

Communicating Toxicogenomics Information to Nonexperts: A Workshop Summary

Committee on Communicating Toxicogenomics Information to Nonexperts, Committee on Emerging Issues and Data on Environmental Contaminants, National Research Council

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COMMUNICATING TOXICOGENOMICS INFORMATION TO NONEXPERTS

A Workshop Summary

Committee on Communicating Toxicogenomics
Information to Nonexperts

Committee on Emerging Issues and Data on
Environmental Contaminants

Board on Environmental Studies and Toxicology

Board on Life Studies

Division on Earth and Life Studies

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Preface

Toxicogenomics, the study of how genomes respond to exposure to toxicants, may ultimately hold the promise of detecting changes in the expression of a person's genes if he or she is exposed to these toxicants. As the technology rapidly develops, it is critical that scientists and the public communicate about the promises and limitations of this new field. Communicating technical information to the public about a developing science can be challenging, particularly when the applications of that science are not yet well understood. The Committee on Communicating Toxicogenomics Information to Nonexperts designed a workshop to consider strategies for communicating toxicogenomic information to the public and other non-expert audiences, specifically addressing the communication of some key social, ethical, and legal issues related to toxicogenomics and addressing how information related to the social implications of toxicogenomics might be perceived by nonexperts.

This workshop summary has been reviewed in draft form by persons chosen for their diverse perspectives and technical expertise in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the summary meets institutional standards of objectivity, evidence, and responsiveness to the study charge.

The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following people for their review of this workshop summary: Marcia Lawson,

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American Chemistry Council; Katherine McComas, Cornell University; Frederica Perera, Columbia University; and Kasisomayajula Viswanath, Harvard School of Public Health.

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations, nor did they see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by Rogene Henderson, Lovelace Respiratory Research Institute. Appointed by the National Research Council, she was responsible for making certain that an independent examination of the workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of the workshop summary rests entirely with the committee and the institution.

The committee gratefully acknowledges the following people for making presentations at the workshop: Julie Downs, Carnegie Mellon University; Sharon Dunwoody, University of Wisconsin-Madison; William Freudenburg, University of California, Santa Barbara; Deirdre Lawrence, National Cancer Institute; Susanna Hornig Priest, University of South Carolina; David Ropeik, Harvard Center for Risk Analysis; Craig Trumbo, University of Vermont; and Kasisomayajula Viswanath, Harvard School of Public Health.

The committee is grateful for the assistance of the NRC staff in preparing this workshop summary: Roberta Wedge and Marilee Shelton-Davenport, project directors; James Reisa, director of the Board on Environmental Studies and Toxicology; Fran Sharples, director of the Board on Life Sciences; Jennifer Saunders and Mirsada Karalic-Loncarevic, research associates; Ruth E. Crossgrove and Norman Grossblatt, senior editors; Lucy Fusco, senior project assistant; and Sam Bardley, library assistant.

Finally, I thank the members of the committee for their dedicated efforts throughout the development of this workshop summary.

Mark A. Rothstein
*Chair, Committee on Communicating
Toxicogenomics Information to Nonexperts*

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**Communicating Toxicogenomics
Information to Nonexperts:
A Workshop Summary**

Abstract

Effectively communicating the promise of new technologies can be challenging, particularly when the science is not yet fully developed and its application is not well defined and understood. Toxicogenomics meshes toxicology with genomic technology (study of the entire expanse of genetic information in an organism) and may hold the promise of detecting changes in the expression of a person's genes if he or she is exposed to toxicants. As defined by the National Center for Toxicogenomics, toxicogenomics is the "collection, interpretation, and storage of information about gene and protein activity in order to identify toxic substances in the environment, and to help treat people at the greatest risk of diseases caused by environmental pollutants or toxicants" (NCT 2002). As the technology develops and more data become available, it is important that scientists and the public discuss the promises and limitations of this new field. The Committee on Communicating Toxicogenomics Information to Nonexperts designed a workshop to consider strategies for communicating toxicogenomics information to the public and other nonexpert audiences, specifically addressing communication issues surrounding some key social, ethical, and legal issues related to toxicogenomics and how information related to the social implications of toxicogenomics may be perceived by nonexperts. Because research on the communication of toxicogenomics to the public is sparse, panelists who are experts in risk and biotechnology communication were asked to present research from their work. They applied their expertise in analogous areas to discuss ways to design an effective strategy to communicate toxicogenomics information. Panelists discussed communication barriers, such

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as poor understanding of scientific principles and emotional responses to risk and uncertainty by the public, and health disparities in communication. The panelists also discussed effective communication tools, such as audience-based communication (focusing efforts on understanding the audience and creating messages based on the informational needs of that specific audience); mental models approach (assessing systematically what kinds of information should be conveyed to the public and then creating messages that meet those needs); public participation (encouraging public input and providing public access to the decision-making process); and developing, testing, and communicating of appropriate messages. They also discussed the importance of how the message is framed for the audience.

The workshop was not intended to develop consensus on the issues related to toxicogenomics communication but to provide useful background information on risk communication that may assist agencies and organizations in effectively communicating toxicogenomics information to the public.

