

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION**

and

**AGENCY FOR TOXIC
SUBSTANCES AND DISEASE REGISTRY**

convene the

OAK RIDGE RESERVATION HEALTH EFFECTS SUBCOMMITTEE

*Oak Ridge, Tennessee
August 26, 2003*

FINAL RECORD OF THE PROCEEDINGS

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Draft Minutes of the Meeting

The Department of Health and Human Services (HHS), the Centers for Disease Control and Prevention (CDC), and the Agency for Toxic Substances and Disease Registry (ATSDR) convened a meeting of the Oak Ridge Reservation Health Effects Subcommittee (ORRHES). The proceedings were held on August 26, 2003 at the U.S. Department of Energy (DOE) Information Center, 475 Oak Ridge Turnpike in Oak Ridge, Tennessee.

Opening Session and Introductions

Dr. Kowetha Davidson, the ORRHES Chair, called the meeting to order at 12:18 p.m. She welcomed the attendees to the proceedings and particularly recognized Ms. Lorine Spencer of ATSDR as the new ORRHES Designated Federal Official (DFO). Dr. Davidson opened the floor for introductions; the following individuals were present to contribute to the discussion.

ORRHES Members

Dr. Kowetha Davidson, Chair
Mr. Donald Box
Dr. Herman Cember
Dr. Robert Craig
Mr. Don Cresia
Ms. Karen Galloway
Mr. George Gartseff
Mr. Jeffrey Hill
Mr. David Johnson
Mr. James Lewis

Dr. Anthony Malinauskas
Dr. Peter Malmquist
Mr. L.C. Manley
Ms. Donna Mosby
Ms. Barbara Sonnenburg
Mr. Charles Washington, Sr.

ORRHES Liaison Representatives

Mr. Chudi Nwangwa (TDEC)
Mr. Jon Richards (EPA)
Ms. Brenda Vowell (TDOH)

Designated Federal Official

Ms. Lorine Spencer
Executive Secretary

ATSDR Representatives

Ms. Martha Boisseau
Dr. Paul Charp
Mr. Burt Cooper
Ms. Melissa Fish (OR Field Office)
Mr. Jack Hanley
Mr. Michael Hatcher
Dr. Elizabeth Howze

Ms. Sandra Isaacs
Ms. Theresa NeSmith
Ms. Marilyn Palmer
Mr. Jerry Pereira
Dr. Terrie Sterling
Dr. William Taylor (OR Field Office)

Point of Contact

Dr. Timothy Joseph (DOE)

Guests

Ms. Faye Martin (Public)

Agenda Review, Correspondence and Announcements

Agenda Review. Dr. Davidson noted the following changes to the published agenda. The discussion on the final draft report of the ORR needs assessment would begin at 2:15 p.m. instead of 2:45 p.m. The floor would be opened for public comments at 2:45 p.m. instead of 3:30 p.m. ORRHES's vote on the needs assessment recommendations at 2:55 p.m. and an open forum with ATSDR staff at 3:00 p.m. were added as separate agenda items. The presentation on next steps in health education activities was deleted from the agenda.

All other agenda items remained the same: the needs assessment overview, discussion and recommendations beginning at 12:35 p.m.; remaining work group reports, recommendations and votes beginning at 4:00 p.m.; an update on the project plan at 5:45 p.m.; and ORRHES business beginning at 6:30 p.m. Mr. Lewis pointed out that before these changes were made to the agenda, an hour was set aside for him to present the Health Education Needs Assessment Work Group (HENAWG) findings and lessons learned from the project. His presentation on the needs assessment recommendations was now included in this agenda item, but his understanding was that the full hour would still be set aside for him to present the original topics.

Regardless of the revisions to the agenda, Mr. Lewis conveyed that the meeting should still be flexible to accommodate his full presentation and other unexpected items arising from ORRHES's deliberations. He also emphasized the need for workgroup discussions to be clearly documented in writing to minimize any misunderstanding. Ms. Sonnenburg conveyed that ORRHES typically listens to presentations, engages in a discussion and takes a break before a vote is taken on recommendations. This

approach allows the members to discuss recommendations off the record before the chair calls for a vote. However, this practice was not followed in the modified agenda.

To address this issue, Dr. Davidson should ask if ORRHES is ready to vote on the needs assessment report or needs more discussion time when the floor is opened for this agenda item. Ms. Sonnenburg added that she was not aware of these changes because the agenda was revised after the Agenda Work Group developed the document. Dr. Davidson responded to the comments as follows. The revised agenda is flexible and accommodates all issues ORRHES needs to address during the meeting. The changes were based on her discussion with ATSDR staff on the previous day. ORRHES's vote on the needs assessment recommendations was added as a separate agenda item before the open forum with ATSDR because staff cannot make any comments to prejudice the vote. However, Dr. Davidson agreed to inquire about ORRHES's readiness to vote on the document when the floor is opened for this agenda item.

Correspondence. No correspondence was noted for the record.

Announcements. Ms. Spencer distributed the current membership roster and asked the members to review their contact information for accuracy or make changes as needed. She mentioned that e-mail messages to some members have been returned to ATSDR as "undeliverable."

Review of the June 2003 ORRHES Meeting Minutes

Dr. Davidson entertained a motion to approve the previous meeting minutes. Mr. Hill so moved; Mr. Washington seconded the motion. There being no abstentions, opposition or further discussion, the June 3, 2003 ORRHES Meeting Minutes were unanimously approved with no changes.

Review of Pending Action Items

Ms. Spencer provided a status report of three items listed as "pending" on the ORRHES list of recommendations and action items.

1. The Division of Health Education and Promotion (DHEP) will return to future ORRHES meetings to discuss health education programs that will be conducted in Phase II of the needs assessment.

2. ATSDR provided ORRHES with data on the uncertainties for air releases modeled in the Task 6 Report. Ms. Susan Kaplan's initial request for this information was included in the briefing packets for the current meeting.
3. Mr. Jack Hanley of ATSDR will speak with Dr. Timothy Joseph of DOE to clarify the suggestion to update the compendium of all health-related research studies conducted at Oak Ridge. The outcome of this discussion will be reported at the next ORRHES meeting.

