Research Advisory Committee on Gulf War Veterans' Illnesses

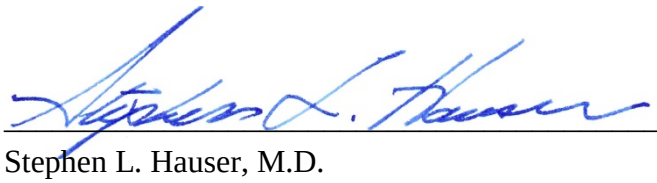
Committee Meeting Minutes
November 7, 2016

U.S. Department of Veterans Affairs
Washington, DC

Research Advisory Committee on Gulf War Veterans' Illnesses

Committee Meeting Minutes

I hereby certify the following minutes as being an accurate record of what transpired at the November 7, 2016, meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses.



Stephen L. Hauser, M.D.
Chair, Research Advisory Committee on Gulf War Veterans' Illnesses

RAC Meeting – November 7, 2016 – Washington, DC

COMMITTEE MEMBERS:
Dr. Stephen Hauser, Chair
Ms. Kimberly Adams
Mr. James Bunker
Dr. Fiona Crawford
Ms. Marylyn Harris
Dr. Stephen Hunt
Dr. Nancy Klimas
Dr. Katherine McGlynn
Mr. Jeffrey Nast
Ms. Frances Perez-Wilhite
Dr. Scott Rauch
Dr. Caroline Tanner
Dr. Mitchell Wallin

INVITED SPEAKERS:
Honorable Robert A. McDonald, Secretary of Veterans Affairs
Mr. Michael Feil
Dr. Walter Koroshetz
Dr. J. Michael McGinnis

SENATE STAFF:
John Kruse

VETERANS:
Charles Blanchard
Ronald Brown
Anthony Hardie
Steve Hohman
Michael Jarrett
Denise Nichols

VHA:
Dr. J. Wesson Ashford (telephone)
Dr. David Atkins
Mr. Stanley Corpus
Dr. Victoria Davey
Dr. Erin Dursa
Dr. R. Loren Erickson
Dr. Drew Helmer
Dr. Robert Jaeger
Dr. Victor Kalasinsky
Ms. Lara Khalil
Dr. Lisa Opanashuk
Dr. Matthew Reinhard
Dr. Peter Rumm
Dr. Jon VanLeeuwen

DEPARTMENT OF DEFENSE:

Mr. Brett Chaney
Dr. Kristy Lidie

MEETING MINUTES

Dr. Stephen Hauser, Chair of the Research Advisory Committee on Gulf War Veterans' Illnesses, and VA Secretary Robert McDonald entered the conference room; then Dr. Hauser called the meeting to order at 9:10am. He introduced himself and asked that committee members introduce themselves. Dr. Hauser then formally introduced Secretary McDonald.

Senior VA Leadership
The Honorable Bob McDonald, Secretary, Department of Veterans Affairs (VA)

Secretary McDonald stressed the importance of doing everything possible to "get Gulf War Veterans everything they need." He expressed appreciation over the collaboration with the various stakeholders, especially in the research organizations. He said that the group's recommendations "do matter," and many are already being implemented. He promised that the VA will continue to fund Gulf War illness (GWI) research.

He said that he was "disappointed" that the presumption for brain cancer was not obtained. He assured the committee that "this is not over," and the issue "will not be forgotten". VA was pursuing a new path forward and was hopeful that it will be successful. The VA was continuing to work on the research to bolster this effort and had requested the IOM to create a new ad hoc committee to review the relevant literature. VA's quarterly teleconferences with researchers will continue, as will animal research and epidemiological studies.

Secretary McDonald referenced the MyVA transformation. He said that the Department was moving towards "human-centered design," i.e., viewing every issue from the standpoint of the Veteran and not from the standpoint of the bureaucracy. They were looking at every "touchpoint" for ways to improve the Veteran experience. Measures of Veterans' trust of the VA had risen by about 14 points but was still very low (he thought it was around 71%).

Over 80% of VA facilities had made quality improvements, and 87% offer same day services. That was to be at 100% soon after the meeting. Vets.gov was designed to become the single website, consolidating the numerous VA websites in use at the time.

MyVA311 was a new toll-free number to replace the "myriad" of other VA telephone lines. The crisis line had also been improved. VA was still working to reduce homelessness for Veterans which was reduced by 17% in the previous year.

In FY16, the VA completed nearly 1.3 million claims. That was the seventh year in a row that they processed over a million claims. At the same time, they had significantly reduced the claims backlog.

All VA employees were being trained on the VA's services and benefits. This is designed to enable them to send Veterans to the right place at the right time. Too often in the past, he said, VA employees were too "siloed" to really know what was happening elsewhere in the Department.

Secretary McDonald stressed that the VA was moving to a "principles-based culture," and away from a rules-based one. Under the latter, employees must abide by strict rules. Under the former, the employees can take risks in order to do the right thing. Secretary McDonald said he was trying to deliver the message that, if questions are asked about an employee deviating from the rules in order to do the right thing, "I'll be the one to testify before Congress…[and] to take the media calls."

Discussion

The committee members stressed the importance of educating VA employees and providers on GWI issues. This committee is only an advisory committee; it is up to the VA to actually implement what is learned. Secretary McDonald replied that he welcomed any input the committee can give him.

Several committee members, including patient advocates, said that too many Veterans continue to find themselves "stopped" within the VA because their symptoms did not "fit in the box…we need to open that box." Secretary McDonald said that he "couldn't agree with you more". He said that VA was about start reviewing claims to ensure that Veterans were not being denied compensation and services for GWI.

After Secretary McDonald exited the conference room, Dr. Hauser asked Dr. Jon VanLeeuwen to make some introductions. Dr. VanLeeuwen introduced Mr. Stanley Corpus, RAC Project Coordinator, and Mr. John Rukkila, Technical Writer and Editor, who recently joined the committee staff in San Francisco. Dr. Hauser then introduced Michael Feil, a West Point graduate and the Director of the MyVA Program Support Office.

MyVA Update: The Path Forward
Michael Feil, MyVA Program Support Office

Mr. Feil reviewed the MyVA transformation, focusing upon the removal of internal siloes and encouraging employees to focus more upon doing the right thing rather than following rules. He said that the RAC can be very helpful in providing advice on what changes need to be implemented to be most useful for Veterans, especially those with GWI issues.

He explained that evaluators were being trained to address Veterans in new ways, to better acknowledge where the Veteran is at that moment in his or her journey. He also presented data on how much more responsive the systems have become for Veterans. The blocked call rate used to be 59%; that had been brought down to less than 1% through the introduction of new technology, staffing, and training.

Mr. Feil acknowledged that the VA has a history of distrusting outsiders. He said that Secretary McDonald had changed that attitude.