Summary of the Workshop

OVERVIEW

Toxicogenomics, a burgeoning field that meshes toxicology with genomic technology, may hold the promise of detecting changes in the expression of a person's genes if he or she is exposed to toxicants. As the technology develops and data become available, it is important to maintain discussion between scientists and the public about the promises and limitations of this new field. The National Academies Committee on Emerging Issues and Data on Environmental Contaminants is engaged in providing a public forum for communication among government, industry, environmental groups, the academic community, and the general public about issues in toxicogenomics. Anticipating the need for effective public communication by agencies and organizations that are conducting or using the results of toxicogenomics research, the committee requested that the National Research Council (NRC) appoint an ad hoc committee to develop and conduct a workshop that would examine the communication of toxicogenomics information to nonexpert audiences (see Statement of Task in Appendix A for more information about the charge to the ad hoc committee). The workshop, titled "Communicating Toxicogenomics Information to Nonexperts," was held on April 22, 2004. (The agenda is included in Appendix B; committee and speaker biographical information is included in Appendixes C and D.)

The general public, communication experts, and interested government officials were invited to attend, including representatives of the National

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Institute of Environmental Health Sciences, the U.S. Environmental Protection Agency, the Food and Drug Administration, and research scientists in industry and nonprofit organizations. The workshop planning committee determined that federal agencies would be interested in framing the concept of toxicogenomics for the public and would recognize the importance of gauging public response to the science, inasmuch as the agencies and other organizations use risk communication for activities as varied as stakeholder meetings at Superfund sites and review of drug advertising.

The workshop began with a presentation of the goals of and need for the workshop by Mark Rothstein, University of Louisville, chair of the workshop planning committee. Mr. Rothstein was followed by Robert Griffin, Marquette University, a planning committee member, who introduced the field of risk communication as an element of social science research. William Greenlee, CIIT Centers for Health Research, a planning committee member, then gave a brief overview of what scientists mean by toxicogenomics and of the technologies used in this new field. The remainder of the workshop was organized around two panels, which are described below. The workshop ended with a discussion among all the panelists and a question-and-answer period with the audience.

Mr. Rothstein identified four primary goals of the workshop: to discuss the relationship between scientific understanding and public misconceptions about science as it relates to toxicogenomics; to consider ethical, legal, and social issues and their impact on communication about toxicogenomics; to describe the analytic tools needed to understand the public's perceptions of toxicology and genomics; and to capture the diversity of factors that lead to different perceptions of risk at the individual, group, and societal levels. To the committee's knowledge, no research has been conducted specifically on communication of toxicogenomics to any audience. Therefore, the ad hoc committee looked to experts in the field of risk communication to consider what communication theories and research on analogous scientific or public-health issues might be applied in the context of toxicogenomics.

Dr. Griffin discussed the workshop format and offered background information regarding risk communication. The workshop was designed to help scientists and policy-makers identify those key communication issues that will arise as research in toxicogenomics progresses. Speakers were asked to identify key social, scientific, and communication research that would be especially insightful and would help to address communication-research gaps.

Dr. Griffin said that most risk-communication research has been based on individual psychology, which seeks to gain a better understanding of how individual members of the public respond to risk information—for

example, by changing their behavior. Much less research has been done on whether social factors affect how individuals and groups access and use risk information. In addition to individual decision-making, toxicogenomics communication can be seen in the contexts of societal decision-making needs. Thus, the workshop was designed to examine the individual aspects (for example, individuals and their responses to risk information) and the less-understood societal aspects (for example, social disparities that result in different access to information by different groups of people) of toxicogenomics communication.

The first panel was asked to address individual decision-making as related to toxicogenomics communication (see agenda in Appendix B for more information about the workshop format). Speakers during this session discussed such topics as how a person might perceive issues as they make decisions; individual information needs; psychological factors, including individual variability in perception of risk; misconceptions about the use of traditional toxicologic data; the promise of analyzing personal risk decisions with a “mental models” approach (a method used to assess systematically what kinds of information should be conveyed to the public and then to create messages commensurate with those needs); and the need to frame toxicogenomics for the public. The second panel focused on broader societal factors and toxicogenomics communication, particularly how social and structural forces can affect an individual’s interpretation and use of risk information. Social forces emanate from the divisions that occur in society, such as those based on power, hierarchy, social status (for example, income and education), ethnicity, sex, and kinds of communities inhabited (smaller vs. larger communities). Structural forces are configurations in a community that influence the generation, distribution, and acquisition of information in a social system (Viswanath and Demers 1999). Structural forces in particular can affect the access people have to services, to opportunities, and to information. Speakers discussed the translation of individual risk perception to societal decision-making and inequality issues related to public access to toxicogenomics information. They also discussed their research in such fields as environmental justice and health disparities, the role of the mass media in shaping public perceptions of risk, and the diversity of audiences for science communication.

Little information is available on toxicogenomics communication; thus, the workshop was not intended to develop consensus on the issues. However, the workshop was designed to provide useful background information on risk communication that may assist agencies and organizations in effectively communicating toxicogenomics information to the public.

