

# NVVLS Registry Newsletter

A Newsletter to Inform Registry Members

## Formation of the NVVLS Registry

March 2017

Issue 1

In the early 1980s there was concern regarding the health and wellbeing of Veterans who served during the Vietnam era. In response to these concerns, Congress passed Public Law 98-60 in 1983, which mandated that the U.S. Department of Veterans Affairs (VA) contract for an independent, national study looking at the frequency and effects of post-traumatic stress disorder (PTSD) and related postwar psychological issues. In 1984 the VA contract was awarded to the Research Triangle Institute (RTI), a for-profit research group, and the study was named the **National Vietnam Veterans Readjustment Study (NVVRS)**.

To determine the frequency and effects of PTSD across a 25 year period, Congress passed Public Law 106-419 in 2000. This required the VA to contract a follow-up study to the NVVRS, which was called the **National Vietnam Veterans Longitudinal Study (NVVLS)** and awarded to Abt, a for-profit research group. This follow-up study filled a critical gap in the understanding of how military service affected adjustment later in life.

A total of 1,450 Veterans participated in at least one of the NVVLS study phases, which included a paper-and-pencil health questionnaire, telephone health interview, and a telephone mental health interview conducted by a professional, clinical interviewer.

Having participated in both NVVRS and NVVLS, you and the data you provided are now part of the **NVVLS Registry**. The NVVLS Registry is housed at the Seattle Epidemiologic Research Information Center (ERIC) in Seattle, WA. The Center is one of several within the Cooperative Studies Program (CSP) of the Department of Veterans Affairs (VA) Office of Research and Development (ORD). The Seattle ERIC acquired stewardship of the NVVRS

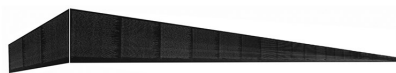
and NVVLS data in April of 2015, and modified it to function as a registry. For information about what a registry is, please see page 2.

### Welcome to the first issue of the NVVLS Registry Newsletter!

This newsletter provides a chronological history of how the National Vietnam Veteran Longitudinal Study (NVVLS) Registry was created and why we are contacting you. It also includes information about how the Registry will operate, and a little bit about us, the Seattle Epidemiologic Research and Information Center (ERIC).

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NATIONAL VIETNAM VETERAN READJUSTMENT STUDY

1984-1988



NATIONAL VIETNAM VETERAN LONGITUDINAL STUDY

2012-2013



2015-Present

# Organization of the NVVLS Registry

## What Does it Mean to Be a Registry Member?

The purpose of the NVVLS Registry is to support research on the health and well-being of Vietnam-era Veterans. The Registry is comprised of 2 parts: (1) a database of contact information, called a “registry”; and (2) research data, called a “research data repository”. The Registry contains contact information from study participants, like you, who have agreed to let us contact them about participating in future research studies. We refer to Registry participants as “members”. Currently, the research data repository includes data collected from the original NVVRS and the follow-up NVVLS.

The NVVLS Registry works by serving as a link between researchers and you, the Registry members. When a researcher is interested in conducting a study that may include Registry members or their information, they contact the NVVLS Registry staff for approval of the research idea. If approved, the researchers invite Registry members, such as you, to participate in a new study and possibly earn monetary stipend for their time. However, sometimes researchers do not want to collect new information, but want to analyze information that is already in the Registry’s data repository. In this instance, the researchers do not need to contact you.



### Seattle ERIC

The Seattle ERIC’s mission is to improve the health and health care of Veterans by promoting the principles and practices of state-of-the-art epidemiologic research within the VA. The ERIC conducts research on the frequency and causes of health conditions and their outcomes in Veterans, publishes information about the health of Veterans, and coordinates its activities with other CSP centers across the United States.

In line with the Seattle ERIC’s mission and goals, this newsletter, [NVVLS Registry Newsletter](#), was created to inform members of the research that is being conducted surrounding Vietnam-era Veterans, and to foster a relationship between the research community and Veterans like you.

