

Research Advisory Committee on Gulf War Veterans' Illnesses
U.S. Department of Veterans Affairs

White Paper

Warriors' Health-Research Network:
A model for an integrated health-research system

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INTRODUCTION

In 2016, the Research Advisory Committee on Gulf War Veterans' Illnesses (RAC-GWVI) recommended that U.S. Department of Veterans Affairs (VA):

Establish a national hub-and-spoke coordinated system of centers within VHA that integrates research and clinical care in a way that meets Veterans' health care needs and advances knowledge of complex chronic conditions of post-deployment. The system should have a presence at the national, VISN and local levels but function as an integrated research and care network committed to improving by continuously learning. Success will require effectively using data from disparate sources and forming strategic partnerships so that VA can fully serve Veterans in understanding and caring for post-deployment health conditions, an area where VA is uniquely positioned to lead.

To further expand on its recommendation, the RAC-GWVI produced an accompanying white paper that provided a framework for the model system. In follow-up to this recommendation, the Committee recommended in 2017 that the VA: *Commit to piloting and establishing a coordinated system of centers and expertise focused on complex chronic conditions of post-deployment and operationalize the beginning stages of such a system by 2019.* Establishing such a system would mark an important step towards integrating research with a model of stepped clinical care, which has the potential to advance research, lead to the development of new therapies, and improve veterans' access to high-quality care. Recruitment and retention of patients in research studies is much more likely to occur if the research enterprise is connected to medical centers that provide comprehensive, patient-centric care. Coupling research with clinical care can also expedite dissemination of evidence-based practices and provide a means to analyze models of care delivery. Developing an integrated health-research network will do more than modernize the VA's approach to clinical care, it will position the VA to pioneer new approaches to health care and create a model system for how a health system can develop, validate, and implement medical advances. We propose the VA call this system the **Warriors' Health-Research Network**, and in this white paper we outline suggested key features of the overall system, the national centers, and individual medical centers.

BACKGROUND

Complex Chronic Conditions Represent a Persistent and Underserved Need

Gulf War Veterans are sicker—the population of Gulf War Veterans treated at the VA tends to have more medical conditions than other Veterans or continuing servicemembers, and deployed Veterans typically have poorer health outcomes than non-deployed Veterans of the same era [1]. Although Veterans from the 1990 – 1991 Gulf War tend to be sicker, the health conditions they suffer from are not unique to that cohort and, in fact, similar complex chronic conditions are observed in Veterans and servicemembers from more recent conflicts [2, 3]. The constellation of symptoms—which may include chronic pain, fatigue, headaches, gastrointestinal issues, and mood/cognitive deficits—that these Veterans suffer from can negatively impact Veterans' lives in profound ways. These chronic conditions have been associated with work absenteeism and activity impairment [4]. Research also indicates that when pain interferes with people's daily lives it can lead to an increased risk of mortality and serve as a predictor of suicidal ideation [1, 5]. Additionally, the chronicity of these types of disorders can lead to increased risk of suicidal ideation and this can be exacerbated when combined with other complex disorders such as PTSD [6, 7]. Even headaches and migraines have been associated with increased

suicidal ideation [8, 9]. Suffering from complex conditions may also pose a risk to well-being as chronic fatigue syndrome (CFS) patients have been shown to have a significant increase in suicide-specific mortality [10]. Chronic Multisymptom Illness (CMI) is a term that covers a range of similar disorders, including Gulf War illness (GWI) and CFS, and the National Academy of Medicine (NAM, formerly the Institute of Medicine) previously offered guidance on how the VA can better approach treatment: “In changing how it treats CMI, the VA can make a significant difference in the lives of veterans who have the condition by helping to ensure they receive more integrated, comprehensive, and responsive health care” [11]. The VA has many valuable resources it can build upon, such as registries, Environmental Health Clinicians and Coordinators, a variety of post-deployment health clinics, and the War Related Illness and Injury Study Centers (WRIISCs). What’s needed is standardization, coordination, and deeper integration with research.

