

September 18, 2018

Recommendations

To the Secretary of Veterans Affairs, the Research Advisory Committee on Gulf War Veterans' Illnesses (RAC-GWVI) makes the following recommendations:

- **Recommendation 1: Form a working group, to include VA's Office of Research and Development (ORD) and Post-Deployment Health Services (PDHS), tasked with identifying steps to operationalize a pilot of the *Warriors' Health-Research Network* in coordination with VA's modernization plan.** In 2016 and 2017 the RAC-GWVI made recommendations pertaining to the VA establishing a coordinated system of centers focused on integrating research and clinical care to better understand and treat complex chronic conditions of post-deployment. To help continue advancing this concept, the RAC-GWVI has suggested key features of the overall system, the national centers, and individual medical centers that would help bring research into closer proximity to clinical care, and we propose the VA call this system the Warriors' Health-Research Network. These ideas are further explained in an accompanying white paper (*Warriors' Health-Research Network: A model for an integrated health-research system*). Understanding and treating deployment-related conditions, both static and progressive over time, must be the highest priority of the VA health system and a focus area of proud distinction. There also exists a magnificent opportunity to create a new model for patient-centered care allied with research activities for chronic conditions. The long-term goal would be to have a fully integrated health-research system that has a presence nationally at specialty centers, regionally across all VISNs, and locally at each VA Medical Center (VAMC). VA already has extensive resources it can leverage to achieve this, such as the WRIISCs (national centers), existing post-deployment health clinics (VISN-level), and Environmental Health Clinicians and Coordinators (VAMC-level). Coordinating and standardizing across these resources will be key to implementing a successful system, as will investing in infrastructure to assist with data management and sharing across the VA components and with key external partners. The resulting learning health-research system

will have tremendous potential to develop, validate, and implement medical advances, which will significantly contribute to VA's modernization efforts and the goal of delivering world-class care to Veterans. A working group that involves ORD and PDHS will facilitate steady progress and support the development of a system that harmonizes the reciprocal components of a learning health-research system: research and clinical care. **The initial focus for the working group could be to develop a demonstration project focused on recruitment and retention of research participants that would be supported by ORD issuing a request for proposals (RFP). Having access to otherwise healthy Veterans who have predominant complaints of pain, fatigue, and other symptoms of interest would be invaluable to efforts to decipher the underlying biology of these vexing health problems.** Furthermore, without connection to Veterans receiving comprehensive clinical care, identifying and recruiting research participants will remain a major impediment to advancing scientific research in areas related to post-deployment health. Future areas of focus for the working group may include: building on the recent VHA Post-Deployment Health Services Needs Assessment to also consider research elements, identifying Deployment Health Champions and forming a council from these champions to interact with researchers and policymakers, selecting pilot sites among VAMCs, and engaging Veterans.

- **Recommendation 2: Ensure that the VA is able to maximize its ongoing commitment to the deep phenotyping study of Gulf War illness (i.e., project IN-DEPTH) by taking steps in the next year that make ORD well positioned to sustain the ongoing study and further extend its research findings over the long-term.** The Committee is delighted the VA has acted on the RAC-GWVI recommendation last year to partner with the National Institutes of Health (NIH) to conduct a deep phenotyping study. Project IN-DEPTH is a hypothesis-generating study and will yield a wealth of information requiring follow-up research in the years to come. Importantly, given the complexity of Gulf War illness and chronic pain and fatigue syndromes, and the advancing age of Gulf War Veterans, it is essential that research prioritize patients by aiming to understand the human biology of these disorders and therapeutic interventions to mitigate their effects; this could be achieved most expeditiously by aligning research

pursuits with clinical activities, which will also be critical to successfully recruiting Veterans to participate in Project IN-DEPTH. Ongoing support and program flexibility will be needed for the VA to make the most of its investment. Towards this end, the appropriate VA program officials should review the projected ORD Gulf War program expenditures for the next 3 to 5 years to ensure continued funding of Project IN-DEPTH until its completion. As part of its review, practices and parameters of funding Gulf War research projects (e.g., number of annual awards, award lengths, funding caps, etc.) should be considered in comparison to other VA research services and government agencies to determine policies that will enable the VA to most effectively allocate its resources. Furthermore, the RAC-GWVI feels strongly that additional funding from ORD to support new projects that may stem from findings produced by Project IN-DEPTH will be essential. ORD should consider both service-directed and investigator-initiated projects when determining future research to support. Lastly, ORD should examine whether it has sufficient access to the best scientists and research tools to pursue the highest impact studies. If found that access is lacking, **VA should consider modifying its eligibility requirements for investigators and explore policy changes that would make partnering with non-VA scientists and clinicians easier and appropriately incentivized.** It is also worth exploring if the recent VA reorganization that aligned ORD with the Office of Academic Affiliations (OAA) will bring added capabilities or if further policy changes could bolster the VA's ability to conduct the best science in service of our Veterans.

- **Recommendation 3: Pursue VA Modernization efforts with a view that VA's research mission is crucial and reciprocally beneficial to its mission to deliver world-class health care for Veterans; importantly, this principle should be applied to the new electronic health record (EHR) by developing it as a tool for both clinical and research use, which would bring tremendous potential to advance the health of Veterans.** Approaching VA clinical activities synergistically with VA research efforts would capitalize on the VA's unique position of an organization that provides health care in parallel to conducting biomedical research, thereby bolstering the capabilities in each domain. Bringing together clinical care with research enhances the ability to understand

disease, develop and validate treatments, and implement effective interventions. This also makes for a more attractive environment for physicians and scientists, and ultimately delivers higher-quality care to Veterans. The future of medicine will critically depend on using the EHR as an analytic tool that will dually support clinical care and research. The VA should take this into consideration when working with Cerner to overhaul the legacy EHR system. **For instance, the newly developed EHR should have the ability to access DoD medical records and deployment as well as support patient identification, recruitment, and monitoring of outcomes for clinical research. The current VISTA data and related databases have been a rich source for both clinicians and researchers. Importantly, the new EHR system should maintain this rich system of data and allow clinicians and researchers to have full access to these data and integrate research functionality. Additionally, full access to data from the legacy system should remain in place.** Physicians as well as researchers should be consulted when designing the capabilities of the new EHR system. The VA led in ushering in the use of electronic health records as a standard component in medical care and now the VA should strive to lead the next wave of innovation by developing an EHR that also serves as a platform to facilitate medical research.