

Roundtable explores benefits and challenges of data sharing

By Pamela Kidron

The 13th workshop in the Institute of Medicine (IOM) Roundtable on Environmental Health Sciences, Research, and Medicine series explored the benefits and challenges of sharing environmental health data, and ways to maximize data sharing and satisfy a federal mandate for public access to government data.

The March 19 workshop in Washington, D.C., "Principles and Best Practices for Sharing Data from Environmental Health Research," brought environmental health science researchers together with experts in law and policy.

"The issue [of data sharing] is very complex and is technologically challenging," said NIEHS and NTP Director Linda Birnbaum, Ph.D., who participated in the workshop along with Gwen Collman, Ph.D., director of the NIEHS Division of Extramural Research and Training, and a number of NIEHS grantees.

In a workshop overview, grantee and roundtable vice chair Lynn Goldman, M.D., dean of the George Washington University School of Public Health and Health Services, noted that data sharing is common to many environmental health research studies, which often depend on national survey data, shared data sets, and pooled data.

Over the course of the seven-hour workshop, researchers also highlighted examples of data sharing with the potential for harm. For example, a case was described where shared data sets with demographic information, such as date of birth, gender, and zip code, were linked to a voter registration list, resulting in identification of study participants who had been promised confidentiality.

Identifying benefits and challenges

Several common themes emerged during the roundtable, including the need to strike a balance between protecting confidentiality and making data broadly accessible, and concern that federal regulations could force researchers to make raw research data publicly available.

Participants explored questions such as whether data should be made available to anyone who requests it. Restricting data access to researchers creates the need to establish who is a legitimate researcher and what is a legitimate research question.

Looking Ahead

Another session identified ways to maximize data sharing. For example, one way to address the costs associated with data sharing could be to build those costs into the design of any study or grant request.

Despite concerns, the field of environmental health science generally supports the possibilities and opportunities that broader data sharing brings to its research. Birnbaum noted that data sharing facilitates secondary data analysis and meta-analysis, thus leveraging existing data resources. She also pointed out that data sharing gives access to study findings that have not been published. Also, reanalysis of data with new technologies can improve understanding.

"Once data is published, the raw data upon which it is based should be fully available for others to use - certainly in a collaborative manner - and many times for others to build upon," said Birnbaum. "Reanalysis of data should be done to build upon the original information and ask additional questions, or to look at the data in alternative ways."

Birnbaum explained that NIH is working actively on strategies to encourage and facilitate broader data sharing among researchers in the field of environmental and health science. NIH currently has a number of data-sharing policies, including a requirement that peer-reviewed, published papers funded by NIH be submitted to PubMed Central.

Birnbaum announced at the workshop that upcoming NIEHS data-sharing events include a public webinar April 3 for new and junior researchers to discuss concerns around data sharing, and a June 13 event to identify opportunities for global integration of toxicogenomics databases.

(Pamela Kidron is a contract writer with the NIEHS office in Bethesda, Md.)



In 2010, Birnbaum was elected to IOM, one of the highest honors in the fields of medicine and health. (Photo courtesy of Steve McCaw)

The Environmental Factor is produced monthly by the [National Institute of Environmental Health Sciences \(NIEHS\)](#)

(<http://www.niehs.nih.gov/>)

, Office of Communications and Public Liaison. The content is not copyrighted, and it can be reprinted without permission. If you use parts of Environmental Factor in your publication, we ask that you provide us with a copy for our records. We welcome your [comments and suggestions](#).
(bruskec@niehs.nih.gov)

This page URL: NIEHS website: <http://www.niehs.nih.gov/>

Email the Web Manager at webmanager@niehs.nih.gov