The VA recently named Post-Deployment Health Services (PDHS) as a foundational service, recognizing its critical role in providing care for Veterans. Importantly, demand for interfacility consults for the WRIISCs has risen over the years, going from under 500 in 2013 to about 800 in 2017, and it is estimated that there are approximately 3.4 WRIISC referrals per 10,000 Veterans Health Administration (VHA) users [12]. For the many Veterans suffering from various complex chronic conditions, there remains an unmet need of having access to high-quality standardized care that is supported by an integrated research environment and accessible at all levels of the VHA system. The VA can address this by better coordinating its research and clinical care resources as part of a cohesive network.

Opportunity for Modernization

There is a longstanding need to implement high-quality standardized care at all levels of VHA. As noted in a National Academy of Medicine (formerly the IOM) report: “VHA has developed extensive infrastructure and support for veterans who have CMI and the clinicians who care for them.... The infrastructure is remarkable and far outstrips the corresponding elements of the civilian health care system, which is generally much less developed. All those efforts notwithstanding, however, veterans who have CMI will remain seriously underserved, and their clinicians will remain unable to serve them adequately, until additional measures are put into place” [11]. Because expertise and resources are asymmetrically available and inconsistently applied throughout VHA, coordination will be key to ensure all Veterans have access to high-quality care and can contribute to research efforts and benefit from research findings. By building on its extensive institutional resources to develop a truly coordinated research-health system, the VA can leverage its strengths and enhance what it does well.

Translational research is core to the VA’s research mission and the VA is exceptionally well-positioned for this work. Moreover, VA medical centers are uniquely situated to bring together the clinical and research domains. How care is structured is a critical step to translating research into effective care. However, the unidirectional flow of information to support evidence-based medicine is insufficient, especially when aiming to care for chronically ill patients suffering from complex conditions of unknown etiologies. Research insights should not just be *applied* in the clinic, they should also be *gleaned* from the clinic in a multitude of ways. The reciprocal relationship between research and clinical care is most effective when the flow of information is bidirectional. More can be done by the VA to maximize its research resources and clinical environment to form a more cohesive system that integrates its research efforts and health care mission. Clinical encounters are key opportunities to collect data that can drive biomedical research. The VA would benefit from approaching the Veterans they serve as partners in research and clinical care. In effect, every Veteran seen in the clinic can and should

simultaneously become a potential participant in research as well. Pairing research and clinical efforts together greatly enhances the health care that can be delivered to Veterans in the near- and long-term.

Beyond the comparative advantage that VA has in integrating research with clinical care, there is a practical urgency that is incumbent on the VA to weigh when considering the best strategy for developing therapeutic interventions intended to benefit Veterans who have been suffering for decades. With the time from discovery to new drug approval taking 30 years on average [13], de novo drug development is rapidly becoming less pragmatic if one is trying to impact the health and livelihood of veterans already in their fifth decade of life. A renewed emphasis on expeditiously bringing safe and effective treatments (e.g., medications, rehabilitation, technology) to the clinic is warranted. Taking an integrated approach to research and clinical care can help identify effective therapeutic interventions and management strategies, and it also provides a means to implement validated approaches with minimal delay.

As the VA continues to take steps towards Veteran-centric care such as through its Whole Health initiative, implementing the Warriors' Health-Research Network would provide a means to bring the Whole Health model to Veterans suffering from chronic conditions of post-deployment. Furthermore, it would also create opportunities to incorporate research as one of the elements that make up the Whole Health framework. Bringing research in closer contact to the clinic and Veterans themselves impacts all parts of the Circle of Health, from more personalized care to strengthening community, which can do much to improve Veterans' health.

Benefits of Integrating Research and Clinical Care

Closer integration of research and clinical care is mutually beneficial to both endeavors.