***“Our mission is to advance the health and care of Veterans through cooperative research studies that produce innovative and effective solutions to Veteran and national healthcare problems.”***

***– VA Cooperative Studies Program (CSP)***

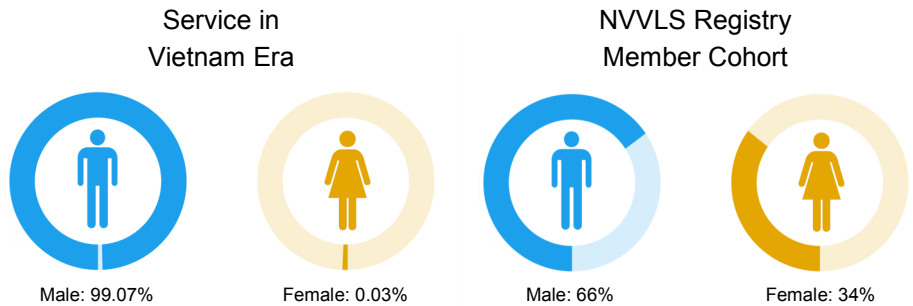
# Breakdown of the NVVLS Registry

Below are some interesting facts about the NVVLS Registry members if you would like to know about other aspects of the registry.

## Sex

The National Vietnam Veterans Longitudinal Study (NVVLS) oversampled females so that there was a better representation of females in the analysis.

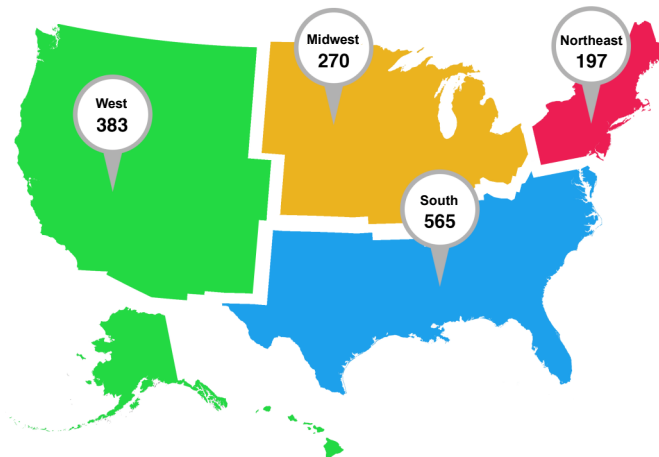
**Source:** National Center for Veterans Analysis and Statistics, NVVLS data



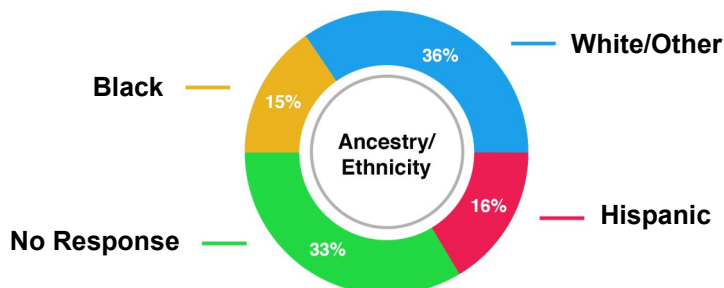
## Home

The National Vietnam Veterans Longitudinal Study (NVVLS) Registry is comprised of about 1,450 members who served during the Vietnam era. This schematic shows the breakdown of where Registry members live in the four major US Regions. Registry members live in all parts of the country and some live outside of the continental US.

**Source:** NVVLS data, 2013



## Ancestry & Ethnicity



Along with sex, both race and ethnicity were also over-sampled so that the study was able to have a good representation of Veterans that served during the Vietnam era.

**Source:** NVVLS data, 2013

# Your Rights and Protections

## How is Your Information Protected?

Before any research can take place, each proposed study requesting to use the NVVLS Registry must be reviewed and approved by the Registry and scientific and human subjects protections review boards. These review boards are committees that make sure research studies are well designed, and that your rights, safety, and welfare as a research participant and member of the Registry, are protected. Registry operations are also reviewed by the VA Privacy and Information Security Offices.

It is very important to the Seattle ERIC that your information is kept confidential, secure, and protected. The NVVLS Registry is housed on VA servers, located at the VA Puget Sound Health Care System in Seattle, WA. Only authorized research personnel can access these data, and they can only use it for research purposes. Everyone interacting with your data is bound to protect it by federal law.

## YOUR RIGHTS

You may decide to withdraw your membership in the Registry now or at any time in the future. If you withdraw, this means you will not be invited to participate in any future studies or receive further contact from the Registry. Note that any data and samples previously collected over the course of your membership may still be used for research after withdrawal. As always, the NVVLS Registry will keep all samples and data confidential, secure, and protected. If you have questions, please contact the NVVLS Registry toll-free at 1-800-329-8387 ext. 61965.