Mr. Feil said that the VA culture was changing. VA needed to consider specific populations and how to best serve them. VA also needed to streamline how a Veteran obtains care. There used to be hundreds of 800 phone numbers; they were consolidated into a single one which can help Veterans find what they need. He said that the VA has historically encouraged facilities to be entrepreneurial. What they did not do was check to see what efforts are actually working; facilities had begun to do that.

Mr. Feil said that the VA was focusing upon empowering VA employees to make the right changes. The five main strategies of MyVA were (1) improving the Veterans' experience, (2) improving internal support services, (3) improving the employee experience, (4) continuous performance improvement, and (5) developing strategic partnerships.

Within the MyVA strategies, Mr. Feil discussed VA's 13 priorities for 2017. On the health side, these included ensuring access to care at all levels; improving the electronic health record, as well as all of the VA IT systems; and fixing the supply chain. Just in the previous year, the VA managed to achieve $150 million in "cost avoidance" through better supply chain management. Other priorities included improving recruitment and accession of employees (HR), internal communications, financial management, shared services, launching the Vets.gov website, enterprise management, reducing homelessness further, improving claims and appeals, and using a strategic operating model.

Mr. Feil acknowledged that many of the identified priorities cannot be finished in a single year. However, VA needed to work on them. Mr. Feil stressed the collaborative efforts driving the transformation. He said that the MyVA Advisory Committee represented the first time some of the Veterans Service Organizations (VSOs) had sat down together on an advisory group.

Discussion

Mr. Bunker asked how much of the MyVA efforts will survive when the new administration takes office in January. Mr. Feil stressed the value of the VA's new openness, both inside and outside the VA. He said that both Veterans and employees had been appreciative of the changes had already occurred. Specifically, stakeholders and partners supported the plan, VA leadership at all levels supported the plan, and VA would be as transparent as possibly with the new administration. All this should help ensure that the momentum continues even in a new Presidential Administration.

Ms. Perez-Wilhite said that she would be interested in knowing more about what was happening with the 13 priorities. Mr. Feil promised to share new documents that he expected to have available in the following week. Ms. Perez-Wilhite also remarked that someone she knows had said that materials from the MyVA Committee could not be shared. Mr. Feil said that sometimes there is a question of when something should be shared.

Dr. Klimas pointed out that for the purposes of research, it is hard for investigators to identify Veterans with GWI. The medical record does not contain a particular code or other standard indication, such as an ICD-9 code. She asked if there was any way to send out targeted communications to the desired population without violating medical privacy laws. Mr. Bunker said that, under data use agreements, information can be obtained from DoD on who served in the Gulf War. He said that is actually better than the VA's data because it would include people who had not come into the VA for care.

Dr. Bob Jaeger, from the VA Office of Research and Development, talked about a new DoD/VA pilot to centralize exposure information to create an individual longitudinal exposure record, "ILER." It is two-year pilot project. Under this, the Veteran would simply identify where he or she served and exposure information would be pulled from DoD records. This would remove some of the information burden that Veterans currently have. He suggested that researchers get in touch with his office to talk about what data they would like to see included in ILER.

A researcher said that information should be collected on both individuals and on units. A lot of information is known and collected about unit exposure that is not captured at the individual level.

Dr. Peter Rumm, from VA's Post-Deployment Health Services, indicated that he, and Drs. Dursa, Ashford, and Kalasinsky, would be discussing Gulf War issues at a conference of the American College of Occupational Medicine in Denver in April 2017. He also suggested that exposure data from our allies and from the countries in Southwest Asia should be reviewed.

Mr. Bunker pointed out that his organization had requested data from VBA regarding the denial rates of claims submitted by Gulf War Veterans. The denial rates were very high, and he attributed that to inadequate compensation and pension exams performed by some VA healthcare providers.

Ms. Harris emphasized that women Veterans should not be left out of the MyVA transformation. In response, Mr. Feil described the work being done by the Center for Women Veterans under the direction of Dr. Kayla Williams.

Mr. Feil promised the researchers that he would take their concerns over gaining access to the appropriate Veterans back to the Department. He promised they would look into concerns that not enough is being done to improve the physical exams, as well, to better identify GWI issues.

After a short break, Dr. Hauser introduced Dr. David Atkins, Acting Chief Research and Development Officer and Director of the Health Services Research and Development branch in VA's Office of Research and Development.

Making VA a Learning Healthcare System
David Atkins, MD, MPH, Acting Chief Research and Development Officer

Dr. Atkins said that the VA offers too much care that is not based on the latest evidence. When there is evidence to guide care, it takes too long to be incorporated into regular practice. In addition, there are too many clinical problems for which good evidence has not yet been collected. Too many research studies simply do not reflect real world patients and real world conditions, partly because studies are based upon select patient groups. Dr. Atkins paraphrased a researcher who had said that if we want more evidence-based patient care, we need to produce more patient-based evidence.

The IOM had issued a report noting that all experience contributes to evidence, and evidence is truly based in experience. Thus, learning must happen in real time, and within the real world. They envisioned a two-step cycle through which evidence is incorporated into care, and then the lessons learned from that are used to further improve the evidence. This is opposed to waiting for a definitive clinical study to guide future practice.

The IOM determined that a truly learning healthcare system must first have a digital infrastructure capable of capturing information. The VA has that within its electronic health record system. That IT infrastructure must be able to make use of the data, and to provide clinical decision support and result in patient-centered care.

The health care system must be aware of community links, and know how to incorporate health care in the community into VA patient-centered care.

The system must make this continuous, and know where to re-engineer to optimize operations. Financial incentives must be aligned with taking advantage of these changes, and the system's actions must be transparent so it would be clear where improvements are needed.

Finally, overall leadership must be fully on board to drive the process forward.

Dr. Atkins also noted that all of these conditions existed at VA. He said that VA was working in this space on a number of care issues. The example he described was dealing with the opioid prescription crisis. The VA system had been exploring using alternative pain treatment and control methods, and collecting data on what is useful in real time and in the real world. The lessons learned are then being used to change clinical practice as necessary on a regular basis.

Dr. Atkins also talked about the VA's use of big data. The VA has billions of data points on clinical issues across the spectrum of health care. VA had used the data to identify and target Veterans most at risk, especially in areas such as hospitalization and death; suicide; and adverse effects of prescription opioid use.

In suicide, VA had managed to identify the 0.01% of enrolled Veterans who were at a 60-fold higher risk of committing suicide. This is a very small population, but they are at particularly high risk. The VA was rolling out ways to intervene with them, and will use the lessons learned from that to expand the targeted population.

Dr. Atkins also gave a brief overview of what the VA was doing with precision medicine. The VA is halfway to its goal of recruiting a million veterans into the genomic and health registry, the Million Veteran Program (MVP). Researchers could then tap into MVP to find genomic links to health outcomes. GWI was one of the first studies to start with the data already collected.