Benefits to Research:

- Research teams closer to their foundational mission: to serve Veterans
- Identification of new research directions
- Access to data and biospecimens for analysis
- Recruitment of participants to research studies
- Opportunity to validate research findings

Benefits to Clinical Care

- Quicker validation and dissemination of therapeutic interventions
- Deeper understanding of health conditions of interest
- Greater Veteran engagement
- Improved ability to recruit and retain top physicians

Bringing together the domains of clinical care and research offers benefits to Veterans as well. For instance, it makes it easier for Veterans to volunteer for research studies, enables Veterans to get more actively involved in their care, deepens Veterans' understanding of their condition, and perhaps offers an element of hope as Veterans become aware of research dedicated to improving their health.

Importantly, closer interaction between research and clinical care creates new opportunities to translate discoveries into effective therapies. It gives researchers and clinicians alike the ability to use clinical

encounters—and the information generated from them—as a way to more fully study Veterans with complex chronic conditions. Advances in our understanding of complex conditions are more likely to come from analyses of large datasets analyzed not only at the population level but also at the level of the individual. Findings from focused research pursuits also serve as valuable complement to help determine how to implement effective treatment and management approaches in the clinic. For instance, the RAC-GWVI previously recommended that the VA pursue a deep phenotyping study of CFS and GWI in partnership with the National Institutes of Health (now called Project IN-DEPTH). This would be the most comprehensive examination of GWI and CFS to date but it is only an intermediate step towards elucidating the biological underpinnings of two vexing conditions. Findings from Project IN-DEPTH can inform the type of exam to conduct and the needed procedures at a given medical center. Therefore, the Warriors' Health-Research Network could serve as a vehicle to investigate medical issues related to deployment on a much larger scale and to arrive at a more comprehensive understanding of the biological pathways and therapeutic intervention opportunities for these heterogenous diseases. In order to achieve this, though, an integrated health-research system is needed. What follows is a discussion of key attributes at the different levels of the Warriors' Health-Research Network that will be important to its overall success.

KEY FEATURES OF THE WARRIORS' HEALTH-RESEARCH NETWORK

System-wide Focus

The overall network would align research more closely with a stepped clinical care approach, as well as educational efforts, to serve the post-deployment health needs of Veterans. The focus would be on complex chronic conditions related to post-deployment.

- Involve Veterans more broadly in research conceptualization, design, and implementation as well as dissemination of research findings.
- Collect biospecimen samples as part of standardized exam and store samples in a centralized biorepository widely available for research purposes (sample collection should be done in accordance with relevant common data elements (CDE), such as GWI CDE and with Department of Defense (DoD) research groups).
- Make clinical data available for research purposes unless the veteran requests to opt out.
- Assure coordination among research and clinical staff to support research integration into a stepped clinical care model.
- Promote ongoing research studies in regions where patients are seen or where recruiting is conducted nationally.
- Leverage resources from VA and DoD databases to identify and recruit participants for research studies.
- Link data from research studies to the participating veteran's medical records and make it available to him/her.
- Educate clinicians, Veterans, and caretakers on the latest research findings pertaining to treatments and best practices for care management.

- ***Opportunities for Implementation:***
 - ***Through collaboration of all VA offices and programs involved in providing care for Veterans following deployment, conduct a needs assessment of post-deployment health throughout the VHA system to better understand how to construct a system capable of meeting care needs and integrating with research.***

- *Issue a request for proposals (RFP) that would support a demonstration project focused on recruitment and retention of healthy and ill Veterans for research studies.*
- *Establish a biorepository that national and individual medical centers can seamlessly contribute data and tissue collection to, including from standardized clinical exams, perhaps by leveraging existing resources (e.g., Million Veteran Program (MVP) or CSP #585).*
- *Set-up a means for data sharing across the Network, perhaps by leveraging existing resources (e.g., Electronic Health Records (EHR), VINCI).*
- *Develop data sharing agreements with DoD for databases and biorepositories.*
- *Identify best practices for “contact points” between research and clinical staff that will enable coordination and collaboration between bench and bedside.*

National Centers

National centers would oversee national and regional activities as well as coordinate with Deployment Health Champions to ensure Veterans have access to high-quality research and clinical care. Centers should be at the forefront of research, convene experts to develop clinical best practices and disseminate pertinent educational and training materials informed by the latest research, and play a lead role in developing a data sharing strategy. The War Related Illness and Injury Study Centers (WRIISCs) already engage in many of these activities and could serve as a natural foundation for the national-level presence of this system.