Update on the ORR Needs Assessment

Overview. Ms. Donna Mosby, the HENAWG Co-Chair, noted that HENAWG received the final draft needs assessment report in June 2003. The document was also distributed in the pre-meeting briefing packets for review by the remaining ORRHES members. She highlighted the key outcomes of the report. The goal of the needs assessment was to facilitate health decision-making of ORR residents. The project was designed to be completed in two phases with the needs assessment being conducted in Phase I and follow-up activities being implemented in Phase II. The purposes of the needs assessment were to develop new knowledge and insights about current health concerns and needs of target communities as well as to provide a summary of the findings.

The objectives of the project were to develop a sound foundation for a health education needs assessment; conduct the needs assessment; report results to the community and project sponsors; and make recommendations for a community health education action plan. Several activities were conducted to achieve the needs assessment objectives. First, efforts were made to interact with the community. The project investigators attended ORRHES and workgroup meetings, held conference calls and gave weekly updates. Second, the ORR historical literature was reviewed. Reports on environmental exposures and health issues related to the ORR site that have been published over the past 15 to 20 years by various health departments, environmental agencies and researchers were accessed and reviewed if available.

These data were used to examine the history and context of health concerns and priorities of residents; understand current issues of residents in a broader context; and finalize questions that would be asked during key resource interviews. Project investigators ensured that key resource interviews included questions about the health and current concerns of residents, educational strategies to address these issues, and the success or failure of previous programs. However, the interviewers did not ask questions about specific health issues to avoid biasing key resource responses.

Third, interviews were held with key resources. Health concerns of area residents were identified from persons who regularly hear about these issues in their professions or volunteer work or those with knowledge of these concerns based on an extensive or long-term relationship with residents. For purposes of the needs assessment, “key resources” were defined as health care providers, public health professionals and community members. Efforts were made to ensure that all health concerns known to key resources were included in telephone surveys and focus groups. The health issues most frequently mentioned during key resource interviews were cancer, respiratory disease, neurological or mental health conditions, heart disease, as well as smoking, substance abuse and other behavioral or social-related issues.

The needs assessment report concluded that findings from the key resource interviews were consistent with health concerns cited in historical Oak Ridge literature. Fourth, telephone surveys were conducted. Health issues of most concern to residents, health information needs, mechanisms to locate health information, and preferred methods to receive information were identified. Feedback was also obtained on whether health resources can be used as a mechanism to address concerns. Of the health conditions most frequently mentioned by telephone survey respondents, 21% listed heart disease as the number one concern and 14% stated cancer was the major issue.

Fifth, focus groups were convened. These discussions were designed to obtain additional information and a deeper insight on health concerns of residents; the rationale for these concerns; and issues mentioned during the telephone surveys. Focus group data were combined with results from the other components of the needs assessment to provide input on the health education action plan. One of the most significant challenges in conducting the focus groups was the disappointingly low number of participants. Nevertheless, two focus groups were convened with workers and elderly persons. The health concerns most frequently mentioned by participants were diabetes, obesity, heart disease, cancer, berylliosis, thyroid disease, autoimmune disease and suicide. Questions asked during the key resource interviews, telephone survey and focus groups are attached to the final needs assessment report in appendices.

The conclusions of the final needs assessment report are as follows. The relatively low response rate in all components of the project may be an indication of “study fatigue” within the ORR population. The needs assessment results may not reflect the views of all ORR residents since participants were somewhat different than the study area population. Health issues identified during the project were consistent with prior ORR reports and publications; these concerns focused on cancer, heart disease and respiratory problems. Physicians were most frequently cited as the method to obtain health information, while short written materials were the preferred format. Comments about health information and educational services widely varied.

Hospital-based programs were often favored, but no single educational strategy or resource was described as the best mechanism to meet the needs of ORR residents. Health information and educational programs are clearly comprehensive strategies to meet the priorities and goals of ORR residents. The needs assessment results were used as the basis to propose a health education action plan and formulate recommendations. The purpose of this component of the project is to enhance the capacity of the ORR population to make informed decisions about health issues by disseminating current health information that is relevant to recent and ongoing community input. The major focus areas of the health education action plan were found to be follow-up activities and future studies at the ORR site.

HENAWG Findings. Mr. James Lewis, the HENAWG Co-Chair, thanked several ORRHES members for their diligent efforts in reviewing the needs assessment report and providing valuable input: Mr. Gartseff, Dr. Malmquist, Ms. Mosby and Ms. Sonnenburg. He particularly recognized Mr. Al Brooks for his contributions in assisting HENAWG. He distributed a document that outlined ORRHES's historical challenges and comments about the overall needs assessment process and also described the background of ORRHES's involvement with the project.

ORRHES charged HENAWG with specific activities: critique the overall needs assessment methodology; assess the purpose, techniques and results of the four project components; review the report; evaluate results; and present formal recommendations to the full ORRHES. HENAWG established several evaluation criteria to fulfill its charge. First, were the priorities, surveys and other methodologies in the project design of the needs assessment appropriate? Second, were geographical areas and surrounding counties identified and included in the project? Third, did George Washington University (GWU) Medical Center, the needs assessment subcontractor, accomplish the goals and objectives established for the literature review, key resource interviews and telephone surveys?

As an additional resource during its evaluation of the needs assessment report, HENAWG also reviewed statements made by President George W. Bush in the *ATSDR Final Performance Plan Report*. "The government should be results-oriented and guided not by process, but guided by performance. There comes a time when every program must be judged whether a success or failure. Where we find success, we should repeat it, share it and make it the standard. And where we find failure, we must call it by its name. Government action that fails in its purpose must be reformed or ended." Mr. Lewis opened the floor for other HENAWG members to weigh in on the final draft needs assessment report.

General

- ATSDR did not oversee its contractor or subcontractor, the Association of Occupational and Environmental Clinics (AOEC) and GWU, respectively. Due to the poor quality of GWU's telephone survey, focus groups and other activities, ORRHES should not accept the final needs assessment report.
- The purpose, goals and objectives of the project are vague, not clearly defined, not associated with specific items, and poorly stated for comparative purposes.
- GWU's flawed approach with the literature review, key resource interviews, telephone survey and focus groups does not present a strong rationale, firm foundation and solid data to build on the needs assessment and advance to Phase II activities.