The VA was also developing a new initiative to examine the value of commercially available genomic tests to select treatments. He said that this was necessary, as things such as 23&Me are providing people with genomic information that may or may not be useful to drive personalized medicine.

The real question is how genomic information can be used to improve health outcomes. In the mental health arena, there is a study examining whether an individual's genome can be used to identify drugs that are more or less indicated for their condition.

Dr. Atkins noted that the costs of conducting clinical research are high, largely due to the cost of recruiting patients and managing the collection of information from them. The VA was organizing two large, simple randomized clinical trials to compare treatments already in use, and to use data routinely collected from the EHR. Informed consent would be obtained by the primary care provider, but the data would be collected through the medical record, without the need for special visits or care managers.

For some conditions, new programs were implemented without strong evidence, such as to reduce suicide or address the opioid crisis. The VA had identified four programs for more intense program evaluations. The programs were rolled out in a random, sequential process, which allows for strong comparisons.

Dr. Atkins closed by referring to Gulf War research and the slow process of clinical trials that is not answering all the questions raised by the these Veterans quickly enough. VA needs to take a closer look at the patients to determine which ones respond to particular treatments. VA has the tools, like virtual training, to keep clinicians current, and he hoped that the RAC can help inform VA of better ways of disseminating research results.

Discussion

Dr. Crawford asked if it is possible to match up the genomic data in the Million Veteran Program (MVP) registry with exposure information. Dr. Helmer, who is one of the investigators on the Gulf War genomic study, said that they are collecting self-reported exposure information. Dr. McGlynn asked if the MVP database is separate from the Precision Medicine Initiative (PMI) database. Dr. Atkins said that both databases have a goal of collecting a million samples, and there will be some people in both registries. He noted, however, that the two databases have different target populations.

In response to Dr. Wallin's question about IT issues with such large databases, Dr. Atkins commented that IT infrastructure is critical to these projects, and VA is working on this. The VINCI system and the redesign of the VA EHR are also part of the effort to streamline the work.

Dr. Hunt asked if there are research results related to implementing care for Gulf War Veterans. Dr. Atkins mentioned the need to ensure that care is of the same high quality around the country. The VA is

"working on a number of different streams" to learn how to identify the best programs and how to diffuse them across the system.

Dr. Rauch asked about VA's ability to respond to new syndromic conditions like Gulf War illness. Dr, Atkins responded that VA's system was not built to respond quickly to an emerging syndrome, which is probably why the VA has had such a hard time with GWI. He said that there is some "early work" on using the learning system methodologies and big data to identify new outbreaks in real time. He does not think progress is as fast as VA would like, but there is progress.

Mr. Bunker asked if anything was being done to address situations where a primary care provider does not recognize GWI and refers the Veteran to mental health care because he does not know what else to do. Dr. Atkins said that clinicians need to be continually educated on emerging issues. He said that the VA needs to examine what tools need to be given to clinicians to make them aware of special programs like the WRIISC and of non-routine kinds of care.

Dr. Atkins agreed with Dr. Hauser that the RAC should receive more information, and even a special presentation, on the MVP from the people directly involved with running that. Dr. Hauser was specifically interested in the demographics of the MVP population.

Dr. Hauser also asked if there was a link between the DoD repository of serum data and VA's medical data. Dr. Wallin said that needs to happen for not only GWI but for more information in general. The committee members wanted easier, more accurate data from DoD that can be linked to what is being seen among Veterans. Dr. Atkins said that "we do have good relationships with DoD." Dr. Jaeger said that DoD and VA have been working together quite a bit to collect data. In particular, they are working to consolidate specific data sources, such as the Millennium Cohort, and bring it into the VA cohort. This would enable them to identify what particular conditions this cohort has. Of the more than 200,000 people in the Millennium Cohort, more than 100,000 have used VHA health care, and more than 4,000 are enrolled in MVP. Dr. Tanner commented that it would be useful to be able to follow a Veteran from the time he or she enlisted in the military, and Dr. Atkins agreed that it was a goal that everyone shares.

Ms. Harris said that VA needs to communicate these advances to researchers and clinicians because in her experience this is not being done well enough. Dr. Atkins agreed.

Dr. Hauser thanked Dr. Atkins and proceeded to introduce the next speaker. Dr. Walter Koroshetz is Director, National Institute of Neurological Disorder and Stroke (NINDS) at the National Institutes of Health (NIH). He went to NINDS in 2007 as Deputy Director. Prior to that, he was on the staff at Massachusetts General Hospital and Harvard University.

Special Opportunities for Impactful VA Research:
Walter J. Koroshetz, MD, Director, National Institute of Neurological Disorder and Stroke

Dr. Koroshetz began by emphasizing that NIH's clinical research cannot cover every topic, so it is important for VA to continue its research. It is difficult for NIH research to identify long-term consequences of the studied interventions. The researchers are often so focused upon a particular issue that comorbidities are not fully studied, nor are their impact upon the final outcomes. Researchers also do not do enough to track pre-morbid characteristics and conditions to determine their role in the development of the disease or the patient's response to interventions. Researchers also find it difficult to recruit diverse populations into studies, and to track people across a long period of time.

He said that NIH tends not to conduct research on issues and conditions that are common to the military population but not seen in the civilian population. For example, NIH does conduct research into PTSD,

but not necessarily combat-related PTSD. It is also difficult for NIH to incorporate research and interventions into daily clinical care, such as the VA can do in its Point of Care Research Program.

Dr. Koroshetz provided a quick review of the NINDS' work which includes up to 400 different disorders. He said that they have a VA representative, Dr. Christopher Bever, on their "Council," which is a FACA committee. He indicated that NINDS is the largest funder of research related to the symptoms of GWI. Projects include studies of the plasticity of the nervous system, and emotional exhaustion and chronic fatigue syndrome. They are also looking at the impact of lead and neurotoxins on people.

He said that there is also an effort from a pharmaceutical company to develop medications in response to research findings in this area.

Dr. Koroshetz talked about research on astroglial scarring found in the brains among some people after blast exposure. He noted that very little is known about the brain, and about how blast exposure impacts them long-term. Other work is being conducted on concussions, which is different from the blast exposure work. Work is also being conducted on chronic traumatic encephalopathy (CTE).

Dr. Koroshetz said that the Army STARRS effort, which ended in 2014, was a major research effort wherein NIH and DoD collaborated to study 72,000 soldiers. The Army is now funding a follow-up study to find out what happened to the people enrolled in it. That study will run until 2020. He praised it as a way to follow the population into the VA and into civilian life.

Dr. Koroshetz also highlighted the NIH's efforts on opioids. He said that this presents a lot of opportunities for collaboration between the VA and NIH. NIH has another FACA, the Interagency Pain Research Coordinating Committee, that includes Dr. Audrey Kusiak as the VA representative. NIH's National Center for Complementary and Integrative Health has initiated a "Collaboratory" Research System thaqt will work with health care systems to improve their processes. Dr. Koroshetz noted possible collaboration with VA in this program.

