

General Guidance for Gulf War Veteran Outreach and Recruitment

Successful Gulf War Veteran subject recruitment for ongoing medical research into Gulf War Illness is a multi-faceted effort, with success contingent on adequate and realistic planning. The following guidance document was developed in collaboration with Veteran subjects who served in the 1990-1991 Persian Gulf War (aka Operations Desert Shield and Desert Storm). **In order to establish an effective and sustainable outreach and recruitment plan, applicants are strongly encouraged to consider these best practices before preparing their applications.**

USE ESTABLISHED CONNECTIONS TO GULF WAR VETERANS

Recruit from an existing cohort of Gulf War Veterans

Researchers should consider recruiting from existing Gulf War cohorts whenever possible. CDMRP Gulf War Illness Research Program (GWIRP) supported cohorts are listed in the “Researcher Resources Initiative” section linked from the main GWIRP webpage <http://cdmrp.army.mil/gwirp>.

Collaborate with a Department of Defense (DoD) or Department of Veterans Affairs (VA) investigator

Consider establishing collaborations with DoD active duty or civilian researchers or a VA investigator, including investigators at the VA War Related Illness and Injury Centers (WRIISC). Such collaboration often enriches studies and facilitates access to DoD or VA databases and repositories. Applicants are encouraged to visit Federal RePORTER to identify actively funded DoD or VA investigators and their areas of interest (<https://federalreporter.nih.gov/>). For VA researchers or those collaborating with VA researchers, access to study subjects using VA resources must specifically be confirmed at the time of application submission. A letter of support, signed by the lowest ranking person with approval authority, should be included for studies involving Veterans and/or VA-controlled study materials and military and/or VA databases.

ADVERTISE TO GULF WAR VETERANS WHERE THEY LIVE

All advertisements and recruitment materials must be approved by the respective Institutional Review Board (IRB) or Ethics Committee (EC) prior to use. Local IRB/EC approval at the time of application submission is not required.

Post flyers or other media in VA treatment centers

Many ill Gulf War Veterans seek treatment at VA facilities. IRB/EC-approved flyers, pamphlets, and video kiosks placed in such facilities can garner attention from the appropriate audience. Permission for posting recruitment materials at these facilities will typically require facility approval. This permission should be specifically obtained in writing prior to application submission.

Reach out through social media

Gulf War Veterans are known to connect through social media. Posting IRB/EC-approved materials on social media sites specifically targeted to Veterans can be a powerful way to leverage a minimal investment. Gulf War Veteran-specific websites that have agreed to publish ready-made recruitment materials include the 91outcomes.com website (<http://91outcomes.com>; Email: (admin@91outcomes.com) and the “Gulf War Illnesses” Facebook page (Email: usmc1one@gmail.com). Gulf War Illness (GWI) researchers have also “tweeted” out information about their studies on Twitter.

Reach out to local Veterans organizations

The National Association of State Directors of Veterans Affairs (www.nasdva.us) may be able to provide contacts in the local/regional area. IRB/EC-approved advertising materials can be posted at Veterans organizations’ buildings and/or meetings. Contacts within local Veterans organizations can provide outreach materials to potential subjects at public or private Veteran-oriented events. These could include regular local meetings or other events, such as Veteran’s Day celebrations and certain commemoration or dedication ceremonies. Presence at a booth, kiosk, or table might attract some interest, and “working the crowd” may also produce some results. Consideration should also be given to securing a slot on the event agenda to publicly present the purpose of the study and the need for subjects as part of the event. Established GWI research institutions have successfully garnered interest by hosting their own annual “Open House” event timed near Veterans Day each year. This event includes short presentations providing overviews of the state of the science and of studies that are currently enrolling and potentially enrolling in the near future on site; interaction with the researchers; facility tours; refreshments; and a boxed lunch. Such annual events are well publicized by local media reporting, posting flyers, and inviting local elected officials to attend to help raise visibility.

Use commercial media to reach Gulf War Veterans

The cost of advertising on broadcast media (radio or television) can be high; however, local media outlets sometimes allow public service announcements for free, which may be worth inquiring about, especially if recruitment is lagging. Some researchers have reported success using billboards in Veteran-dense rural areas. Newspaper advertising may be effective in some communities, and advertising in Veteran-oriented magazines can reach a specifically targeted audience nationwide.

Reach out to treating clinicians

One approach that is not often reported is reaching out to treating clinicians at VA facilities and elsewhere to make them aware of the purpose of the study and the need for research subjects. Physicians and other caregivers may not pay much attention to flyers and kiosk presentations posted at their institutions, so direct awareness campaigns that include emails and short presentations at staff gatherings may be more effective. One approach to targeting the appropriate healthcare professionals outside of the VA could be to contact medical practice groups specializing in disorders related to the specific GWI symptoms addressed in a proposed study. For example, a study involving fatigue may garner subjects from a practice group specializing in chronic fatigue syndrome.

