

Confidentiality

To meet the goals of the research project, the UMDES team will ask questions about personal habits, measure the levels of dioxins in the bodies of interviewed persons, and the levels of dioxins found in and around the interviewed person's property.

This is highly sensitive information, and there are three safeguards in place to protect it from being revealed to anyone other than the interviewed person.

The **first** is the design of the study itself. Only "aggregate" data – summaries of the information – will be released publicly. Study reports will not contain any information that can be linked back to any individual or property.

The **second** comes from internal processes designed specifically to ensure confidentiality. Individual respondents are assigned unique identification numbers (IDs). Dust, soil and blood samples are each assigned different ID numbers to prevent linking of test results by anyone outside of the immediate research team. All ID numbers, and the keys that link them, are held in a secured location at the University's Institute for Social Research which is accessible to only a very few UMDES research staff members with a need to know. Payments to respondents and even telephone records – anything that could be used to identify an individual participant or property as a participant in the UMDES – are kept outside of University financial statements.

The **third** safeguard is a provision of federal law that was specifically designed to protect the confidentiality of research subjects. Personal information is protected by a **Certificate of Confidentiality** issued by the National Institutes of Health.

The Certificate of Confidentiality ensures that study participants, the UMDES team and the University of Michigan cannot be forced to reveal "sensitive," personally identifiable information. No court, agency or other body can compel release of information that could affect a subject's financial standing, employability, reputation or insurability, or have any other adverse effects.

If you are a UMDES participant, neither you nor any members of the study team can be forced to reveal any information about the dioxin levels in your body or on your property ... nor your answers to any of the survey questions.

Participants may, however, choose to receive a confidential report of their blood, soil and dust dioxin levels. If you are a participant and you **do** receive this information, the Certificate of Confidentiality cannot protect information that you have received. Real estate sales and other transactions may require you to disclose this information if you receive your results.

For More Information

The UMDES study team will be holding public meetings in the study area. If you have questions or would like more information, please contact our toll-free number: 1-888-689-0006.

Or visit the UMDES Web site at www.umdioxin.org.

We hope that you will consider participating in this important and valuable study. If you would like more information, please call our toll-free number: **1-888-689-0006**.

University of Michigan Investigators

David Garabrant, MD, MPH
Alfred Franzblau, MD
Brenda Gillespie, PhD
Peter Adriaens, PhD, PE
James Lepkowski, PhD

Scientific Advisory Board

David Kleinbaum, PhD
Emory University
Linda Birnbaum, PhD, DABT
US Environmental Protection Agency
Paolo Boffetta, MD, MPH
Intl Agency for Research on Cancer
Ronald Hites, PhD
Indiana University

The University
of Michigan

Dioxin Exposure Study

INDEPENDENCE, INTEGRITY
AND CONFIDENTIALITY



The University of Michigan

School of Public Health

College of Engineering

Center for Statistical Consultation
and Research

Institute for Social Research

1-888-689-0006

UMDES Web site: <http://www.umdioxin.org>

The University of Michigan Dioxin Exposure Study

The University of Michigan is one of the nation's largest and most-respected research institutions, especially in the field of health. It is among the top 10 recipients of research grant funds from the National Institutes of Health. The Institute for Scientific Information ranked the impact of UM's research in the top 10 among the nation's top 100 federally funded U.S. universities.

A multi-disciplinary research team from the University is conducting a study of dioxin exposure in Michigan. The study is designed to see if there is a relationship between levels of dioxins in soil and household dust and levels in people's bodies. It will also examine other factors – where people have lived, what they eat, their jobs and their hobbies – that may be associated with levels of dioxins in their bodies.

This study involves human subjects, and sensitive issues such as their health and property values. Like many research projects, this study is funded in part by a grant from a corporate underwriter.

For these two reasons, it is important that you understand three core values of the University of Michigan research – and the rules and processes that enforce them.



Independence

The mission of the University of Michigan is to generate and disseminate knowledge in the public interest. Two fundamental principles are essential to this mission: open scholarly exchange and academic freedom.

To protect these principles, the University of Michigan Regents adopted a policy in 1987 to protect the independence of University research – regardless of the source of funding for the research.

Many research projects are funded by grants from government agencies, corporations and other private donors. Financial support for the UMDES comes from a grant from The Dow Chemical Company. Dow is considered to be the source of dioxin contamination in the Tittabawassee River.

Dow's funding, however, is part of a contract, and that contract is subject to key provisions of the Regents' Policy.

Under this contract, the funder **cannot**:

- restrict the University's freedom to disclose the project sponsor, scope or purpose;
- limit the research team's freedom to publish or present research results;
- review the study results before they are made public; or
- restrict the timing of the research project or the release of its results.

These provisions of the contract ensure that the UMDES team will uphold its responsibility to:

- ensure that the research fits the mission of the University;
- provide open scholarly exchange and academic freedom; and
- work toward the University's goal of enhancing human life and the human condition.

The work of the UMDES team is overseen by the University's Office of the Vice President for Research. This office is responsible for ensuring that the UMDES – and any other UM research project – complies with the Regents' Policy.

Integrity

There are many reasons the University of Michigan is a widely respected research institution. Academic integrity is one of the most important ones.

Integrity in scholarship and teaching is one of the University's founding values. It is critical for the faculty, staff, students and administration of the University of Michigan to maintain the trust of the public in its research and scholarly activity.

The University has policies governing the conduct of its research. These provide safeguards against breaches such as:

- dishonesty in reporting results, whether by fabricating or manipulating data;
- taking credit for the work of others;
- violating confidentiality.

These breaches and other major misconduct are grounds for dismissal from the University.

More often, lapses in integrity are the result of carelessness or oversight, rather than dishonesty. To prevent these lapses, the University has guidelines for conducting research.

This research project also has a Scientific Advisory Board. This is a team of internationally recognized experts who review and report on the methodology of the study – from design to execution.

Because human subjects are involved, each element of the project is also reviewed and approved by an Institutional Review Board. This is a panel of doctors, scientists, ethicists and lay people who ensure that every part of the study follows ethical principles and guidelines to protect those human subjects. These principles ensure:

- a basic respect for the study subjects;
- the research will be beneficial to the study subject and to society as a whole;
- both the benefits and the burdens of the research are distributed in a just and fair manner;
- people participating in the study have given their consent and fully understand what they may expect;
- the benefits of the research outweigh its risks.