He said that the VA needs to "take a close look" at its data sharing stance in terms of collaboration. He understood the concerns of data leaks, but he indicated that the VA's approach was not friendly to researchers. He said that siloing VA data so closely would not serve Veterans well in the long run, as researchers could not get access to that information. He wanted the VA to look into ways to release data without personally identifiable information. The NIH was also working with the DoD in this area. They have seen greater success with DoD than with the VA. Dr. Koroshetz suggested that this might be something the RAC might want to address directly.

The Department of Transportation was in the process of initiating a multi-agency project on fatigue. Dr. Koroshetz said that he would "love" to involve the VA and DoD.

The NIH was also trying to mount a program to better understand chronic fatigue syndrome. He wanted VA involved in this, as well. NIH was looking to set up coordinated care centers around the country.

Dr. Koroshetz also talked about the BRAIN Initiative. They were working to better understand the brain's circuits. He stressed that "clearly circuits are abnormal" in all kinds of conditions, both neurological and psychological. This initiative would develop new technologies for understanding the human brain. He expected it to "open the door" to better understand things such as what is happening with PTSD and who is at higher risk of committing suicide.

Dr. Koroshetz concluded by saying that there was a lot of exciting research going on. VA has tremendous possibilities and unique capabilities to build bridges with what NIH is trying to do. Looking into the ways in which NIH could help VA's mission could be quite productive.

Discussion

Dr. Wallin asked what kinds of projects might be the most important to complete if VA and DoD could share data. Dr. Koroshetz used blast injury as an example to point out that VA would be better able to treat these patients if there was better data sharing. DoD has many brains from service members who were injured by blasts, but DoD cannot or will not allow those brains to be studied outside of DoD because of consent and privacy concerns.

Dr. Tanner pointed out the difficulty of using animal models to try to integrate basic science into treatments for Veterans, and Dr. Koroshetz agreed.

Dr. Klimas expressed some frustration about the inability to get location and exposure data from DoD that would be crucial to VA in understanding and treating the health problems of Gulf War Veterans. Perhaps a trans-NIH working group will be able to get multiple agencies together to resolve the problems.

Mr. Bunker reminded everyone that Gulf War Veterans were exposed to many different toxicants and that it is difficult to determine which exposure led to a particular symptom. Dr. Koroshetz agreed and indicated that NIH is not likely to fund a project where the toxicant is not known. He mentioned Eastern medicine as a means of treating symptoms even when the cause is not known.

Dr. Rauch recalled Secretary McDonald's comments earlier about the VA's efforts to be mission-driven rather than rules-driven. The Committee could send a strong message to the VA about the need to be more open with their data, and Dr. Rauch asked if NIH institutes could work more closely together. Dr. Koroshetz agreed that improvements were necessary and said that the recent PMI program might be the mechanism to accomplish that goal.

Dr. Hauser asked for a clarification of the issues surrounding the brain tissue at the DoD Dover mortuary. Dr. Koroshetz said that studies of brain tissue would be very helpful in diagnosing chronic effects like those that show up in Veterans such as Gulf War Veterans. Dr. Hunt suggested that engaging veterans is the best way to determine how to recruit veterans for brain studies.

Ms. Adams stated that one of the things that she sees in the practical world of a veteran having PTSD is that they sometimes cannot make decisions about important issues that confront us all each day. She continued to say that many veterans get so disenfranchised that they essentially give up trying to understand their problems, and their families and friends get frustrated trying to help. She also pointed out that service members "sign everything away" when they join the military and wondered if agreeing to donate to the brain bank could be part of the entrance process. Dr. Koroshetz indicated that research involving civilians requires consent forms signed by the participants and that these are not very easy to obtain.

Dr. Kalasinsky described the Gulf War brain bank at VA and indicated the difficulties and sensitivities associated with recruiting participants. Dr. Koroshetz agreed that there are problems with recruiting but suggested that primary care providers can discuss the importance of these repositories and answer veteran questions. Mr. Bunker said that it is important to have brochures and other descriptive materials available at VAMCs to inform veterans of projects like the brain bank.

Mr. Jeffrey Nast asked if NIH was involved with studies of NFL players. Dr. Koroshetz indicated the NIH was funding the VA Boston University brain bank to do studies on the brains of NFL players. They had the largest collection of NFL brains, and the percentage of CTE in those brains was in the range of 80 to 90%. Dr. Koroshetz said that they have the ability to see if blast injury is different from concussions. Dr. Anne McKee at BU had not seen the effects of blast like Dr. Dan Perl at USUHS had, but VA is well positioned to do this work because many of the VA personnel are affiliated with BU.

Dr. Hauser thanked Dr. Koroshetz and called for a lunch break.

When the meeting resumed, Dr. Kalasinsky of the VA announced that the following committee members had been reappointed for additional two-year terms by Secretary McDonald: Mr. James Bunker, Dr. Fiona Crawford, Dr. Nancy Klimas, and chairman Dr. Stephen Hauser.

Dr. Hauser then introduced the next speaker. Dr. Michael McGinnis is the Leonard D. Schaeffer Executive Officer at the National Academy of Medicine. He is a member of the NAM, executive director of the NAM leadership consortium on value and science-driven healthcare, and founder of its learning health system initiative.

Achieving a Learning Health System
J. Michael McGinnis, MD, National Academy of Medicine (NAM)

Dr. McGinnis indicated that the formal NAM report "The Path to Continuous Learning Health Care in America" appeared in 2012 but the NAM had been working on the concept since 2006. In such a system, the vision is that science, informatics, incentives, and culture would be aligned for continuous improvement and innovation, with best practices seamlessly integrated in the delivery process.

The approach was to look at other industries to determine which aspects of their "business plans" were working well and how they could be applied to health care. This information was then put into the context of the progress health care had made since 2000. Since then we have (1) achieved much better computing capacity and connectivity, (2) systems and process improvement strategies that are working in many places, (3) patient and clinician culture change strategies in play with the democratization of healthcare beginning to take hold in some places, and (4) policy levers, especially with the elements of the Affordable Care Act, for incentives related to continuous learning, transparency, accountability, and engagement.

Dr. McGinnis indicated that the NAM committee made a number of recommendations. He discussed the digital infrastructure and data utility as the foundational elements of the recommendations because they are absolutely essential for a continuous learning health system.

The NAM committee also listed priorities for progress in the categories of informatics, science, incentives, and culture.

Dr. McGinnis said that the National Academy of Medicine is trying (1) to foster a continuous learning health system, (2) to steward action to help make it possible for the right thing to happen through innovation collaborations, (3) to link stakeholders, executives, and patients and families into networks that are growing in order to support both on the supply and demand sides, and (4) to sharpen the assessment program.