Consider out-of-state recruitment activities

Veterans suffering from GWI have said that they might be willing to travel cross-country to participate in research studies, provided adequate reimbursement and incentives were included. Investigators should consider the potential benefits and costs of recruitment outside of the usual catchment of the clinical research facility. See the Compensation, Incentives, and Other Accommodation Considerations section below for further information in this area.

EFFECTIVE CHOICES OF RECRUITMENT MATERIALS

Use a variety of materials

Applicants are reminded that only IRB/EC-approved recruitment materials may be disseminated and are encouraged to consider a variety of different media for advertising a study. At minimum, information provided should include a specific point of contact, including phone number, email address, and website; the location of the study, including city and state; whether travel reimbursement is provided; whether compensation is provided; and specific study benefits to study participants. Types of media can include, but are not limited to, the following:

- Printed materials
- Website materials, (PDF, Word)
- Materials for Facebook or Twitter (GIF, JPG)
- Audio/video materials for video kiosks or broadcast (video, audio, slideshows)
- Event swag, balloons, etc.
- Banners, billboards, etc.

Develop a compelling message

Many Veterans suffering from GWI are reluctant to participate in research funded by Government agencies. Some Veterans have suggested that strongly identifying the research as a Congressionally directed GWIRP effort may encourage participation.

Healthy Veterans have little motive to participate as controls, so an incentive for recruitment of healthy controls should be included. While recruitment materials must accurately reflect the study and not be coercive or offer undue inducements, researchers will find it beneficial to include a clear message and theme to gain interest in learning about the study. Suggested recruitment themes include the following:

- “Participation may help you better understand and cope with your own illness”
- “You can help up to 250,000 fellow 1990-1991 Persian Gulf War Veterans who continue to suffer”
- “You may be able to help Service Members from later conflicts who may have had similar toxic exposures”

COMPENSATION, INCENTIVES, AND OTHER ACCOMMODATION CONSIDERATIONS

Veterans suffering from GWI have suggested the expenses related to travel and lack of accommodations at the study create barriers to participation. Many of these Veterans are unemployed due to their illnesses.

Offer ample reimbursements and incentives

Investigators are strongly encouraged to provide reimbursement for costs and monetary or other forms of incentive, including consideration for control participants. Investigators should be aware that evaluation of payment proposals is performed by the respective IRB/EC to determine whether the amount and schedule of a proposed payment are ethically acceptable. At a minimum, consideration should be given to the following areas:

- Travel
- Lodging
- Meals
- Fair incentives for participation based on study activities

Physical and Logistical Accommodation of Subjects

Effort should be made during the planning of clinical studies to make Veteran subjects feel comfortable during the entire study participation process. Veteran subjects may be unfamiliar with the trial facility and may need assistance finding or obtaining transportation to the facility. Once they arrive, they may need special logistical assistance. Ill subjects can tire easily and may need wheelchair transportation. Subjects may also need directions for navigating within the facility. It is important for subjects to be assigned to a specific personal point of contact, such as a readily available staff member who can answer questions or provide assistance as needed.

STUDY EXCLUSION CRITERIA CONSIDERATIONS

In some cases, eligibility requirements prove a greater barrier to accrual of a sufficient number of subjects than does recruitment. The population of Veterans deployed during the 1990-1991 Persian Gulf War is aging, and the frequency of comorbid conditions is increasing. Finding a population of Veterans suffering from GWI that are free from exclusionary conditions and/or lifestyle practices can be difficult. Investigators should carefully consider the effects of exclusion criteria on subject accrual and attempt to balance the elimination of confounding/comorbid conditions with the need to recruit an adequate number of subjects. In some cases, it may be more practical to control for conditions than to exclude them.

ENSURE YOUR STAFF IS PROPERLY TRAINED

Gulf War Veteran subjects participating in research may be burdened with pain, fatigue, and other chronic symptoms related to their illness prior to starting a clinical research study. In some cases, these pre-existing symptoms may be intensified by participation in a study. To ensure continued participation, they should be attentively treated and given courtesy. Recruitment staff and staff on site should be taught a customer service-type model. Staff personnel are encouraged to have ready answers to frequently asked questions. Providing staff with set “scripts” is one method of assuring that study participants are given consistent answers. Staff should be trained to escalate queries or requests to higher or more knowledgeable personnel when the need arises. One resource that subjects are most consciously aware of donating is their own personal time. As such, staff should make every effort to respond to queries and requests rapidly and make the most of the time the subject or recruit has or will invest in the study.

ENSURE STUDY RESULTS GET BACK TO THE VETERAN COMMUNITY

Dissemination of aggregate, final study results as a reprint of an article or link to a journal article may meet the essential requirement; however, provision of a more lay-accessible summary would provide much more benefit to most Veterans.

In addition, test subjects are often extremely interested in results from individual tests performed during the study that may give them insight into their own condition. Informing participants of their individual results, as well as the aggregate, final study results, acknowledges their contribution and shows respect. Results dissemination plans should occur alongside protocol development when designing the study.