# Future Recruitment Into Studies

## When Can You Expect to Be Contacted?

When a new NVVLS Registry study is approved and requires contact with Registry members, Seattle ERIC staff will contact you by mail or telephone to see if you are interested in participating in the study.

The studies you may be contacted about might collect information in different ways. You may be asked to participate in a mailed or telephone survey, or to participate in an in-person study that might include health assessments. We will also send you an annual newsletter, like this one, that will provide updates on recent Registry activity.

## YOUR PARTICIPATION IN STUDIES

When you join a new NVVLS Registry study, you will be asked to review the informed consent form that describes the particular study in detail. Certain studies may not appeal to you. Participation is voluntary for all NVVLS Registry studies. You are free to decide not to participate in any study and still remain a member of the Registry.

If you participate in a NVVLS Registry study, the researchers will give us a copy of study data that was collected from you. We will put this data in our research data repository to combine with the information we have gathered from previous studies. We will keep this data indefinitely and it will be used and protected as described earlier.

If you participate in a study and decide you want to withdraw from that study, you may do so at any time. If you withdraw from a study, the study will keep and use any information you have already provided, but the data will be de-identified and the study will not contact you any further. The study's consent form will have specific instructions for how to withdraw.



# Seattle ERIC Projects

In addition to the NVVLS Registry, the Seattle ERIC is currently involved in the following major CSP research projects:

## Million Veteran Program (MVP)



MVP is a national research program that examines how genes affect health. The goal is to collect blood samples and health information from one million Veteran volunteers. These Veterans will be followed to study the development of disease over the coming decades. For more information, see: <http://www.research.va.gov/mvp/>

## Vietnam-Era Twin (VET) Registry



The Vietnam-Era Twin Registry (VET Registry), created in the 1980s, is a unique sample of more than 7,000 Vietnam-era Veteran male-male twin pairs and some of their family members. VET Registry studies examine the genetic and environmental causes for numerous health conditions including posttraumatic stress disorder (PTSD), heart disease, substance abuse, and cognitive decline. For more information, see: <http://www.seattle.eric.research.va.gov/VETR/Home.asp>

## Millennium Cohort Study



The primary objective of the Millennium Cohort study is to evaluate the long-term health impacts of military service, including deployments and other work exposures, on those serving in the 21st century. The study includes more than 200,000 current and former service members, and collects diagnoses, as well as measures of symptoms and health. For more information, see: <https://www.millenniumcohort.org/>

### Nicholas L. Smith, PhD

Dr. Smith is the Director of the Seattle ERIC, the VET Registry, and the NVVLS Registry. He is a Professor of Epidemiology at the University of Washington. Dr. Smith has been directing the Seattle ERIC since 2006 and has been active in VA epidemiologic and health services research for over 20 years.



*The NVVLS Registry Staff*

# Contact Update Form

Please update your contact information by filling out and returning the form below in the enclosed business reply envelope.

Title \_\_\_\_\_ First Name \_\_\_\_\_ MI \_\_\_\_\_ Last Name \_\_\_\_\_

Address 1 \_\_\_\_\_ Address 2 \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_

Zip \_\_\_\_\_ - \_\_\_\_\_ Country \_\_\_\_\_ Zip \_\_\_\_\_ - \_\_\_\_\_ Country \_\_\_\_\_

Home Phone \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Email 1 \_\_\_\_\_

Cell Phone \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Email 2 \_\_\_\_\_

Work Phone \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Other Phone \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Phone Type \_\_\_\_\_

## Mail To

Seattle ERIC  
NVVLS Registry  
VA Puget Sound Health Care System  
1660 S Columbian Way S-152-E  
Seattle, WA 98108

## By Phone

If you prefer to update by phone,  
give us a call at **1-800-329-8387**  
**ext. 61965**. *You may skip the  
operator message by dialing the  
extension at any time.*

### Not Interested?

You may decide to withdraw your membership in the Registry now or at any time in the future. If you withdraw, this means you will not be invited to participate in any future studies or receive further contact from the Registry. Note that data and samples that were previously collected while you were a member may still be used for research. As always, the NVVLS Registry will keep all samples and data confidential, secure, and protected. To opt-out, contact us toll free at **1-800-329-8387 ext. 61965**.