Dr. McGinnis outlined the NAM hierarchical strategy for achieving those priorities. The foundation began with the "motivating challenges." Next was a focus on the vision, rather than the many distractions that prevent progress.

The next level was a series of dedicated assessment strategies to understand how to improve patient engagement, evidence standards, financial incentives, IT, clinical research, and so forth. Then there are publications dedicated to the learning health system.

The innovation collaborations that NAM was trying to advance were (1) value incentives and systems, (2) care culture and decision-making, (3) clinical effectiveness research, and (4) digital learning. And the idea was that it would be possible through the interaction and collaboration of the various stakeholders to accelerate progress on outcomes and on creating better value.

Dr. McGinnis indicated that some progress had been made in each of the necessary areas, but there was room for improvement. To move the process along a leadership consortium for value and science-driven healthcare was convened as a national government medicine consortium. It consisted of almost three dozen CEO-level people from different sectors (health care, research, pharmaceuticals, etc.) in addition to patients, clinicians, and the heads of FDA and NIH.

Dr. McGinnis finished by saying that VA research will benefit as the learning health care system becomes successful. VA is a very strong partner in all of these activities. He also stated that the rest of the country's health care systems could learn a lot from VA, especially as they negotiate through the profile of the next generation electronic health record through the VA. Dr. McGinnis mentioned that he had been at VA with the Secretary in the previous week on that issue with their advisory group.

Discussion

Dr. Hauser indicated that one of the ongoing issues that was discussed in the morning session was the connection between applied evidence-based clinical care and developing new evidence through research. The challenge associated with a chronic condition is how to improve the connections between the translational research enterprise and the clinical care patients. Since it is difficult to get adequate numbers of patients into research studies, Dr. Hauser wondered if the NAM had considered this challenging problem of how to integrate research into the clinical care.

Dr. McGinnis said that they think that they have an answer. They have had three sessions with CEOs of systems, looking at the kinds of infrastructure capacity that is needed in order to essentially accomplish the necessary infrastructure. So what they were doing through the executive leadership network was trying to identify the various elements at intersection points to identify ways in which different healthcare delivery organizations take an advantage of the opportunity in electives, and then spread that across systems, all the while developing a strategy framework system in that direction. Currently, this will be one of the interest points in the project that they have underway in developing purchasing specifications for new regional systems.

He indicated that it was possible to conduct a cluster randomized MRSA trial by taking advantage of the large number of patients throughout the whole HCA system and using a set of interventions that were in place, and randomizing institutions to one another. Dr. McGinnis acknowledged that some problems would require engagement of more than one system just because of the numbers of requirements. They are trying to work with NIH in identifying ways in which they can pool the activities of multiple systems in streamlining research design protocols.

Dr. Hauser asked about potential financial limitations, and Dr. McGinnis responded that there are usually enough finances for infrastructure, but the value of proprietary data is a major consideration.

With the promising efforts at NIH, with the promise instruments, and in the vital signs effort coming out of that work, Dr. Klimas wondered how all this was going to transition in a way that we could all buy in on.

Dr. McGinnis admitted that it is difficult to view a health care system with thousands of requirements for collecting data and narrow that down to 15 core measures that would be comprised of around 100 or so component measures. He indicated that what is needed is that constant set of reliable measures that can then be overlaid as necessary. They have not given up on this by any means; the NGA, AHA, and AMA are on board.

Dr. Klimas said that the RAC has discussed aspects of standardizing research projects by advising VA-funded investigators to use a set of core instruments, for example, but it is difficult to do.

Dr. McGinnis was pleased to hear that the RAC discussed issues like that and suggested that researchers could be encouraged to work with NAM and to conduct pilot studies to evaluate the composite measures. He said that NAM was discussing a pilot with five large healthcare delivery systems who are interested in implementing this on a pilot basis.

Dr. Hauser thanked Dr. McGinnis and explained that the main goal of the afternoon was to approve the 2016 recommendations and the white paper that accompanied them.

Committee Updates and Discussion

White Paper on Post-Deployment Center Structure

The first recommendation considered was one to establish a coordinated system of centers which was described by Dr. Wallin. A subcommittee had been formed and held teleconferences over a two-month period. Dr. VanLeeuwen helped write the recommendation and white paper for post-deployment clinics in medical centers across VA. The subcommittee consisted of six RAC members in addition to Dr. VanLeeuwen. They also reached out to the three WRIISC directors, to Dr. Erickson, and to other folks at central office individually and on the calls.

He indicated that the plan addressed some of the major issues that have hampered research efforts and clinical referrals for Veterans with complex chronic conditions of post-deployment, especially for Gulf War illness and other related conditions. He hoped to get feedback from the Committee.

The focus would be on the chronic conditions and not on conditions currently studied at existing centers of excellence. VA does have polytrauma centers that deal with post-deployment exposures in general, but broader attention to Gulf War illness specifically is needed.

Dr. Wallin showed a sketch of the structure of the "hub and spoke" network that the subcommittee felt would be necessary to catalyze development of research in clinical care. At the national level, there would be centers that would oversee and coordinate research at the VISN level and help coordinate referrals, with a minimum of one post-deployment healthcare clinic in each of the 23 VISNs. This would provide a mechanism for every major VAMC ("local") to make referrals.

For this structure (Section III) there were three specific action items. The first was to consider how the WRIISCs, which are the natural, national centers, would be leveraged to provide oversight, education, and support to the VISN-level centers and also to the local VA. Action item number two was to create one post-deployment clinic in each VISN without a WRIISC. Number three was to ensure that there would be a coordinator of some kind for post-deployment health at the local medical center level. Each

VAMC should already have an environmental health coordinator who is involved with the registries for Gulf War and other topics.

Section IV dealt with integration of post-deployment research and clinical care, so the system could function as a continuing, continuous learning health system environment, as described earlier by Dr. McGinnis. The first action item was to explore how QUERI (Quality Enhancements Research Initiatives) and point-of-care research could work with this kind of a system. This might involve using some mechanisms that VA has to explore best practices in post-deployment health.

The second action item was to reduce barriers for people who are and who are not eligible for VA care to participate in research. Only about 30% of all veterans are in the healthcare system. The third action item extends this notion to establishing an ideal Gulf War cohort. It would be useful for longitudinal analyses and clinical trials to have a well-characterized cohort of Gulf War Veterans and have them phenotyped, looked at clinically with the latest imaging tools, and have bio-bank specimens.

Section V was data integration. It was discussed earlier in the day; data are often siloed within both VA and DOD, and there need to be pathways, cross-linkages, between databases and efficient storage structures. The action items were to ensure interoperability of data within VA and between VA and DoD; to identify additional non-VA data sources such as environmental data; and to enable the pooling of data.

