

Summary of the June 18, 2008 meeting to discuss the health survey

Participants: Mike Tencate, Mike White, Kim Parker-Brown, Kelly Dreyer, Scott Williams, Craig Sakai, Mary Ann Simmons, Uzo Chukwuma, Perri Ruckart, Frank Bove

General Comments:

- 1.) Participants agreed that the meeting was for discussion/planning purposes only and that final agreements on moving forward/funding would have to be vetted through the MOU/APOW process.
- 2.) Participants agreed that the Congressional language did not require a full blown study, but rather it required a survey that collected information that may be able to be used for a study in the future. However, the participants also recognized/agreed that any survey proposal that lacked a legitimate study purpose would likely not pass the OMB process.

NAS/NRC Panel on Camp Lejeune:

Agreement was reached that the National Academy of Sciences/National Research Council panel on Camp Lejeune should review ATSDR's feasibility assessment of future health studies at the base and the protocols for the future studies (i.e., the mortality study, cancer incidence data linkage study, and the health survey). If necessary, the USMC might extend the life of this panel so that they can review our protocols.

ATSDR 1999-2002 Survey:

Agreement was reached that ATSDR would provide the database to the USMC contractor by July 31, 2008 containing the necessary variables for locating (e.g., name, address, social security number, date of birth, dates of active duty on base). ATSDR will also email the contractor the names and contact information of those people who have contacted CDC or ATSDR (about 600). The USMC will have the contractor sign a nondisclosure agreement. ATSDR will compose a letter to be sent to these people by July 31. ATSDR understands that the contractor will first check with the post office to determine if the addresses are valid. For those that are not valid, the contractor will send the names and other identifying information to the IRS to forward the notification letter.

Notification Process:

USMC's contractor checks the validity of the DMDC addresses with the post office. If valid, then a notification letter is sent. If the letters are returned without having reached the recipient, or if the address was not valid to begin with, social security numbers will be sent to the IRS and the IRS will forward the letter to the recipient along with a statement that explains the IRS' role in this project. The USMC has received registrations from approximately 13,000 as of June 15, 2008 and has mailed the notification letter to about

50,000 in the DMDC database. The rest of the names in the DMDC database will be sent to the IRS so that the IRS can forward the notification letters to them.

Health Survey:

The meeting participants noted that the language in the Authorization Act mandating the health survey was vague and confusing. The language does explicitly state that ATSDR will develop the survey instrument and that the USMC will distribute the survey.

A literature review of the epidemiological literature will provide a basis for deciding what diseases will be included in the survey. Agreement was reached that the survey should be conducted in a way that enhances its scientific credibility (including confirming disease diagnoses and utilizing several mail and phone contacts to increase response rates). ATSDR will develop a hard copy as well as a web-based survey instrument. Agreement was not reached on additional epidemiological studies based on the survey results. Any additional studies/funding will need to be vetted through the MOU/APOW process.

Participants agreed to work together to develop a process to maximize participation and results. However, no specifics were agreed upon. Likewise nothing was taken off of the table. Maximum participation and accurate usable results would be the goal.

The survey will be sent to everyone in the combined database that includes: (1) all who have registered with the USMC, (2) those who have contacted CDC/ATSDR, (3) those who participated in the 1999-2002 ATSDR survey, (4) those included in the DMDC data on active duty Marines and Navy personnel who were stationed at any time at Camp Lejeune during the period, 1975-1985, (5) those included in the DMDC data on civilian employees who worked at any time at Camp Lejeune during the period, 1972-1985, and (6) a sample of 50,000 active duty and 10,000 civilian employees who were stationed at Camp Pendleton (or another USMC base without drinking water contamination) during the period 1975-1985 and who never were stationed at Camp Lejeune during the period when the drinking water was contaminated with VOCs.

Additional mailings and phone contacts to increase the response rate will be conducted by ATSDR. ATSDR proposed in the draft protocol that within two weeks after the survey is mailed, a postcard reminder/thank you will be sent to all participants as well as an email reminder/thank you if possible. A second survey mailed with a letter similar to the initial survey mailing and a second email reminder if possible will be sent to those participants who have not responded within four weeks after receiving the postcard reminder. Telephone reminders will also be conducted if participants have not responded to the survey within two weeks after the second mailing.

ATSDR requested comments from the USMC on the health survey protocol and its attachments including the survey instrument. Initial comments and questions can be provided verbally to ATSDR. Formal written comments to ATSDR are requested by the time the protocol is ready for the peer review process, by September 15, 2008.

Note: Navy/Marine Corps is reviewing the health survey and attachments and will provide comments soon.

Timeline for future studies:

ATSDR distributed a draft timeline for comment.