

ADVISORY COMMITTEE MANAGEMENT OFFICE (ACMO)
Annual Assessment of Committee Activities

January 1, 2020 through December 31, 2020

Committee Name: Research Advisory Committee on Gulf War Veterans' Illnesses (RACGWVI)

Calendar Year 2020 Committee Goals: State whether the goals were fully met, partial met or not met and provide measurable results for every goal the committee management identified for calendar year

The Committee fully met the projected FY20 goals.

VA Strategic Goals: The Committee met the projected goals:

1. Committee meetings and activities. In FY20, the RACGWVI parent and subcommittee successfully held three open public meetings. The first subcommittee meeting was accessible to the public in person, on-line and by phone. The RACGWVI parent Committee meetings were held virtually due to CDC- and VA-guidelines and restrictions of travel due to the Coronavirus (COVID-19) pandemic, March 2020. Given the global pandemic, the RACGWVI Committee decided to address COVID-19 in the context of Gulf War Illness as part of the theme for the first parent committee meeting in July 2020. Although a connection between GWI and COVID-19 has not been established, Gulf War Veterans with Gulf War illness were concerned if there was increased or decreased risk for contracting COVID-19 and if their prognosis would be affected with COVID-19 infection due to chronic multi-symptom illness and key comorbidities. Invited guests presented national VA planned and in-progress research efforts related to COVID-19. This meeting also included the RACGWVI sub-committee's report from the Atlanta Veteran Engagement Session to the parent Committee, as well as invited speakers on the Depleted Uranium and Embedded Fragments cohort, Gulf War Veterans benefits, pharmacology for PTSD and a novel treatment for depression. The final FY20 meeting in November 2020 was an open meeting to discuss strategic planning for the first VA-DoD Gulf War Illness State of the Science (SOTS) Conference that was held in August 2020.

The RACGWVI Committee staff worked throughout the year organizing committee and subcommittee meetings and identifying and distributing current research alerts related to understanding and treating all health conditions affecting Gulf War Veterans to the committee members. The Committee staff also stayed in contact with Gulf War Veterans met at the subcommittee Veteran outreach meetings in person and by phone, building trust within the Gulf War community. Additional efforts were spent on logistics of converting the plans for in-person meetings to determining a VA acceptable online platform and toll-free phone line to hold the national public meetings virtually. The Committee staff also assisted the State of the Science Conference planning committee with marketing for this important conference.

2. Form a sub-committee and hold Gulf War Veteran Engagement sessions to better understand current Gulf War Veterans' health and quality of life concerns and trust issues.

A RACGWVI subcommittee was formed January 2019 to support the VA's and RACGWVI committee's mission to provide clear information, build trust, and support world class customer service. The subcommittee included the RAC Chair, DFO, committee managing director, VA-physician and a VA researcher with expertise on chronic multi-symptom illness, a women's advocate, and Gulf War Veterans. Two subcommittee meetings or "Veteran Engagement Sessions" were planned this year at the Atlanta GA VAMC and Birmingham AL VAMC. The VAMCs were chosen to bring the Gulf War Veterans to the VA, in a safe environment, where they could share their stories and interact directly with the subcommittee members. The

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listening session held in Atlanta VA in Feb 2020 allowed Veterans and their family members to describe existing and new health conditions and quality of life concerns. Other issues that arose during this in-person meeting were the inability to get needed medical equipment, Veteran homelessness, the need for greater outreach and marketing, sharing of research findings, and a need for more specialists, clinical experts and patient advocates to enhance trust and quality of care in the VA.

The subcommittee members educated the Gulf War Veterans and their families on the many historical VA-supported research breakthroughs and discussed the importance of research participation to drive evidence-based treatments and development of prognostic or disease markers. In addition, the subcommittee was able to assist these Gulf War Veterans by contacting Atlanta VAMC local resources to meet with a Gulf War Veteran who needed a wheelchair and his spouse allowing the family to get a wheelchair within 3 days of the meeting. The Atlanta VA Chaplain and Social Work service were contacted to meet with the homeless female Veterans to offer their support and resources. In addition, a Gulf War Veteran committee member commented on the need to increase outreach to women and other disadvantaged Veterans including homeless and those of color as well as LGBTQIA who she stated are also deserving of access to quality care at the VA.