Section VI was key partnerships. For the system to work well, it will be necessary to DoD and to academic partners, nonprofits, Veteran service organizations and businesses.

Dr. Wallin concluded by saying that the white paper is a reasonable working document which captures many of the points that have been discussed by the RAC over the past two years.

Dr. Rauch suggested that, since some new group (within VA) would probably be charged to consider, refine, and implement a plan like this one, it might be optimal for the RAC to present the plan in its current form and "not let the perfect be the enemy of the good."

Dr. Wallin indicated that this could be a working document that could move forward in VA. Ideas like these have been discussed from time to time within the WRIISCs. He said that they are not all that controversial, and they would help us take better care of Veterans.

Mr. Bunker said that it was a good document and that he liked it. He viewed it as good advice to give to the Secretary.

Dr. VanLeeuwen reminded the group that there is a set of five recommendations that has been circulated. The second one refers specifically to the center and the white paper. He reiterated Dr. Wallin's comment that it is a work in progress and added that there will be opportunities to engage in the future.

Dr. Klimas said that she was told that the VISN actually has the resources to do this sort of thing, but she did not think it would happen unless the Secretary says it should happen.

Dr. Hauser mentioned that the Committee's efforts might be time sensitive given that there would be a change in administration. He viewed the hub-and-spoke model as a blueprint for the future, but wondered how to begin the process of resourcing such a system. He thanked Dr. R. Loren Erickson from VA's Post-Deployment Health Services group for joining the discussion and asked if he had any thoughts. Dr. Erickson introduced himself and reminded the group that the Secretary said that he could use all the advice he can get.

Dr. Erickson indicated that the document that the RAC sends to the Secretary would come to Post-Deployment Health Services and to Dr. Kalasinsky in the Office of Research and Development, and they would be asked to prepare a response. He acknowledged that the Committee had touched on a key issue, and that was funding. His office and the WRIISCs were already "stretched" because they serve other Veteran cohorts in addition to the 1990-1991 Gulf War cohort. He suggested that they would need "fenced" resources for such a project.

Dr. Erickson also emphasized that VA is greatly appreciative of all the work that the RAC is doing. All of the actionable recommendations seemed reasonable, even if a few might be difficult.

He offered to share some of PDHS' ideas for moving forward at a future RAC meeting. He noted that it is difficult to talk about research in isolation from clinical care and from education. Dr. Erickson ended by promising that the RAC's VA colleagues and collaborators would respond to the recommendations, and in doing so will help to perfect some of these concepts.

Dr. Hauser thanked Dr. Erickson for his comments.

Dr. Klimas wondered if there was a way to get a cost analysis so the Committee could be more precise in its request.

Dr. Erickson suggested that VA could estimate some of the costs, but that it was unlikely that there would be significant funding for new programs. On the other hand, he repeated what had been implied earlier, that post-deployment care is not likely to be available in the civilian medical community through the Choice Act.

Dr. Wallin asked if Dr. Stephen Hunt could give his views from the perspective of having operated a post-deployment in Seattle for many years.

Dr. Hunt explained that he had started a Gulf War clinic early on. It is an interdisciplinary clinic with social workers, medical providers, and mental health providers. He pushed out this notion of integrated post-deployment care, and Veterans seemed to like it. It was expanded into what is now called PDICI, Post-Deployment Integrated Care Initiative. By 2010, 18 months after the program was initiated, 84% of the VA medical centers in the country had integrated care platforms for returning combat veterans. He said that the biggest question facing the clinics was whether we even knew what Gulf War Veterans needed. It is also difficult to do a cost-benefit analysis because the benefit has nothing to do with money; instead it has to do with how Gulf War Veterans are doing after they visit the clinics. He indicated that we need to know what would have helped a Veteran better when he/she came back, what support was not available that a Veteran needed, and what a Veteran would like to see in place the next time he/she goes to VA for care.

He pointed out that the recommendation should address those kinds of issues. Dr. Hunt commented that he was the point of contact for his VISN even though he was located in one of the local VAMCs in Dr. Wallin's diagram. He appreciated what the WRIISCs do, and he himself did many e-consultations and telephone consultations.

Dr. Hunt wondered what the new system would do for Gulf War Veterans. He agreed that the research part is very important; Veterans frequently told him that they wanted a research center and they wanted to participate.

He also pointed out that some of the local VAMCs (the gray circles) are weaker than others, so his VISN sponsors a monthly call. He said that the education and research pieces are very important, but he was

not sure about the clinical piece. The bottom line is that we need to know what Gulf War Veterans need and where they need to go to get it.

Dr. Klimas responded by saying that it almost sounded like Dr. Hunt was saying that VA already had this system in place, and she disagreed with that assessment. If Veterans go to the post-deployment clinic at her VAMC, they were probably just back from wherever they were deployed. They would not necessarily get any follow-up; they get care once and then they are put into the VA system. They are chronically ill people who make one-hour or two-hour appointments. She felt that VA needs complex-care-focused clinics to take care of the Veterans who are still sick.

Dr. Hauser suggested that some Veterans want to participate in research to please their care givers. It is not only to help fellow Veterans. That is one of the reasons why he believes so strongly that research needs to be tied to patient care; it is bidirectional. We do everything we can to help them, and they do what they can to help us.

His experience with Alzheimer Disease and the Cleveland Clinic's experience with multiple sclerosis were that the brain banks are full. Patients and their families wanted to give back. It is essential to improve the clinical care, to standardize the clinical care, if we are to really have the populations that we need for the research.

Dr. Hunt said that they had 60 Gulf War Veterans from their center participate in their MBSR project. The Veterans did not look at it as our research; they looked at it as their research. It all comes down to creating communities of care for Veterans.

Mr. Bunker reminded everyone that care is not standardized. Veterans who go from one VA to another are not treated the same. If they return from a WRIISC and go to their local VAMC, they don't get the same quality care. The RAC was trying to address all of this within the white paper, and he thought it would that's going to help out some. The system would also get education to the people who need it and help get people into the research.

Ms. Adams said that one of the issues she and her colleagues have is that their jurisdiction is limited, so a hub-and-spoke model is great because it would give Veterans a clear path for receiving help. She was certain that Veterans will not “buy in” if they always have to travel long distances. She also pointed ou that when Veterans return post-deployment, they do not always know what to do because everything has changed. VA really needs to work to bring Veterans back because the Veterans and their families are the stakeholders. Once VA gets that buy-in from Veterans, it will be possible to get them to sign up for research.

Mr. Bunker emphasized that it is difficult for Veterans to travel, especially Desert Storm Veterans, but the age of tele-medicine might change that. He thought that the hub-and-spoke model is a great way of doing things, and that is what the Committee needs to encourage the VA to start doing. He repeated that they needed to move the document forward.

Dr. Klimas said that when she does a telemedicine consult, the primary care doctor is in the room with the patient. That really gets buy-in. The WRIISC does the same kind of thing and it is a very useful strategy to put education into the treatment plan.

