

THE UNIVERSITY OF MICHIGAN DIOXIN EXPOSURE STUDY – COMMUNICATION AND COMMUNITY INVOLVEMENT

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Introduction

The University of Michigan Dioxin Exposure Study (UMDES) was motivated because of concerns about possible human exposure to dioxins discharged as a result of historical industrial activities of the Dow Chemical Company located in Midland, Michigan, USA. The study was initiated in late 2003, field data were collected in 2004 and 2005, and results were first reported to scientists and the involved communities in August, 2006. Subsequently, more than 20 papers have appeared in the peer-reviewed literature. The study is tentatively scheduled to conclude at the end of 2011. This was a large field study of potential pathways of human exposure to dioxins in the environment. Not surprisingly, residents in the communities that were studied had many questions and concerns, ranging from questions about health effects to possible impact of dioxin contamination on local property values. Many residents expressed concerns about the independence of the study. From the start, the UMDES engaged in a number of steps to involve stakeholders and community residents and to keep them informed about the progress of the study and results of the study. This paper provides an overview of the approaches used by the UMDES to enhance communication with stakeholders and community residents.

Materials and Methods

A central scientific goal of the UMDES was to assess pathways of exposure to dioxins in the environment, and, in particular, to assess the degree to which historical releases of dioxins from the Dow Chemical Company facilities in Midland, Michigan, may have contributed to dioxin exposures in the local population living in Midland county, Saginaw county and a small portion of Bay county ('Midland and Saginaw counties'). This was not a health study, and no health outcomes were investigated. The study involved a stratified, multistage area probability sample of households and persons in two regions: Midland and Saginaw counties, the contaminated region; and a referent population from Jackson and Calhoun counties, located more than 100 miles away and in which there were no unusual sources of dioxins. Eligible persons were invited to complete an hour-long interview, to provide a blood sample, to allow samples of soil to be taken from around their home, and to allow samples of house dust to be taken from within their home. A total of 946 persons provided blood samples. All blood, dust and soil samples were analyzed for the 29 compounds that have been assigned Toxic Equivalency Factors (TEFs) by the World Health Organization¹. Full details of the study design have been published and detailed study protocols are available on the web^{2,3}.

The UMDES investigators recognized early on that the overall success of the study would depend, in part, on communication and involvement of stakeholders and community residents. Activities related to communication and community involvement began with the earliest efforts on the project. These included: setting up a web site to post documents and other information; stakeholder involvement in study design and other activities; appointment of an independent scientific advisory board (SAB) and regular meetings of the SAB with stakeholders; use of focus groups to assess community beliefs and to solicit feedback; formation of Community Advisory Panels; and a multipronged outreach program including open public meetings, web postings, communication with local public health officials, area physicians, mailings to study participants and other local residents, and the media (print, radio and television). This paper provides a brief summary of these activities.

Results and Discussion

The web site for the UMDES was set up in early 2004, and has played a central role in most aspects of communication related to the study³. The web site allowed for rapid public dissemination of a wide variety of materials, including study documents (e.g., study protocols, consent forms for subjects, the National Institutes of Health Certificate of Confidentiality, comments from stakeholders and responses from the UMDES), presentations made by UMDES investigators (more than 100 given at international conferences plus many given in various community and stakeholder meetings), peer-reviewed papers (more than 20 published), publicly available information about dioxins (e.g., fish advisories from Michigan Department of Community Health, and documents from other government agencies such as the ATSDR), and many hundreds of pages of study findings and results. The web site has many hot-links to web sites of relevant government agencies and local media. The UMDES web site has grown to many thousands of pages, and serves as a repository of information about the study. In retrospect, it would appear that most of the other communication activities described below would have been significantly diminished or impeded without the complementary role of the web site.

Various stakeholders were invited to participate in meetings and phone conferences during the study design phase. Stakeholders included multiple government agencies (local, county, state and federal), environmental organizations, and the Dow Chemical company. In addition to meetings, stakeholders were invited to offer written comments and suggestions on draft study design documents. These written stakeholder comments, along with written responses from the UMDES study team, were all posted to the UMDES web site. Stakeholder input resulted in a number of major changes and improvements to the study design, including changes to the questionnaire, addition of Jackson and Calhoun counties as 'control' areas, and identification of a separate area downwind of the Dow facilities (i.e., the 'plume' area) as a separate region for sampling and analyses.