- **Clinical and Research Integration**
 - Recruit population-based national cohort for 1990 – 1991 Gulf War veterans and more recent conflicts.
 - Contribute biospecimen samples to centralized biorepositories.
 - Coordinate with experts and draw on the most-recent scientific research and standards in the field to develop best practices for assessing and treating patients with chronic conditions of post-deployment.
- **Research Activities and Capabilities**
 - Lead primary research projects.
 - Promote research studies in the region.
 - Help manage cohorts and veteran relationships to support recruitment for future research studies.
- **Data Management and Sharing**
 - Ensures sufficient management of a widely accessible central biorepository that includes biospecimens collected from comprehensive clinical exams and research studies.
 - Ensures support of a registrar and sufficient information technology (IT) management of a central information commons/database that is interoperable with other key digital health data sources (e.g., EHR, MVP, forthcoming Individual Longitudinal Exposure Record (ILER), etc.).
 - Coordinates analytic strategy for utilizing central biorepository and data commons.
- **Key Partnerships**
 - Work with local Deployment Health Champions from relevant VISNs to develop policies and best practices informed by the latest research for dissemination throughout the network.

- Integrate with established databases and biorepositories in VA (e.g., MVP, CSP 585, Gulf War Veterans' Illnesses Biorepository, etc.), DoD, and elsewhere.
- Coordinate with Veterans and Veterans Service Organizations.
- ***Opportunities for Implementation:***
 - ***Incorporate these best practices into the WRIISCs.***
 - ***Create a national council of VISN-level Deployment Health Champions to work closely with national centers and VA Central Office to guide research and policy.***
 - ***Ensure national centers serve as MVP enrollment sites.***

VISN-level: Medical Center Exemplars and Deployment Health Champions

Engaging expertise at the local level will be critical to the success of this system. There are a number of post-deployment clinics and potential Deployment Health Champions that could help achieve a VISN-level presence for this system. This could extend to a broad number of VA Medical Centers by drawing on Environmental Health Clinicians and Champions. Collectively, these personnel would serve as hubs for relevant research, collect valuable data and samples for biorepositories, direct Veterans to appropriate care and VA-sponsored registries, and make referrals to national centers. Appropriate staffing and support would be required to enable proper coordination of local sites and communication with the national centers.

- **Clinical and Research Integration**
 - Collect biospecimen samples as part of standard post-deployment health exam and send to centralized biorepository.
 - Make clinical data available for research purposes unless the Veteran requests to opt out.
 - Create **Deployment Health Champions** to serve as experts and lead contacts for post-deployment health in the region and also become knowledgeable about current research. May eventually need about 3 – 6 Deployment Health Champions per VISN and one would serve on a national council of VISN-level champions.
- **Research Activities and Capabilities**
 - Serve as a hub for information on research studies, including promoting recruitment, within VISNs.
 - Facilitate dissemination of findings resulting from research conducted in the region.
 - Help manage cohorts and veteran relationships to support recruitment for future research studies.
- **Data Management and Sharing (Requires a Core of Dedicated Staff (Registrars) and IT Staff to assist)**
 - Contribute biospecimen samples to centralized biorepositories.
 - Adhere to good data stewardship for research and clinical data contributed to the centralized database.
 - Ensure medical centers in the VISN ascribe to good data stewardship and participation when collecting biospecimens and capturing and sharing data.
- **Key Partnerships**
 - Coordinate with other centers/clinics in VISN through Deployment Health Champion network.