She was very excited about the idea that there could be VISN-level resources because it would really forces the local care well beyond the hospital-based care. She concluded by saying that she thought the system could really work even though there are some operationalization issues to sort out.

Dr. Tanner affirmed that this would be an excellent way of doing this. She said that the Parkinson's Centers of Excellence have a very similar structure. There can be multi-disciplinary care in the specialty center, but it must also be delivered telemedicine. They have started to be able to reach out to the state Veteran homes which are a little more logistically challenging. They also do video to home so if people and their families cannot even get to a clinical center, they can provide care to the home. They can have their whole team involved, including the social worker, the chaplain, the pharmacist, the doctor, and the nurse.

The VA is able to take advantage of the resources available. This model can be used by VA to learn as we are delivering care, and then to develop the educational materials that are needed that can be an on-line resource for people in the VA. She concluded by saying that it is an excellent model and the RAC should really endorse moving it forward.

Dr. Crawford said that she completely agreed. She is convinced that Veterans' participation in research comes from their experiences at the clinical end. She also said that she was struck by what the Secretary said in the morning about mission-driven activities, and she planned to share that notion when she returns to her home VAMC. She did have concerns about the scalability. How will it be possible to maintain all of those best practices as VA grows this and implements it across the entire VA system. In closing, she reiterated that she completely endorsed getting this document out.

Dr. Klimas commented that she had never had a single patient refuse to sign up for what she called their "national history study" which gives her permission to use all the leftover blood and clinical data, to re-contact them for studies, and to do retrospective chart reviews. And it is all covered by their IRB approval. The keep their data set in a REDCap platform.

Mr. Bunker moved that the white paper and its recommendations be approved as is. Dr. Tanner seconded.

Dr. Hauser wondered if there should be a bullet at the end to develop a cost analysis estimate for the core program. Mr. Bunker said that the subcommittee had brought up about the cost question. Dr. Hauser asked if they decided that such a bullet was unnecessary. Dr. Wallin reminded everyone that VA has many unfunded mandates. Dr. Erickson indicated that the RAC could recommend a cost analysis because it was very likely that some new resource allocation would be required.

Dr. Wallin suggested that they recommend a cost analysis for that system of care along with a sentence saying that the system would require new resource allocation.

Dr. Hauser called for a vote, and the recommendation, with change, was unanimously passed. He thanked everyone and extended a special thanks to Dr. Wallin and the subcommittee.

He then asked for an update regarding the Gulf War Research Strategic Plan and indicated that there would be a vote on the remaining four recommendations afterwards.

Gulf War Research Strategic Plan Update

Dr. Kalasinsky said that a working group had just one teleconference, and in that teleconference they discussed whether to discard the existing research strategic plan and start anew or modify the existing plan. It appeared that some sections would be completely changed while others would simply be modified. The group planned monthly teleconferences in October, November, and December, and individuals had been asked to look at the different sections, some sections by two or three people, to

determine how much work was needed in each section. He concluded that the update was in its early stages.

Dr. Hauser thanked Dr. Kalasinsky and reminded the Committee that the strategic plan update is the second of five proposed RAC recommendations for 2016. The mandate to update the strategic plan and the recommendation to establish the national hub and spoke coordinated system were the major statements from the Committee. The other three recommendations were proposed by different members of RAC.

Additional Recommendations

Recommendation number three was to actively seek strategic partnerships to enhance research capabilities for Gulf War research. Number four was to identify and reduce barriers to recruiting research participants. Number five was to develop an approach to address comparison groups, including deployment status issues and limitations of ICD-9/10 code usage.

Dr. Klimas suggested that they could work on ICD-11 codes, too. She indicated that no such work had ever been done and that GWI had never been coded properly.

Mr. Bunker said that he did not find reference to the ICD-9 codes being used. Dr. Klimas indicated that it was the intent of the final recommendation. Mr. Bunker said that the intent was not spelled out well enough. There should be another bullet saying that medical records should have better coding.

Dr. Klimas said that when she is providing care for a patient, she has to fill out a problem list with ICD-10 codes. There is also a checklist associated with every laboratory test she orders to mark whether the test is related to a service-connected problem. She would like to see a check-box for environmental exposure specifically or Gulf War illness explicitly because the VA already has a system for creating little check boxes in the electronic health record.

Mr. Bunker said that in 1992 when he got into the VA system, they put a purple sticker on his medical record folder that said "Gulf War." Dr. Klimas reminded him that there are no longer paper charts to put purple stickers onto. There needs to be a check box. Mr. Bunker agreed that the electronic file should be changed so it will say that the patient is a Desert Storm Veteran. Dr. Klimas said that she also wanted a check box that indicated whether a Veteran had Gulf War illness. When treating Gulf War Veterans, she needed to know what their exposures were. Mr. Bunker said that researchers want to know who is and who is not a Gulf War Veteran or a member of other cohorts.

Dr. Hauser asked if Dr. VanLeeuwen could give some background and propose a solution. Dr. VanLeeuwen said that the intent was to make it possible for researchers to identify what cohort a Veteran was in. It is necessary to be able to distinguish Gulf War from other conflicts. Mr. Bunker asked about deployments. Dr. VanLeeuwen said that deployment status is called out specifically there. After there is a VA response and implementation plan, the RAC could offer more specifics to make sure it meets the needs for care providers and for Veterans. Mr. Bunker remarked that there was not even a single case definition.

Dr. Rauch suggested that after the word "research," the phrase "as well as clinical" could be added, i.e., "from a research (as well as clinical) perspective." He also noted that any interventions the RAC would propose for research would bear more weight if they underscore how these were also critical from the clinical standpoint.

Ms. Harris had a comment about our third recommendation. She liked the part of the MyVA slides (slide four) that says a cultural shift is occurring at VA. VA is moving away from a culture that is skeptical of outsiders to a culture that actively pursues and engages partners. Dr. VanLeeuwen said that they were changing the wording to "the Committee recommends VA actively pursue and engage with strategic partners." Ms. Harris said that MyVA is totally in line with what the RAC was asking for in this recommendation.

Dr. Hauser asked for a vote after including Dr. Rauch's amendment. In the final bullet, "from a research and clinical perspective" was added. The vote for approval was unanimous. After the vote, he asked Dr. Klimas for a quick update of the CoQ10 study.

CoQ10 Clinical Trial Update

Dr. Klimas began by mentioning an international conference in south Florida a week before called the International Association for CFS/ME, and they had a one-day pre-conference that was on Gulf War illness and CFS. Dr. Kalasinsky from VA, Dr. Kristy Lidie from DoD, Dr. Vicky Wittemore from NIH, and Dr. Beth Unger from the CDC attended and represented their agencies. There were approximately 150 people in attendance, mostly investigators, and around 850 people streaming on-line. For the GWI pre-conference, there were approximately 1,000 people. Many Veterans with Gulf War illness were streaming and sending comments. The meeting garnered a lot of attention for the field.