Community Interaction

- GWU attended ORRHES and HENAWG meetings to obtain feedback on appropriate methods to outreach to the community and increase participation in the needs assessment. However, the techniques described in the final draft report and the extremely low participation rate in the project indicate that GWU did not implement ORRHES's suggestions.
- Figure I-1 in the report depicts interaction with the Oak Ridge area community during all seven steps of the project: the proposal, literature review, site visit, key resource interviews, telephone survey, focus groups and final report. However, GWU's communication with ORRHES dramatically decreased after the key resource interviews were conducted. Moreover, ORRHES had minimal input in the selection process for focus group participants and development of survey questions.
- Planning, marketing and community outreach strategies were weak. The advertisement seeking focus group participants was generic, vague and only mentioned "health concerns." The two newspapers where the advertisement was published and the two radio stations where an announcement about the project was broadcast were not identified in the report. Therefore, few persons outside the Oak Ridge area would see the advertisement if the *Oak Ridger* was used. The same situation would be true for the *Roane County News* because no individuals in Meigs, Loudon, Knox or Morgan counties would see the advertisement. Only one day was set aside for focus group sessions.

- GWU asked each HENAWG member and the 70 key resources to provide names and telephone numbers of potential focus group participants. The report does not describe GWU's outreach efforts to contact these individuals or the percentage of residents who accepted or declined the offer to participate in focus groups.

Telephone Survey

- The report states that GWU identified all telephone exchanges in the eight-county target area, but only 33% were used. The randomization process to select telephone exchanges was not transparent; the actual numbers GWU used were not identified as well. The 400 telephone calls made in the survey did not cover the entire Oak Ridge area. For example, one of the most impacted areas would not have been surveyed if the 376 exchange in Roane County was not used. The methodology was inappropriate and is an extreme shortcoming of the project. Sample telephone surveys should have been conducted in each of the eight target counties to ensure that all areas potentially affected by the ORR site were represented in the needs assessment.
- The report states that the needs assessment was designed to identify current health issues of residents in the ORR area and nearby counties. During the telephone surveys, however, GWU obtained information about current health issues of adult residents in Tennessee. This introduction may have contributed to the 70% of residents who refused to be interviewed. Of the 30% of telephone survey respondents, 84% were not interested in additional information about their health concerns.
- GWU did not mention uranium or other specific contaminants to avoid biasing the telephone surveys, but this technique yielded extremely generic responses. The needs assessment should have been conducted in a manner similar to the ORR dose reconstruction. This project was more specific and generated meaningful results that could be tracked. GWU's approach with the telephone surveys is questionable and does not validate the project.

Focus Groups

- HENAWG spent a considerable amount of time and effort in identifying 15 categories of residents who should be contacted as focus group participants, including former ORR workers; surviving relatives of deceased persons; long-term residents downstream of the Clinch River; persons with long-term exposures to airborne plumes; children with genetic defects; and persons with long-term exposures and illnesses not directly related to ORR releases. HENAWG did not recommend hardly any of the categories GWU selected to participate in focus groups: mid-life women, long-term elderly residents, persons with respiratory diseases, cancer patients, heart disease patients, ill workers, and three groups of general residents. The final draft report does not list the 15 categories originally identified by HENAWG.
- The methodology to recruit focus group participants was severely flawed. The majority of information gathered during the focus groups was from eight workers, but onsite exposures among this population are beyond ATSDR's mandate and ORRHES's charter. The only other focus group was convened for elderly persons; only one individual participated.
- GWU did not review successful techniques that have been used to convene focus groups at other sites. For example, clergy, teachers and other groups trusted by the local community were extensively involved in recruiting participants.
- Key resources and focus group participants were interested in health information or education from credible and trustworthy sources only. The low participation rate in the focus groups suggests that the ORR community did not find GWU to be credible.

Key Resource Interviews

- The report mentions that physicians and other key resources at the ORR site rarely returned GWU's telephone calls. The low response rate was heavily impacted by GWU's location in Washington, DC and its inability to directly interact with key resources on a regular basis. GWU should have asked the Oak Ridge Field Office to hold face-to-face meetings with key resources and gather information.

Literature Review

- GWU was provided historical data from technical reports, telephone surveys, interviews, focus groups and other activities conducted at the ORR site over the past ten to 20 years. Dr. Henry Falk, the ATSDR

Assistant Administrator, made statements to GWU about the project during the January 2001 ORRHES meeting. He hoped that the ORR needs assessment would assist in defining and clarifying concerns and issues and would also help ATSDR's focus in completing site activities. Dr. Falk also informed GWU of ATSDR's efforts in gathering community needs and concerns at the beginning of the project. Despite its access to ORR historical data and knowledge of Dr. Falk's comments, GWU did not provide a detailed summary of community concerns in the final draft needs assessment report.

- GWU did not apply significant outcomes from historical data. For example, the final draft needs assessment report states that "study burnout" contributed to the low participation rate in the project. The state of Tennessee reached the same conclusion in the ORR dose reconstruction eight years previously.
- The report misinterprets historical data in some instances. For example, Table III-3 shows K-25 water contamination from 1940 to 2000, but K-25 was not built in 1940.

Public Comment Period

The Chair called for public comments on the needs assessment only; no attendees responded.

Update on the ORR Needs Assessment [continued]

HENAWG Recommendations. Mr. Lewis noted that the recommendations on the final needs assessment report are a direct result of HENAWG's findings from its critique of the overall methodology; assessment of the purpose, techniques and results of the four project components; review of the final draft report; and evaluation of the results. Ms. Mosby read HENAWG's formal recommendations into the record.

The Needs Assessment Working Group (NAWG) of the Oak Ridge Reservation Health Effects Subcommittee (ORRHES) recommends that the ORRHES adopt the following recommendations and submit them to the Agency for Toxic Substances and Disease Registry:

"Whereas, the report, *Assessing the Health Education Needs of Residents In the Area of the Oak Ridge, Tennessee – Final Report May 23, 2003*, has been received by the NAWG and has been reviewed by members of both NAWG and the broader ORR community, and

Whereas, the totality of the many and diverse comments have been collected in detail and summarized by an ad hoc NAWG committee in an attached report, *Summary and Compilation of All Comments on the GWU Health Education Needs Report*, and

Whereas, the collected comments reveal serious deficiencies in the report and generally reject the report as a further basis for any Public Health Education Program (PHEP), be it therefore

Recommended that the subject report not be used as the basis for any future public health education program conducted in the ORR region, and be it further,

Recommended that any future ATSDR/PHEP activities related to PHA be based upon the findings of the Public Health Assessment Program (PHAP) which should, with the advice of ORRHES, ascertain the following:

- 1) The degree to which releases of contaminants from the DOE sites contributed to regional public health problems,
- 2) The degree to which there is a need for additional public health educational services,
- 3) The degree to which the existing Public Health and medical services establishment can supply any substantive unmet public health education needs in both the rural and urban areas,
- 4) The degree to which ATSDR might meet any additional needs by augmenting the current system by printed material or presentations by experts. Not to do this will very probably result in the duplication of much effort as well as be an affront to the existing health care system,
- 5) The degree to which any necessary educational effort can avoid the onus of distrust that has cursed all previous efforts,

and be it further,

Recommended that ATSDR examine the project structural and management components which enabled the report and project to reach this state without ATSDR overview and without subcommittee or working group review that could have remedied its shortcomings.”