- Work with relevant VA registries (e.g., Gulf War Registry Health Exam, Airborne Hazards and Open Burn Pit Registry) active in its VISN and associated personnel (e.g., Environmental Health Coordinators and Clinicians).
- Coordinate with Veterans and Veterans Service Organizations.
- ***Opportunities for Implementation:***
 - ***Identify an appropriately scaled number of local Deployment Health Champions in different VISNs.***
 - ***Incorporate into standardized exams the collection of data and biospecimens for inclusion in databases and biorepositories.***
 - ***Work with Environmental Health Clinicians and Coordinators to achieve standardization of registry exams and data management across VHA, ensuring their usefulness for research and clinical care.***

SUPPLEMENTAL I

Overview of the Veterans Health Administration (VHA)

VHA is the largest integrated health care system in the United States that as of [March 9, 2017](#) provided:

- **1,233** health care facilities,
 - including **168** VA Medical Centers and
 - **1,053** outpatient sites of care of varying complexity (VHA outpatient clinics), and
- served more than **8.9 million** Veterans each year.

The [VA Choice Program](#) allows veterans to receive private sector health care within their community outside of the VHA system. VA processed 18.9 million claims for all community care programs in fiscal year 2016.

Medical Center: [VHA](#) Medical Centers provide a wide range of services including traditional hospital-based services such as surgery, critical care, mental health, orthopedics, pharmacy, radiology and physical therapy. In addition, most of VA medical centers offer additional medical and surgical specialty services including audiology and speech pathology, dermatology, dental, geriatrics, neurology, oncology, podiatry, prosthetics, urology, and vision care. Some medical centers also offer advanced services such as organ transplants and plastic surgery.

Health Care System: In many areas of the country, several medical centers and clinics work together to offer services to area Veterans as a Health Care System (HCS) to provide more efficient care and provide Veterans easier access to advanced medical care closer to their homes.

Community-Based Outpatient Clinic: To make access to health care easier and closer to home, VHA utilizes more than 800 Community-Based Outpatient Clinics (CBOCs) across the country. These clinics provide the most common outpatient services, including health and wellness visits, without the hassle of visiting a larger medical center. VHA continues to expand the network of CBOCs to include more rural locations.

Community Living Center: Community Living Centers (CLC) are skilled nursing facilities, often referred to as nursing homes. Veterans with chronic stable conditions such as dementia, those requiring rehabilitation, or those who need comfort and care at the end of life are served within one of our 135 Community Living Centers*.

Domiciliary: Forty-eight VHA Domiciliaries* with a safe, secure homelike environment provide a variety of care to Veterans who suffer from a wide range of medical, psychiatric, vocational, educational, or social problems and illnesses.