The CoQ10 trial is a phase III clinical trial on Ubiquinol which was approved the previous Spring. The IRB process over the Summer and Fall trying to get four different sites to agree to the same informed consent had been difficult. The Boston VA approved the study that morning (Monday), and their research committee was to approve it on Wednesday. Boston was the final one of the four sites requiring approval. The kickoff meeting was held in August in Boston with the whole team represented. The Minneapolis, Bronx, Boston, and Miami VAMCs are participating, and the Boston University is the data management core. The sites already had their key people, and recruitment was scheduled to begin in the following week.

Veterans Seminar/Symposium

Mr. Bunker announced that he held a GWI symposium at the end of September. He wanted to thank the participation of WRIISC personnel, to thank Dr. Klimas for presenting via video conference, to thank Georgetown University personnel for talking about chronic fatigue syndrome. He hoped to put on another such symposium the day before the next RAC meeting, so that Veterans who come to one can also go to the other. His organization received cash donations at the symposium and afterwards. He also wanted to hold a symposium in Minneapolis where there could be talks about the Gulf War MEG (magnetoencephalography) study.

Future Meetings

Dr. Hauser said that Dr. VanLeeuwen would be sending out possible dates for the 2017 meetings. He hoped for March or April, then July, and then maybe next October or November. He suggested that one meeting might focus on repositories – the Million Veteran Program repository, the DoD serum repository, and other repositories. Dr. Klimas noted that it would be very helpful not just to know what the repositories are, but what their limitations are, within the VA and outside VA. And Dr. Hauser added that it would be useful to know any privacy limitations.

Dr. VanLeeuwen reminded everyone that the RAC staff will be able to research those types of things. If people had or knew of data repositories or databases, they were asked to e-mail Dr. VanLeeuwen any

pertinent information. Dr. Klimas noted that Dr. Rosemary Toomey at Boston University has done a lot of work in this area. Dr. Jaeger said that he would send Dr. VanLeeuwen a link for an OSTP-supervised, Smithsonian-led effort on cataloging all scientific collections.

Dr. Hauser thanked everyone and called for a 10-minute break before the Public Comment session.

Public Comment

After the recess, Dr. VanLeeuwen asked everyone to take their seats to begin the Public Comments session. Each speaker would be allowed five minutes.

Mr. Charles Blanchard said he was impressed with the work the RAC was doing. He wanted to remind everyone that when Veterans are struggling it is difficult to find an hour and a half or two hours to commute to VAMCs. He also liked the idea of the video care to interact with physicians. As a reservist, he also commented that it is important to separate active duty troops from National Guard and Reserve troops. Being thrust back into the civilian is a stressor that active duty troops did not have to deal with. He did not know that he could get care through the VA until about five years ago. He asked that the RAC look at the National Guard and the Reserve troops to see if they have more problems.

Ms. Denise Nichols noted that, when the meeting agenda becomes available, it would be useful to Veterans to know if there was a specific objective for the meeting and to know the connection of each speaker's talk to Gulf War illness. She also asked if there were any new Committee members. She commented that if there is Gulf War illness training for doctors and nurses that includes CME credits, Veterans would like to know about it so they could pass that information to their primary care providers.

She also raised the issue of meeting locations. She suggested Minneapolis, Denver, Salt Lake City, Alabama (Dr. Younger's location), and Florida (where Drs. Crawford and Klimas are located). She thought that the RAC should involve researchers at medical universities for meeting sites and to inform them of meeting with something like a trifold pamphlet.

In communications with other GW Veterans, she had found out that there are concerns about pituitary gland problems, Gulf War rashes and other dermatology problems, and longer term issues like diabetes and cancer. Ms. Nichols suggested that mortality and morbidity studies should be available every couple of months. She noted that VA used to distribute data on claims, and she also thought that Veterans needed information on healthcare and the diagnoses that are showing up. She mentioned that spouses and children of GW Veterans were having health problems, and they do not know if they are related or not.

Mr. Steve Hohman began by commending the efforts of the RAC. He would like to see more collaboration between VA and DoD. He also runs into Desert Storm Veterans in North Carolina who do not know anything about the RAC or Gulf War research, and some of them work for VA. He noted that many VA doctors still have the idea that Gulf War illness is a mental issue because they are not informed or reading the research literature. In his estimation, the doctors do not want to deal with GW Veterans, and they do not understand why the tension is there. He indicated frustration with the slow pace of the research; after 25 years, it seemed to him that VA is dragging out the process out until the Veterans die.

After Dr. Hunt asked where Mr. Hohman lived, he said that he was in Fayetteville, North Carolina, and that he was going to the VAMC there. He added, however, that it was difficult to get appointments, and as soon as he gets a good doctor, he gets transferred to somebody new or the doctor disappears because he is overworked. Dr. Hunt told Mr. Hohman to get in touch if he ever needed support or advocacy around his VA care, and he pointed out that the RAC was meeting to address the problems of Gulf War Veterans and that they appreciated his input.

Ms. Nichols suggested that the WRIISCs need to add infectious diseases, rheumatology, dermatology/rashes, and possibly hematology to their consultations, and follow-up should be done after people leave the WRIISCs. Chronic fatigue and fibromyalgia should also be added as consult at the WRIISCs.

She mentioned that there would be a parade in New York on Veterans Day, November 11, and Gulf War Desert Storm veterans were invited to participate. She could provide additional information to whoever might be interested if they e-mailed her at dsnurse1@yahoo.com. There was also a parade on Memorial Day in Washington, DC. Approximately 500 Gulf War Veterans attended, and the DC VA Medical Center had a table at the meet-and-greet meeting.

Ms. Nichols suggested that there should be an opportunity once or twice a year where Veterans could call in and discuss their problems, related to research or care, with VA officials.

She noted that she had not seen Gulf War research in connection with MyVA. She wanted there to be involvement in MyVA for Veterans or their advocates.

Ms. Nichols said that the telephone line had failed when new committee members were mentioned and when Dr. McGinnis had been speaking. She asked for clarification for the former and slides for the latter. She then thanked everyone for their work for Gulf War Veterans.

Dr. Kalasinsky thanked Ms. Nichols and indicated that there were no new members on the RAC; instead VA decided to reappoint for two years the members whose terms were expiring.

Dr. VanLeeuwen said that there was not yet a date for the next meeting, but they will try to schedule all of 2017 at once. This should be helpful to the Veterans as well so that they can make their travel plans.

Dr. Ashford thanked everyone and commented that the WRIISC really wants to help out with the plan that the RAC had proposed.

Dr. Kalasinsky thanked Dr. Ashford and thanked everyone for coming to the meeting.