The recommendations and comments on the final draft needs assessment report were submitted into the record and are collectively appended to the minutes as Attachment 1. A motion for HENAWG’s formal recommendations and supporting materials to be adopted and forwarded to ATSDR was properly made and seconded by Dr. Malmquist and Ms. Sonnenburg, respectively. There being no abstentions, opposition or further discussion, the motion unanimously carried.

HENAWG Lessons Learned. Mr. Lewis conveyed that three major issues caused problems with the needs assessment process. First, ATSDR management did not perform periodic reviews of key steps. This approach would have provided an opportunity for HENAWG to inform GWU if efforts from previous site activities were being duplicated; if ORR historical data were being fully utilized; and if next steps in the project were appropriate. Regular status reports also would have provided an opportunity for ATSDR and HENAWG to review and modify the project time-line as needed. For example, in November 2000, HENAWG asked ATSDR to present a model needs assessment to strengthen the knowledge of the members in evaluating the ORR study. ATSDR did not respond to this request for nearly 28 months, but HENAWG met its deadlines in providing ATSDR with target areas and contact information for potential focus group participants.

GWU informed HENAWG of problems associated with Institutional Review Board approval, but these delays should have been anticipated when the project was originally developed and the time-line should have been modified accordingly. Poor planning and management of the project indicate that the time-line was not thoroughly reviewed before being presented to HENAWG. Overall, the lack of oversight resulted in a product that failed to meet ORRHES’s expectations.

Second, the decision by ATSDR management to block collaboration between HENAWG and GWU resulted in a loss of trust and suspicion in the needs assessment effort. After a HENAWG meeting, GWU refused to communicate with and provide feedback to the members. As a result, HENAWG was forced to conduct its activities without input from GWU. Third, GWU’s failure to identify historical health concerns from the literature or obtain similar information from the needs assessment interviews or telephone survey resulted in a loss of critical data essential to the public health assessment (PHA) effort and the community. According to ATSDR’s *Public Health Assessment Guidance Manual*

(PHAGM), environmental data, community health concerns and health outcome data are the three major components of a PHA.

The PHAGM further states that community health concerns associated with a site constitute a key data point for all PHAs since this information is needed to evaluate exposures and health effects. Dr. Falk has made statements that are consistent with the PHAGM, but ATSDR's implementation of these guiding principles is questionable. During the June 2003 ORRHES meeting, for example, Dr. Falk noted that public comment periods are not an effective mechanism to engage the public and address community health concerns. A review of historical data to capture comments previously voiced by residents in various counties would yield more meaningful results.

As evidenced in its recommendations to ORRHES, HENAWG has rejected the outcomes in three of the seven steps of the needs assessment: key resource interviews, telephone survey and focus groups. If ATSDR accepts ORRHES's recommendations, the needs assessment will revert back to the literature review outlined in step two of the study design. Mr. Lewis acknowledged that HENAWG is uncertain about the future direction of the project at this time. However, the ORR community deserves a solid product and an accurate accounting of health concerns at the site, particularly since ATSDR and ORRHES have devoted nearly three years to the needs assessment. Several actions can be taken to improve overall performance and meet the needs of the ORR community.

A mechanism should be developed to identify and fully utilize existing resources. ATSDR should provide ORRHES with additional details about the health education plan and the process by which this activity will be integrated with documented community concerns. Some activities conducted by ORRHES workgroups should be combined to complete the needs assessment in a more efficient and timely manner. The goals and time-line of the project should be clearly defined in writing; concrete examples of needs assessments completed at other sites should be provided to HENAWG as well. ATSDR should seek input and support from ORRHES.

Despite these deficiencies, Mr. Lewis was pleased that ATSDR's efforts to gather community concerns and issues have significantly improved over the past three months. New staff members with community expertise have been hired; ATSDR has a stronger presence at workgroup meetings; and documents about ORR site activities are more widely disseminated. He clarified that HENAWG's critique of the needs assessment is not intended to dwell on past mistakes. Instead, ATSDR should use the lessons learned to develop a solid plan and advance to next steps in the project.

Open Forum with ATSDR. Dr. Elizabeth Howze, the DHEP Director, thanked Mr. Lewis and the other HENAWG members for contributing their time and effort in providing

valuable input during the needs assessment process, critiquing the final draft report and formulating solid recommendations. She emphasized that DHEP is committed to engaging in a collaborative effort with ORRHES to develop health education activities at the site. DHEP will also be responsive to issues and concerns ORRHES and the community have raised about the project. Similar to ORRHES, ATSDR also learned several lessons about the needs assessment and has expressed similar concerns about the final draft report.

The document did not meet DHEP's expectations of a needs assessment since this activity is specifically designed to identify information, programs and other activities that will be useful to a site in the future. DHEP is currently discussing its concerns and lessons learned about the needs assessment with GWU. ORRHES's comments, findings and formal recommendations will be communicated to GWU as well. Dr. Howze clarified that the cover page shows the May 23, 2003 version as a "final report," but the document is actually a draft. A final report will be developed to reflect ORRHES's concerns and formal recommendations and also to incorporate additional data requested by ATSDR. In the future, ATSDR will clearly define its expectations of a needs assessment before the project is developed. The community will be actively engaged throughout all components of the study. ATSDR will provide much more oversight and follow-up of its contractors.