3. Reports and Recommendations. New recommendations were not submitted in FY20, however information was discussed in the November strategic planning committee meeting to prepare recommendations to the SECVA. An update on FY18 recommendations is provided below.

Recommendation 1: Form a working group to operationalize a Warriors' Health-Research Network. Non-Concur. No further action required.

Recommendation 2: Commit to supporting the Gulf War Deep Phenotyping Study short- and long-term between ORD and National Institutes of Health (NIH). Concur. Actions to launch the first known VA:NIH partnership continue using intramural NIH clinical facilities. The goals are to generate data- and biologics-repository for subsequent hypothesis-driven projects funded by ORD and provide biological insights now to the scientific teams engaged in this endeavor. Regulatory documents between VA ORD and NIH are in the final stages of preparation. The scientific team is preparing the protocol package for the VA Central Institutional Review Board. In sync with the parent Committee meeting on VA and other national efforts in response to COVID-19, the protocol has been modified to ensure patient and staff safety, such as making accommodations for less direct contact (e.g. mobile phlebotomy, telehealth screening) and other novel modifications in line with COVID-19 restrictions.

Recommendation 3: Aligning ORD (10X2) with VA modernization efforts to develop a tool within the electronic health record (eHR) for VA-approved researcher access. Concur-in-principle.

VA actively utilizes integration of Gulf War research into clinical practice through the War-Related Illness and Injury Study Center (WRIISC) at its three sites. In the future VA is planning to create a research platform to access modernized electronic health care records for VA-funded researchers engaged in longitudinal and other evidence-based trials, which will overtime satisfy Recommendation 3 without the need of cost associated analysis and re-alignment. In addition, information from the VA Airborne Hazards and Open Burn Pit Registry, an important source of information on the effects of military service on health, is being reviewed to improve the Registry, develop a plan to integrate with DoD data sources, increase recruitment by encouraging participation with the Gulf War Registry, and refining the questionnaire to enhance the utility of the Registry for clinicians use in routine care and as a source for researchers. In September 2020, Gulf War and Health (Volume 12) addressed

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'Respiratory Health Effects of Airborne Hazards Exposures in the Southwest Asia Theatre of Military Operations' providing further recommendations to identify knowledge gaps and inform the research field.

4. Offer guidance on the development of the Office of Research and Development's (ORD) Gulf War Research Strategic Plan. The ORD Gulf War senior program manager has set FY29 strategic goals in line with the Chief Research & Development Officer (CRADO) and SECVA's top priorities including increasing Veterans' access to quality clinical trials, make VA data a National Resource, increase the real-world impact of VA research and building Institutional trust with the Veterans. The RACGWVI Committee's work directly addresses these goals through inviting VA-funded research and subject matter experts to describe their on-going research studies and discussing the importance of participating in research to influence health, healthcare and policy. The RACGWVI Committee presented high level summaries of federally funded research presented at the VA:DoD State of the Science Conference to determine which research would be most valuable to carry forward. In addition, the subcommittee traveled to gather input directly from Gulf War Veterans during the open meeting sessions. These Gulf War Veteran engagement sessions aim to improve communication around future research opportunities and improve participation by leveraging Veteran engagement. Speakers this year also informed the RACGWVI Committee about newly launched VA COVID-19 research projects including a deep dive study into the effects of COVID-19 on Veterans and a rapid response platform to track future infections, among other national and international partnerships in research to combat the coronavirus; mental health research related to COVID-19, and the VA's clinical response to the pandemic to keep Gulf War Veterans informed and connected.

Committee Activities:

The activities of the Committee in FY20 fully supported accomplishing its mission and aligned with VA Strategic Goals:

Goal 1: Veterans choose VA for easy access, greater choices, and clear information to make informed decisions:

The RACGWVI Committee and subcommittee efforts to engage Gulf War Veterans has reconnected Gulf War Veterans to their VA health care centers and reenergized conversations between them. This is important, as the biggest feedback we get from ODS/DS Gulf War Era veterans is the lack of trust for VA. The outreach exercise has exceeded its expectations with the Committee, preparing targeted agendas geared toward the underlying topics of Gulf War veteran health concerns, education of research, and the importance of enrollment into available Registries. Notably, we have seen a tripling of Gulf War veterans participating in RACGWVI meetings and providing feedback. Moreover, Gulf War Veterans who have participated in past listening sessions have also become champions for VA research, sharing resources and research opportunities, future RACGWVI Committee meetings and other VA research conferences and resources. The Committee was informed of other issues during the listening sessions this year, such as Veteran homelessness and lack of access to proper medical equipment and was able to connect these Veterans with local VA resources to help them meet their needs.

