do not form unrealistic expectations about the value of participation or the capabilities of the registry.

...VA enhance the utility of the AH&OBP registry by developing a concise version of participant's questionnaire responses focused on information that would be most useful in a routine clinical encounter and make it available for download.

...VA continue its efforts to make it easier for participants to schedule and get the optional health examination offered as part of the AH&OBP registry—such as through targeted follow-up of respondents who indicate interest—and that it investigate the reasons why such a small percentage of respondents who indicate interest in an exam (~2.5%, to date) request one.

**Committee on the Assessment of the Department of
Veterans Affairs Airborne Hazards and Open Burn Pit
Registry**

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