Dr. Howze was pleased that despite the problems with the needs assessment, ORRHES is still willing to partner with DHEP in the project and advance to next steps. As an initial effort, DHEP proposes to meet with ORRHES to jointly identify and discuss the future direction of environmental health-related activities at the ORR site. She acknowledged that ATSDR is fully aware of the need for federal agencies to communicate with the community when site activities are conducted. As the first step in this direction, DHEP looks forward to its partnership with ORRHES in addressing critically important issues in the community.

Dr. Cember pointed out that the target audience is not clearly identified in the needs assessment report. The "community" covers a wide range of diverse populations, including physicians and kindergarten students. Dr. Howze agreed that this issue was another shortcoming in the report. A needs assessment should provide guidance in identifying residents with specific needs in certain geographical areas of a site, such as those who believe they are at higher risk of exposure or those who believe they need health information. She acknowledged that the ORR needs assessment failed to produce this information.

Ms. Sonnenburg noted that ATSDR contracted AOEC and GWU to conduct the needs assessment before ORRHES was established. Since the decision to focus on health education needs at the site was made without feedback from the members, ORRHES

was not provided an opportunity to discuss the needs of the community and provide input on this issue early in the process. Although the ORR community can benefit from a needs assessment, the need to include "health education" in the project is uncertain. Based on Ms. Sonnenburg's experience, ORR residents are more interested in prevention, care and treatment of environmental health problems rather than health education.

Dr. Howze recognized that many residents often misinterpret health education as a classroom lecture, but the activity actually has a much broader scope. For example, a community member with exposure to a contaminant may present to a physician who has no knowledge or skills to address environmental health concerns. This situation would cause stress to the physician, patient, family members and ultimately the broader community. To address this concern, ATSDR would provide educational materials and hold training sessions to strengthen the capacity of local providers to diagnose, counsel, treat and follow patients with environmental health problems. In conducting health education activities, ATSDR also attempts to identify and utilize resources within the community. For example, many residents have expertise in health care, while others serve as strong leaders at the local level.

Mr. Lewis mentioned that ATSDR has completed several successful health education projects, such as materials on iodine-131 for the Hanford site and the chelation videotape. He questioned whether ATSDR plans to duplicate some of these models in the ORR community. Dr. Howze confirmed that ATSDR tailors environmental health materials for a particular site and distributes information to address specific concerns of the community. However, she reiterated that the decision to disseminate health education materials or conduct other types of projects at ORR will be made in full partnership with ORRHES. ATSDR will also seek ORRHES's input on appropriate target audiences, effective delivery methods, and the proper strategy to translate scientific data for the lay public.

In the interim of these discussions, Dr. Howze described two site-specific health education projects for ORRHES to consider. After past chemical releases in Toms River, New Jersey were found to be the source of a cancer cluster among young persons, ATSDR attended public meetings, discussion groups and other events held by the community. ATSDR also met one-on-one with individual residents. In response to the community's request, ATSDR facilitated grand rounds on leukemia and children's health with local physicians. ATSDR also partnered with the school system to develop an environmental health curriculum and train teachers in disseminating age-appropriate materials and educating students in grades K-12. The legacy of the environmental health curriculum is a direct result of ATSDR's extensive interaction with the Toms River community.

Dr. Howze also reported that in Fallon, Nevada, ATSDR assisted residents in developing a focused community response to childhood deaths from leukemia. The community provided support to affected family members by ensuring that mental health services and other programs were more accessible. Under the community response plan, agencies at federal, state and local levels actively involved Fallon residents in the ongoing investigation at the site. Mr. Washington agreed with Ms. Sonnenburg that the needs assessment will be beneficial to the ORR community. Residents are interested in obtaining credible information about fish, vegetable or milk consumption, air emissions, breast-feeding, exposure to contaminants, and other potential risks from living near the ORR site.

Mr. Washington was confident that solid data produced by the needs assessment will allow the community to separate fact from fiction. Dr. Howze confirmed that DHEP will communicate scientifically sound results from the needs assessment to the Division of Health Assessment and Consultation to ensure public health assessors apply these findings to ORR PHAs. Mr. Johnson noticed that ATSDR's health education activities are targeted to providers. He asked if similar products have been developed for community residents. Dr. Howze replied that ATSDR has not developed community-based health education initiatives, but several projects are underway in this effort. A pilot program was recently launched and a community toolbox with information, references and other resources for residents is currently being developed.

Dr. Howze added that generic community-based health education activities are extremely difficult to design because issues, concerns and other site characteristics are different in each community. As a result, ATSDR partners with the community to tailor materials and activities that will be specific, appropriate and relevant to the site. In some areas, ATSDR is training local spokespersons, influential residents and other community leaders about health concerns and scientific issues at the site. The lay health advisors then educate the broader community and disseminate health education materials. This approach increases public access to health information.

Dr. Davidson acknowledged that the majority of ORRHES's comments on the needs assessment were directed to GWU. As the contractor of the project, however, AOEC had a responsibility to oversee GWU's activities. AOEC should have thoroughly reviewed and approved GWU's deliverables before submission to ATSDR. Dr. Howze emphasized that ATSDR does not plan to subcontract any of its activities in the future. Moreover, ATSDR expects to develop Phase II of the ORR study in collaboration with ORRHES rather than use AOEC as a contractor on the project.

Dr. Malinauskas strongly suggested that ORR historical data be reviewed to strengthen the final needs assessment report. Specific concerns previously voiced by ORR residents and needs that were identified at the site should be included in the final

document. This approach may address study fatigue at the ORR site that contributed to the low participation rate in the needs assessment. Dr. Malinauskas noted that the final draft report indicates GWU ignored existing data. Dr. Cember described a model for ATSDR to consider in providing environmental health education to physicians. A program was developed to increase the knowledge of physicians in radiation. Training sessions were held at a resort hotel for one weekend each year for ten years. Attendees who completed the course received continuing medical credits. The program was eventually tailored to school teachers.

Dr. Howze agreed that federal agencies must explore innovative methods to increase health education to both physicians and the community. She pointed out that the clergy, teachers and other resources in the community could assist in this effort. Dr. Davidson thanked DHEP staff for attending and participating in the open forum. Based on the discussion, she charged HENAWG as follows. The members should closely collaborate with DHEP to identify next steps in the health education process for the ORR site; develop a strategy to achieve these goals; and present the plan to ORRHES for review, comment and approval. HENAWG should be prepared to present the plan no later than the December 2003 ORRHES meeting. Any HENAWG member who needs clarification on the new charge should contact Dr. Davidson.