Given the high-profile nature of the study, and the fact that the funding came from the Dow Chemical Company, the presumed source of the pollution, the study incorporated a number of steps to enhance the reality and the perception of independence and integrity of the research and the UM investigators. Standard University of Michigan procedures for ownership and control of the data by the University investigators (not Dow or any other stakeholder) applied – in other words, the UM investigators, not Dow or anyone else, retained complete ownership and control of the data. All collected data were treated as confidential, and a Certificate of Confidentiality was obtained from the National Institutes of Health to provide an additional layer of protection of confidentiality to study participants. No personally identifiable data have been released publicly, or to Dow or any of the other stakeholders. In addition, the investigators solicited nominations from stakeholders of persons who might serve on an independent scientific advisory board (SAB). The investigators (not Dow or any other stakeholder) appointed four scientists based on independence, qualifications related to dioxin research, and scientific stature. All study findings and results were reviewed by the SAB prior to release to stakeholders (including Dow), the scientific community and the involved communities. In particular, Dow has never had any opportunity for 'early' review of data or results prior to review by the SAB, and Dow has only seen results at the same time they were released to stakeholders, the scientific community, and/or the general public.

The SAB met face-to-face with UM investigators and stakeholders approximately twice a year beginning in 2004 through 2009. These meetings included opportunity for stakeholders to meet with UMDES investigators and the SAB, and also for stakeholders to meet privately with the SAB (without UMDES or Dow representatives present) so they could express concerns and provide input.

Early on in the study focus groups were employed to assess community beliefs and to solicit feedback. This helped in study design (e.g., the questionnaire), and was also a central mechanism for soliciting names of prominent local residents to serve on Community Advisory Panels (CAPs). Names of potential CAP members were also solicited during interviews with key-persons in the community. The UM investigators invited people to serve on the CAPs based on their independence, representation of community groups (e.g., local churches, local government, and non-profit community organizations),

Beginning during the data collection phase in 2004, and up to and including the first public release of results in August, 2006, there were public meetings held every 3-4 months in the involved communities. These meetings were overseen by the CAPs, and included presentations by UMDES investigators on the progress of the study,

and ultimately, findings of the study. All PowerPoint presentations were subsequently posted to the UMDES web site. These meetings were announced in advance in local media, and were open to the public and the media.

UMDES investigators held meetings and/or offered presentations to a variety of local organizations, including medical grand rounds for physicians at local hospitals, meetings of community service organizations (e.g., local Chamber of Commerce), elected officials at the state, county and local levels, public health officials, and press briefings and interviews with local media (local newspapers, local radio talk shows, and local cable access television).

In August, 2006, the UMDES released a 41-page results booklet that provided a lay summary of key findings of the study. This booklet was mailed directly to all study participants, and copies were placed in major public locations in the involved communities (e.g., public libraries). A PDF copy was also posted to the UMDES web site. After more than four years of additional data analyses, in January, 2011, the UMDES released a revised 48-page results booklet that provided a lay summary of key findings, and copies were again distributed to major public locations, and a PDF version was posted to the UMDES web site. In addition, a brief 4-page summary of the 2011 results booklet was mailed directly to all residential households in Midland and Saginaw counties (more than 110,000 households).

In addition to these public communication efforts, the UMDES also communicated in a confidential manner directly with study participants. Each study participant was offered the option of receiving, or not receiving a confidential letter with their personal results of dioxin analyses for their blood, household dust, and/or soil. The reason for such an option was related to risk. The major risk to study participants was possible loss of property value if the household dust and/or soil from their property were found to be contaminated with dioxins, and, in particular, if the level exceeded the applicable regulatory threshold of 90 parts per trillion TEQ for soil. If a study participant received their results, then they might be obligated to reveal such results to any potential buyer. This risk was explained to study participants in the consent documents. While it is not surprising that about 95% of study participants chose to receive their personal blood results (there was no financial risk related to contamination levels in blood), it was somewhat surprising that, despite the potential risk, approximately 65% of subjects chose to receive their dust and/or soil results.

Overall, the participation rates among eligible subjects were high (>80%) not only in the affected regions (i.e., Midland and Saginaw counties), but also in the control areas (Jackson and Calhoun counties). We believe that such high participation enhances the quality of the data and our ability to make accurate inferences involving the populations we studied. The extensive communication efforts were a key factor in achieving such a high rate of participation among eligible members of the study communities.

Acknowledgements

Financial support for this study comes from the Dow Chemical Company through an unrestricted grant to the University of Michigan. The authors acknowledge Drs. L. Birnbaum, R. Hites, P. Boffetta, and M. H. Sweeney for their guidance as members of the UMDES Scientific Advisory Board from 2004 to 2010.

References:

1. Van den Berg M, Birnbaum LS, Denison M, De Vito M, Farland W, Feeley M, et al. (2006); *Toxicological Sciences*. 93(2): 223-241.
2. Garabrant DH, Franzblau A, Lepkowski J, Gillespie BW, Adriaens P, Demond A, et al. (2009); *Environ Health Perspectives*. 117(5): 803-810.
3. www.umdioxin.org. Accessed May 12, 2011.