Goal 2: Veterans receive highly reliable and integrated care and support and excellent customer service that emphasizes their well-being and independence through their life journey.

The Committee and sub-committee are dedicated to understanding the health consequences of military service in the Southwest Asia theater of operations during the Gulf War, and the

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impact on their quality of life. Veteran engagement sessions are planned to continue in FY21. Virtual sessions are planned until VA travel restrictions due to COVID-19 are lifted. The goal is to reach Gulf War Veterans nationwide with this method until in-person contact is safe. In addition, the 30th anniversary of the first Gulf War was honored at the Gulf War State of the Science Conference and will be a highlight of the next Veteran engagement session in February 2021, the 30th anniversary of the ground war Desert Storm.

Goal 3: Veterans trust VA to be consistently accountable and transparent.

In support of the VA transparency and trust mission, the RACGWVI Chair invited subject matter experts to provide information in response to the following:

- a) Concern that the coronavirus pandemic may affect Gulf War Veterans' existing health issues or contribute to increased or decreased susceptibility to the coronavirus. Newly launched VA research was described by leaders in the Office of Research and Development and the VA Post Deployment Integrated Care Initiative. Efforts to incorporate information to identify Gulf War Veterans in new COVID-19 health questionnaires were noted.
- b) The Director of the Depleted Uranium and Embedded Fragments Cohorts gave an overview of how VA identifies at-risk Veterans, measures exposure, and the potential effects of foreign body reaction and systemic health effects.
- c) Special topic interests including the VA ketamine therapy program for refractory depression and pharmacology treatment for post-traumatic stress disorder (PTSD). VA-DoD practice guidelines were described for physical and mental disorders that are designed to inform and facilitate decision making, but not to define standard of care. It was noted more, and innovative, medication research is needed.

Goal 4: VA will transform business operations by modernizing systems and focusing resources more efficiently to be competitive and to provide world-class customer service to Veterans and it's employees.

Activities of the RACGWVI facilitating communication and understanding of Gulf War Veterans concerns, reaching out to Veterans in more rural areas and those hesitant to use the VA, contribute to this goal of providing excellent customer service and making the VA a place Veterans actively choose and trust. The RACGWVI staying abreast of current events and efforts to address research needs with the modernization of the electronic medical record will directly affect the quality of their health and health care. While travel is not an option right now, the RACGWVI Committee will reach out to Gulf War Veterans virtually to maintain flow of updated information and trust.

Reports and Recommendations: No new recommendations for FY20.

Senior VA leadership Participation: Unexpected travel restrictions and a shortened virtual meeting limited participation. The RACGWVI Committee shared VA Secretary Wilkie's prepared message at the November 2020 committee meeting and hope future travel will be allowed for senior leadership to participate in the planned FY21 in-person meeting in Washington DC if safety allows.

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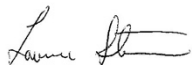
Program Office Assessment: Committee meetings have focused on different aspects of research aimed at the health problems of Gulf War Veterans. Presentations of new studies, existing Registries, and results of existing studies will inform a wide range of issues in Gulf War Veteran health. Adding questions to identify Gulf War Veterans within newly launched studies of COVID-19 will add to future information on any added or long-term effects of the coronavirus on Gulf War Illness. Opening the door to communication and information on PTSD and depression for Gulf War Veterans was a direct result of feedback from the subcommittee's Veteran engagement sessions. Quickly changing plans from an in-person national meeting to two virtual national meetings was successful with an increase in Gulf War Veteran attendance. This may be an alternative venue going forward, as necessary.

General Comments: The committee had 7 members whose terms expired. Dr. Karen Block, Designated Federal Officer and Chair, Dr. Larry Steinman of the RACGWVI, nominated 2 new Committee members, experts in the field of Gulf War and the Veteran experience. This nomination package has been approved.

Signatures:

DFO's Signature

Date



November 29, 2020

Chair's Signature

Date

Program Office Signature (SES or SES Equivalent)

Date