Dr. Howze asked ORRHES to consider two additions to the charge. First, the plan should also include a clearly defined process for DHEP to collaborate and communicate with HENAWG and ORRHES. Second, HENAWG should be renamed to ensure that the members and DHEP begin developing health education activities for the ORR site without dwelling on past mistakes in the needs assessment. Dr. Davidson amended the charge to include Dr. Howze's suggestions. The members should develop a strategy for DHEP to collaborate and communicate with ORRHES and HENAWG. The members should review and discuss HENAWG's current role as outlined in the ORRHES bylaws.

If HENAWG determines that its purpose should be redefined and updated and the change requires a modification to the ORRHES bylaws, Dr. Davidson will assign this task to the Guidelines and Procedures Work Group. Ms. Sonnenburg asked the HENAWG co-chairs to invite Ms. Adkins and Ms. Kaplan to future meetings with DHEP. These ORRHES members can offer insights about the community's lack of trust with local physicians that have been expressed by some residents. Ms. Mosby clarified that both Ms. Atkinson and Ms. Kaplan are HENAWG members.

Public Comment Period

The Chair called for public comments; no attendees responded.

Work Group Reports

Public Health Assessment Work Group (PHAWG). Dr. Malmquist mentioned that the members were charged with reviewing cancer incidence data at the ORR site and reporting these findings to ORRHES. In conducting this activity, however, PHAWG realized that a health statistics review (HSR) by ATSDR and the Tennessee Department of Health (TDOH) Cancer Registry would be more appropriate. PHAWG is now asking that its charge be amended to conduct the HSR rather than collect cancer incidence data. The members have already drafted a rough outline for the project. In collaboration with the TDOH Cancer Registry, Ms. Dhelia Williamson of ATSDR will collect existing data from the registry from 1990-1996 on 26 different types of cancer. Cancer incidence data by county and region will be compared to the state and age adjusted for each county.

TDOH will not release cancer incidence data by census tract due to the small population and the ability for individual residents to be identified. However, efforts will be made to identify cancer clusters in census tracts. The HSR will not be designed to link cancers to a contaminant or other source. Instead, the project will focus on the incidence of cancer at the ORR site from 1990-1996 only. PHAWG, Ms. Williamson and Dr. William Taylor of the Oak Ridge Field Office will convene a conference call within the next two weeks to review the draft outline and discuss next steps in the HSR. PHAWG hopes to present a status report of the project by the December 2003 ORRHES meeting.

Mr. Lewis proposed that all health outcomes at the ORR site from 1990-1996 be included in the HSR, but Dr. Malmquist did not support this suggestion. Although Dr. Cember agreed the HSR should only focus on cancer, he pointed out that the name is misleading. He clarified that a "cancer statistics review" (CSR) would be more appropriate. ORRHES accepted the name change by general agreement. A motion to approve the recommendation was properly made and seconded by Ms. Sonnenburg and Dr. Malinauskas, respectively. PHAWG will conduct the CSR in collaboration with ATSDR and the TDOH Cancer Registry. The CSR will be implemented in ORRHES's geographical area of concern to support the PHA process. There being no abstentions, opposition or further discussion, the motion unanimously carried.

Dr. Davidson called ORRHES's attention to the second PHAWG recommendation that was distributed in the pre-meeting briefing packets. PHAWG requested that the U.S. Environmental Protection Agency (EPA) Headquarters and Region IV be invited to a future ORRHES meeting to address concerns about the ORR site and discuss procedures EPA uses to interact with ATSDR and ORRHES. Dr. Davidson explained that PHAWG's recommendation is based on two different sets of comments EPA Headquarters and Region IV submitted to ATSDR on the Y-12 uranium PHA. ORRHES was understandably confused and negatively impacted by this process. She asked if

Headquarters and the specific EPA region for a site attempt to reconcile comments on public documents.

Dr. Malinauskas pointed out that the lack of communication was another concern with this process. ORRHES discussed the article that was published in a local newspaper regarding the response by EPA Headquarters to the public comment version of the PHA on uranium releases from the Y-12 plant. Mr. Jon Richards of Region IV weighed in on PHAWG's recommendation from EPA's perspective. Although comments by Headquarters were more detailed than those by Region IV, both sets were consistent. Region IV reviewed all comments on the Y-12 uranium PHA made by Headquarters before submission to ATSDR and also convened conference calls with ATSDR to resolve any differences. Headquarters and Region IV submitted comments on the PHA by e-mail only to ATSDR and an ORRHES member upon request.

Comments by Headquarters were published in a newspaper through actions taken by an ORRHES member; EPA played no role in disseminating the comments to the media or public. Overall, Headquarters can become involved with any EPA activity throughout the country either independently or through the specific region for the site. Dr. Charp and Mr. Hanley weighed in on PHAWG's recommendation from ATSDR's perspective. ATSDR disagrees with EPA's position that comments between Headquarters and Region IV were consistent. Nevertheless, ATSDR will respond to the two sets of comments submitted by both Headquarters and Region IV. One set of comments was in response to the initial release, while the other set addressed the public comment draft.

ATSDR generally communicates with Region IV for ORR activities, but Headquarters specifically requested a copy of the Y-12 uranium PHA. ATSDR received comments on the initial draft from Region IV and then received comments from Headquarters two months later after the public comment draft was released. The comments from EPA Headquarters related to the initial draft of the document; many of the comments had previously been addressed in the public comment version of the document. ATSDR will present its responses to comments by Headquarters and Region IV to both PHAWG and ORRHES. The difference between versions of documents is as follows. ATSDR only distributes an initial release or data validation document to DOE, EPA, the state or other agency involved with the activity. The purpose of this draft is for agencies to provide ATSDR with additional data, correct existing information in the report and submit comments.

For ORR activities, ATSDR agreed to also release data validation documents to ORRHES for review and comment. Despite this consideration, however, other agencies are still not required to submit comments on initial drafts to ORRHES. A data validation document serves as an internal government working draft and is not shared with the

public. ATSDR revises the initial draft based on comments from the agencies and then widely releases the document to the public. Similar to EPA, ATSDR also has no knowledge of actions that were taken to distribute initial draft comments by Headquarters to the media and ORR community.