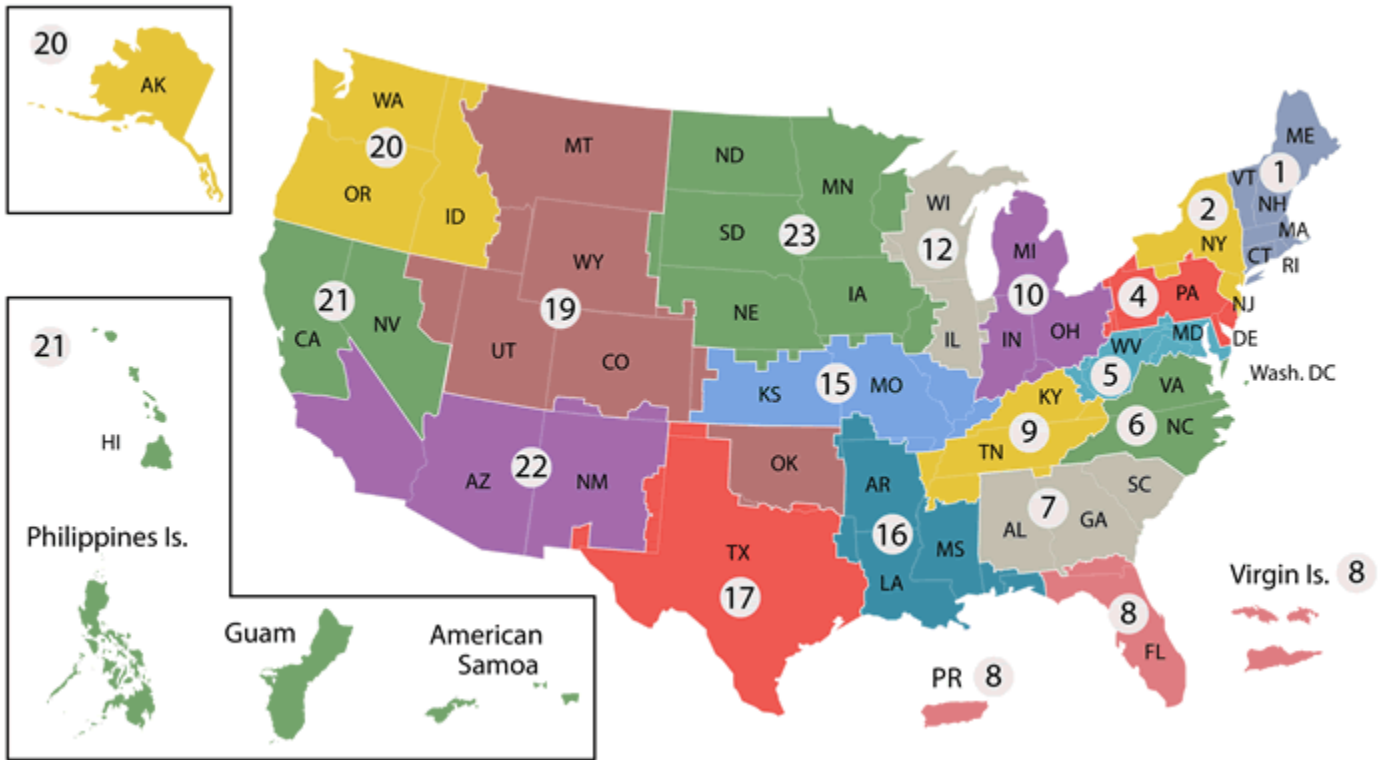
Vet Center: Vet Centers provide readjustment counseling and outreach services to all Veterans who served in any combat zone. Services are also available for family members dealing with military related issues. VHA operates 278 community based Vet Centers* in all fifty states, the District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands.

VISN: The U.S. was divided into 21 (now realigned to 18) [Veterans Integrated Service Networks](#), or VISNs — regional systems of care working together to better meet local health care needs and provide greater access to care.

* *From the National Center for Veterans Analysis and Statistics — www.va.gov/vetdata*

Veterans Integrated Services Network (VISN) Locations and Maps

Per realignment, the VISN total is 18 because no VISN 3, 11, 13, 14, or 18 for VISNs 1 thru 23 listed.



Veterans Integrated Service Networks (VISNs):

[VISN 1: VA New England Healthcare System](#)

[VISN 2: New York/New Jersey VA Health Care Network](#)

[VISN 4: VA Healthcare - VISN 4](#)

[VISN 5: VA Capitol Health Care Network](#)

[VISN 6: VA Mid-Atlantic Health Care Network](#)

[VISN 7: VA Southeast Network](#)

[VISN 8: VA Sunshine Healthcare Network](#)

[VISN 9: VA MidSouth Healthcare Network](#)

[VISN 10: VA Healthcare System](#)

[VISN 12: VA Great Lakes Health Care System](#)

[VISN 15: VA Heartland Network](#)

[VISN 16: South Central VA Health Care Network](#)

[VISN 17: VA Heart of Texas Health Care Network](#)

[VISN 19: Rocky Mountain Network](#)

[VISN 20: Northwest Network](#)

[VISN 21: Sierra Pacific Network](#)

[VISN 22: Desert Pacific Healthcare Network](#)

[VISN 23: VA Midwest Health Care Network](#)

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