Responses to Recommendations From the National Academy of Sciences Regarding Communications of the Hanford Thyroid Disease Study (HTDS) Final Report

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In 2000, the National Academy of Sciences (NAS)--National Research Council (Committee on an Assessment of Centers for Disease Control and Prevention Radiation Studies from DOE Contractor Sites: Subcommittee to Review the Hanford Thyroid Disease Study [HTDS] Final Results and Report) issued a peer review of the HTDS Draft Final Report ("Review of the Hanford Thyroid Disease Study Draft Final Report").

The NAS peer review concentrated on five subjects for evaluation: design of the HTDS, estimated radiation exposures, data analysis, statistical power, and communications. This paper addresses the communications issues.

Below are the communications recommendations (E.1, E.2, E.3, and E.4) in the executive summary of the NAS report, "Review of the Hanford Thyroid Disease Study Draft Final Report," and CDC's response to each.

NAS Recommendation E.1

Delivering an unpopular message requires sensitivity to the audiences' health concerns and fears. In communications about the HTDS Final Report, implications for individuals and families that have suffered because of thyroid disease should be carefully explained. If there are plausible alternative interpretations of the results, they should be acknowledged.

CDC Response

CDC recognizes the range of public emotions and feelings about the issues raised in the HTDS and that some audiences reacted negatively to the draft findings and to the communications of those findings when the HTDS Draft Report was released in 1999. CDC also recognizes the importance of being sensitive to the reality of thyroid disease in the region.

In order to better understand audiences' fears, concerns, and information needs related to the HTDS Final Report, CDC gathered feedback from representatives of affected audiences. Before the release of the HTDS Final Report, CDC used focus groups, round

table discussions, and in-depth interviews to get input from representatives of public interest groups, HTDS participants, Hanford area citizens, and government officials. Based on the needs expressed by participants in the groups and interviews, CDC created specific materials to address public concerns about the HTDS. CDC also drew lessons from the release of the HTDS Draft Report in the development of public materials for the release of the Final Report.

CDC's public information materials (presentations, posters, print materials, and Web site) address issues raised by participants in the groups and interviews. The materials acknowledge the reality of thyroid disease in the region, explaining that no epidemiologic study can determine the cause of an individual's thyroid disease. In addition, the agency addresses such issues as the benefits and limitations of epidemiologic studies, how the HTDS relates to other radiation studies and scientific approaches, and the range of factors that need to be considered in the study of thyroid disease.

NAS Recommendation E.2

The subcommittee supports CDC's open-communication policy and strongly recommends that it continue. It recommends that a new communications plan be devised for the release of the Final HTDS Report and accompanying public documents, taking into account the problems that have already been encountered.

CDC Response

CDC has developed a new communications plan for the release of the HTDS Final Report. The plan is based on the NAS recommendations and responds to public input gained from prerelease focus groups and interviews. This plan continues CDC's opencommunication approach, as recommended by NAS.

The communications plan includes a public education event in Richland, Washington, on June 21, 2002. The meeting is designed to help the public both learn about the findings from the HTDS research team and talk individually with HTDS scientists.

The public event will include a presentation on the HTDS findings and display stations addressing different aspects of the study: "Findings of the HTDS," "What Happened at Hanford," "About Thyroid Disease," "About Epidemiology," "About Radiation," and "Hanford Community Health Project." HTDS investigators will be available at each display station to answer questions, respond to public concerns, and discuss study implications. In order to reach members of the public who are unable to attend the meeting, CDC will post video segments of the public event on CDC's HTDS Web site.

In addition to the public meeting, CDC has developed print and electronic materials to help the public understand the findings from the HTDS. A 24-page brochure entitled "A Guide to the Hanford Thyroid Disease Study Final Report" and a three-page brochure summarizing the findings will be available from CDC. The summary document will be available in Spanish as well.

CDC has developed additional channels for public information about the report: a Web page dedicated to the HTDS study (http://www.cdc.gov/nceh/radiation), a toll-free number, and an E-mail address for the public to ask questions about the study. The HTDS study and additional resources will be posted at <u>www.cdc.gov/nceh/radiation</u>. In addition, users will be able to review and download both summary and detailed information about the study. CDC's Web page includes a "Contact Us" feature that the public can use to ask questions or raise concerns about the study. The HTSD Final Report and supporting resources will also be available in public libraries in the region.

Some specific audiences have expressed special interest in the study. To meet their needs, CDC conducted a prerelease direct mailing to citizen groups who have participated in the HTDS process and to public officials, government agencies, healthcare providers, and health educators. The mailing provided information about the public event and other communications activities to about 5,000 individuals and organizations.

In order to address the public's ongoing concerns and questions, CDC is collaborating with its sister agencies in the U.S. Department of Health and Human Services – the Agency for Toxic Substances and Disease Registry and the National Cancer Institute – to provide the public with information about health effects, iodine-131, and related issues.

NAS Recommendation E.3

In the HTDS Final Report and all public documents, any significant changes made from the Draft Final Report should be clearly outlined and explained, and all remaining uncertainties should be noted and explained.

CDC Response

The HTDS Final Report describes all of the most significant changes made subsequent to the release of the HTDS Draft Report. Work completed since the release of the draft report will be explained to the public in CDC's presentation of the findings during the public event. The agency addresses the issues of statistical power and uncertainty in the HTDS Final Report and HTDS brochure, "A Guide to the Hanford Thyroid Disease Study Final Report."

NAS Recommendation E.4

Careful consideration should be given to how to release controversial reports to the public more effectively. The subcommittee suggests that CDC convene a workshop to discuss this and other communications issues of concern.

CDC Response

CDC recognizes the complications of releasing controversial reports such as the HTDS Final Report. Reaching concerned audiences with timely and accurate information requires careful planning and coordination between scientists, media representatives, and government agencies. CDC's plan to release the HTDS Final Report includes specific steps to increase the likelihood that accurate information reaches the public most affected by the HTDS. To increase attendance at the public event, CDC sent announcements about the meeting to people with special interest in the HTDS. The public meeting was designed to provide one-on-one interaction between the public and scientists so that the primary investigators for the study could address individual concerns and questions.

Because the media plays such an important role in creating public perceptions about the HTDS, CDC sent media kits to local and regional media outlets. These kits were sent via FedEx to arrive the morning of June 21, 2002. All information contained in the media kit will be embargoed until 6:00 p.m. that evening, which is when the public event begins.

CDC conducted an internal briefing (with the Department of Health and Human Services) and a briefing for the congressional delegations from Washington, Idaho, and Oregon on June 21, 2002, the day of the public event. Representatives of the Department of Energy and the affected state health departments were informally notified by telephone the day of the final release.

Although CDC has not yet sponsored a risk communication workshop specifically focused on the HTDS, risk communication concepts were applied throughout the development of public materials about the HTDS. CDC believes that a risk communications workshop is a good means to define benefits, disadvantages, and consequences of the various options for releasing future draft studies. CDC hopes to hold such a risk communication forum prior to release of any other draft studies on radiation health effects.