The publication confused ORRHES because comments in the newspaper related to the initial draft that ATSDR had previously addressed. Initial draft comments by Region IV were not leaked to the public. Dr. Davidson acknowledged that other agencies are not required to communicate with ORRHES, but adverse effects on the ORR PHA process from any source must still be conveyed. Ms. Mosby pointed out that this problem is another example of members fighting the ORRHES process. Her position was that ORRHES members cause more harm to the advisory process than agencies. Mr. Lewis indicated that the leak of EPA's comments to the media and public stems from frustration in the community. If ORRHES convenes effective meetings and produces solid products in a timely manner, these types of problems will significantly decrease. Based on Mr. Richards' remarks, Dr. Malinauskas suggested that PHAWG's recommendation be withdrawn. No motion was made to approve the recommendation.

Communications and Outreach Work Group (COWG). Mr. Lewis underscored the need to emphasize key presentations in ORRHES meeting minutes. He plans to recommend to COWG that comments made by Dr. Falk during the June 2003 ORRHES meeting be incorporated into the record. This approach is extremely important since messages conveyed by Dr. Falk do not always filter down to ATSDR staff. Dr. Falk's comments also need to be reviewed to identify the impact on ORRHES.

Agenda Work Group (AWG). Ms. Sonnenburg plans to discuss with the members at the next meeting whether AWG is still needed.

Guidelines and Procedures Work Group (GPWG). Ms. Galloway reported that the members have not met, but a process to correct minutes for all ORRHES workgroups is on the GPWG agenda. GPWG plans to meet soon to review a rough draft Ms. Galloway is currently developing. The new guidelines for correcting and editing workgroup meeting minutes will be based on a previously developed process as well as comments from ATSDR. Ms. Galloway plans to present the document to ORRHES at the next meeting for review and approval.

Mr. Lewis pointed out that workgroup members should specify the type of document needed, such as detailed minutes, a verbatim transcript, a record of discussion or minimum requirements of minutes based on Roberts Rules of Order. Solid meeting minutes will result in less challenges from the public. Most notably, key activities completed by the workgroups should be clearly documented to increase public awareness and sustain a strong legacy at the ORR site.

Public Comment Period

The Chair called for public comments; no attendees responded.

Update on the Project Plan

Mr. Jerry Pereira, the ORR Project Manager, covered the following issues in his status report. One, ORRHES should be responsible for information ATSDR presents and should also take ownership of its completed activities. Based on its limited number of years in operation, ORRHES has been the most successful health effects subcommittee in communicating with and providing feedback to a federal agency. This guidance continues to be extremely valuable to ATSDR. Two, ATSDR and the CDC National Center for Environmental Health are currently being consolidated. Dr. Falk was recently appointed as the new director of the combined agency. The transition will require the full attention of Dr. Falk and other senior personnel over the next few months.

The consolidation at the director's level is scheduled to be completed by October 1, 2003. Functions by both agencies are not expected to change. Three, the PHAGM is currently being updated with a chapter solely devoted to community involvement. Four, new personnel have allowed ATSDR to become more proactive and make improvements despite budget constraints. Management and operation of the Oak Ridge Field Office have significantly improved with the addition of Dr. Taylor and Ms. Melissa Fish. Administrative tasks, clerical duties, data entry and filing are now completed on a more timely basis. In her new role as the DFO, Ms. Spencer will continue to extensively interact with ORRHES.

Five, all public documents produced by ATSDR will continue to undergo a management review, but Dr. Falk recently instituted a "focus site review." ATSDR defines these communities as high-priority sites with significant visibility from Congress, the media, public or other sources. ATSDR classifies ORR as a focus site. All documents ATSDR releases or reissues from a focus site are subject to this type of review. The process has not had a major impact on ORRHES activities to date, but the project plan will be delayed to some degree. For example, time to conduct a focus site review must be incorporated into each ORR PHA. The new policy will require ATSDR and ORRHES to identify community needs for the specific PHA, such as a public availability session, fliers, newsletters or a public meeting in the community.

A focus site review must also be integrated into all ORR community involvement activities. Ms. Spencer will continue to provide support in this effort and Ms. Marilyn Palmer, the ORRHES Committee Management Specialist, will play a greater role in

these projects. Additional staff will be temporarily assigned to specific activities on an as-needed basis. Six, the terms of all members currently seated on ORRHES are scheduled to expire in December 2004. Since ATSDR expects to complete all activities on the project plan no later than June 2005, a request will be made to extend the terms of all ORRHES members with an interest in continuing to serve for 180 days past December 2004. However, Mr. Pereira has no knowledge whether the request will be approved.

To date, ATSDR has been unsuccessful in its efforts to fill current ORRHES vacancies with a sick worker and physician. However, the ability of new members to make valuable contributions and a strong commitment to ORRHES is more important than the category of the individual selected. Current members can suggest names of potential candidates for ATSDR to consider at any time so long as a completed application packet is submitted. Seven, the current status of the ORRHES project plan is as follows. The screening of current chemical exposures was initially designed to be included in each PHA as an executive summary, but the activity has now been added to the project plan as a new standalone PHA. The PHA is ahead of schedule with an initial release date targeted for July 2004.

The PHAs for PCB releases and TSCA incineration are both on schedule and were initiated in August 2003. The K-25 uranium releases PHA is also on schedule and will be initiated in September 2003. Four PHAs are currently delayed. The final version of the Y-12 uranium releases PHA was due on August 26, 2003. ATSDR plans to complete and distribute the document during the October 2003 ORRHES meeting. The delay was caused by postponement of a recent ORRHES meeting, the focus site review and extension of the public comment period. ATSDR distributed the initial release of the White Oak Creek (WOC) releases PHA to PHAWG on July 28, 2003, but the data validation is delayed by two months. ATSDR expects to distribute this version of the document in October 2003. The delay was caused by the focus site review and development of the PHA.

Dr. Taylor has taken responsibility for the Y-12 mercury PHA and is developing a step-wise approach that will be presented to PHAWG. This process will be related to the dose reconstruction, key technical reviews and comments. ATSDR discussed current exposures with PHAWG in April 2003; Dr. Taylor will address past exposures in the new approach he is developing. ATSDR expects to release the PHA early in 2004. The additional activities undertaken by Dr. Taylor will not adversely affect the time-line of any PHA. The iodine-131 PHA is delayed by three months. Dr. Charp has taken responsibility for this activity and will present a plan to address iodine-131 to both PHAWG and ORRHES by the October 2003 meeting.

Mr. Pereira and other technical staff will continue to closely monitor the focus site review process to ensure current delays do not increase. If the new policy begins to significantly affect the ORRHES project plan, Mr. Pereira will inform Dr. Falk that more time and resources are needed. Dr. Malinauskas noticed that the project plan requires PHAWG to review the PHAs in rapid succession. He asked ATSDR to stagger the schedule to provide PHAWG with down time between each document review. Mr. Pereira confirmed that ATSDR will incorporate as much down time as possible for PHAWG so long as the PHAs are reviewed by the time the members' terms are scheduled to expire. He also committed to incorporating DHEP's activities with HENAWG into the project plan. Although Dr. Davidson found the project plan to be optimistic, Mr. Pereira indicated that completing the schedule is feasible barring any unforeseen circumstances.

Unfinished/New Business and Outstanding Issues/Concerns

Ms. Spencer called ORRHES's attention to the "Gallup Stakeholder Engagement Survey" distributed in the pre-meeting briefing packets. The web-based survey was conducted by the General Services Administration Office of Government-wide Policy (OGP) on December 13, 2002-January 22, 2003. The purpose of the survey was to provide OGP with a standardized method to collect performance measurement data related to stakeholder engagement. Ms. Spencer provided ORRHES with basic information about the project, including the background, list of survey questions and response rate.

The complete survey was displayed on the table of meeting materials for the members to review; two copies will be available for viewing at the Oak Ridge Field Office. The members can also view the on-line survey at the web site listed in the pre-meeting briefing packets. Since ATSDR did not have e-mail addresses for all ORRHES members, some persons did not participate. However, the ORRHES master roster is currently updated to ensure that members with up-to-date information will be included when the survey is repeated in 2004.

PHAWG generally agreed to reschedule its next meeting to September 2, 2003 due to the federal holiday on September 1, 2003. Mr. Hill pointed out that the final draft needs assessment report shows heart disease as one of the most significant health concerns voiced by telephone survey respondents and focus group participants. He did not recall ORRHES's focus on this issue or DOE's release of heart disease studies. Based on the concern expressed by the ORR community, Mr. Hill suggested that ORRHES review the incidence of heart disease at the site to determine whether this condition is related to the environment. Dr. Davidson confirmed that health issues unrelated to ORR releases can be addressed within the health education needs assessment process.

Mr. Lewis added that at a future meeting, ATSDR should explain to ORRHES the process and limitations in evaluating health outcomes other than cancer. He informed the members that PHAWG reviewed the ATSDR web site to obtain information on performance measures. The web site showed that ATSDR "exceeds its targets" with PHAs, but PHAWG was unable to locate the ORR site in the performance plan. PHAWG discussed the possibility of inviting Mr. Peter McCumiskey, the ATSDR Deputy Assistant Administrator, to a future meeting to outline ORRHES's position in the performance plan.

Dr. Charp explained that ORR is more complex than ATSDR's other Superfund sites due to its multiple facilities, waste sites and contaminants. Of the 18 DOE sites on the National Priorities List, ATSDR ranked ORR in the middle in terms of complexity. Moreover, ATSDR has chartered committees under the Federal Advisory Committee Act only for ORR and Hanford. Ms. Spencer was pleased to announce that ATSDR has taken stronger efforts to improve the ORRHES web site. ATSDR is exploring a proposal to redesign the web site to be more user-friendly as well as to incorporate a cross-index of issues. A budget proposal will be submitted to request funding to accomplish this task. ATSDR will update ORRHES on whether or not the proposal was approved.

Mr. Pereira mentioned that after Ms. Spencer and Ms. Palmer are trained in providing minor updates to the ORRHES web site, approved meeting minutes and an updated calendar are expected to be posted in a timelier manner. Mr. Hill inquired about the status of a previous suggestion to hold future ORRHES meetings in locations other than Oak Ridge. He noticed that public attendance at recent meetings has dramatically decreased. Dr. Craig proposed that PHAWG's future meeting on the WOC PHA be held in the White Oak area around Kingston. Dr. Davidson advised each workgroup to meet with the DFO to discuss the logistics of convening future meetings at locations other than Oak Ridge.

New Action Items

Ms. Spencer reviewed the action items raised during the meeting.

- DHEP to present examples of health education projects completed at other sites during the October 2003 ORRHES meeting.
- Mr. Pereira to distribute the revised PHAGM to ORRHES after the document is approved for release.
- Dr. Charp to present a plan to address iodine-131 during the October 2003 ORRHES meeting.

Housekeeping Issues

No announcements were made for the record.

Closing Session

The next ORRHES meetings will be held on October 21, 2003 and December 2, 2003. There being no further business or discussion, Dr. Davidson adjourned the ORRHES meeting at 5:31 p.m.

I hereby certify that to the best of my knowledge, the foregoing Minutes of the proceedings are accurate and complete.

Date

Kowetha A. Davidson, Ph.D., D.A.B.T.
ORRHES Chair

Glossary Key

AOEC	—	Association of Occupational and Environmental Clinics
ATSDR	—	Agency for Toxic Substances and Disease Registry
AWG	—	Agenda Work Group
CDC	—	Centers for Disease Control and Prevention
COWG	—	Communications and Outreach Work Group
CSR	—	Cancer Statistics Review
DFO	—	Designated Federal Official
DHEP	—	Division of Health Education and Promotion
DOE	—	U.S. Department of Energy
EPA	—	U.S. Environmental Protection Agency
GPWG	—	Guidelines and Procedures Work Group
GWU	—	George Washington University
HENAWG	—	Health Education Needs Assessment Work Group
HHS	—	Department of Health and Human Services
HSR	—	Health Statistics Review
OGP	—	Office of Government-wide Policy
ORRHES	—	Oak Ridge Reservation Health Effects Subcommittee
PHA	—	Public Health Assessment
PHAGM	—	Public Health Assessment Guidance Manual
PHAP	—	Public Health Assessment Program
PHAWG	—	Public Health Assessment Work Group
PHEP	—	Public Health Education Program
TDEC	—	Tennessee Department of Environment and Conservation
TDOH	—	Tennessee Department of Health
WOC	—	White Oak Creek