Four Risk-Communication Issues

Through discussion during both panel sessions, four main issues in risk communication became evident; they are described below. Each of the issues can be evaluated at the individual level or societal level and often at both levels. Not all factors that play a role in communicating toxicogenomics information to the public were discussed in the workshop. Other factors that may play a role in effectively communicating toxicogenomics information include risk perception and control issues (see Figure 1).

- *Sufficiency of information.* Broadly speaking, sufficiency of information is the availability of risk-related information that is useful for decision-making. There are societal applications, but sufficiency of information is usually assessed at the individual level, for example, whether a person believes that he or she has enough information to decide how to deal with risks in daily life or believes that he or she has enough information to decide whether to support a public policy related to a risk. Workshop presenters suggested that two questions be considered: What do people already know or believe about toxicogenomics? What will people need to know to make a decision? Major issues identified regarding information sufficiency include uncertainty and common misperceptions about toxicity.

- *Capacity of the individual or society to access and understand information.* A person's capacity to obtain and understand information reflects "one's perceived ability to perform the information-seeking and processing steps necessary for the outcome one desires" (Griffin et al. 1999). Issues identified regarding the capacity of the individual to obtain and use toxicogenomics information include the ability to deal with probabilistic information. At the societal level, there are important challenges regarding people's capacity to obtain and understand risk information. Also, there is a need for sensitivity in communicating with culturally and socioeconomically diverse audiences. It is critical to reach disadvantaged groups.

- *Emotional responses to risks.* In considering how people might respond emotionally to toxicogenomics information, it is important to take into account such factors as the strength of a person's beliefs, his or her perception of risk, and his or her comfort with uncertainty.

- *Trust in scientific and government agencies and mass-media organizations that oversee communication channels.* Trust is a primary component of effective risk communication. Research on public trust in government agencies has found that trust is easier to destroy than to build.

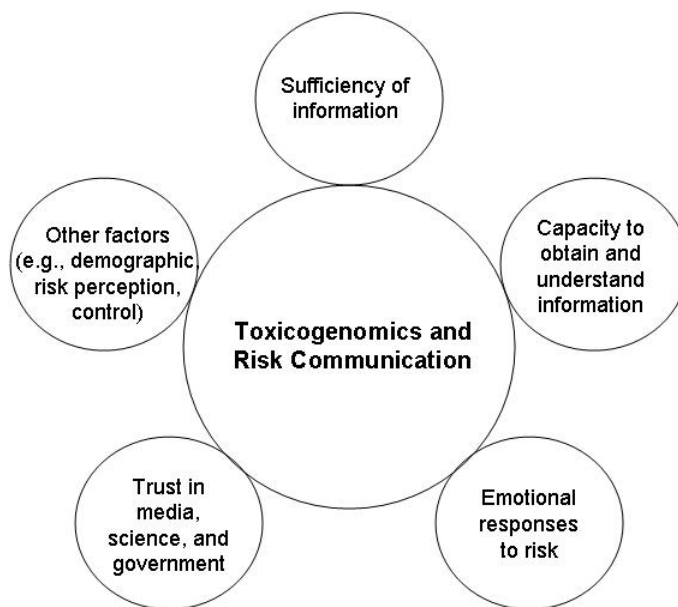


FIGURE 1 Factors that can affect how nonexperts seek, process, and use risk information.

A person's level of trust may vary by topic, source of information, and the channel by which information is received. Furthermore, people probably know less today about the technologies they use than earlier generations knew about the technologies affecting their lives. Increased dependence on poorly understood technology may lead to more uncertainty and more skepticism about government, industry, and other technology sources. Public skepticism about scientific and government institutions is a challenge to risk communication that cannot be ignored by scientists and policy-makers.

The ad hoc committee was interested primarily in exploring audience-based approaches to toxicogenomics communications. Dr. Griffin noted that audience-based approaches focus on how the "everyday person, a nonexpert, will encounter information on toxicogenomics, which is highly technical," and how such approaches might have implications for future decisions about health and behavior. The audience-based approach, Dr. Griffin stated, "is consistent with a recommendation from the National

Research Council (NRC 1989) to understand what it's like to communicate with nonexperts, not just to them." It will help scientists to understand better what information people think they need for making decisions as opposed to what information scientists think the public should have for making decisions.

INTRODUCTION TO TOXICOGENOMICS

Genomics has generated extensive data about genetic variation and how genes are expressed. However, these data are not yet well understood. Toxicogenomics seeks to translate those data into an understanding of the underlying biologic systems in organisms, including humans, and the eventual effects of changes in the systems on organisms and their health. Toxicogenomics, as defined by Dr. William Greenlee, is the "application of global gene expression profiling, including DNA microarray technologies and proteomics, to study the relationship between exposure and disease and to understand gene-environment interactions and their impact on human health." The field of toxicogenomics encompasses a number of technical approaches, including genomics, proteomics (the study of proteins), metabolomics (the study of changes in metabolite concentrations), and transcriptomics (the study of simultaneous changes in gene expression). Scientists hope that toxicogenomics will improve and refine their ability to predict how exposure to environmental agents will affect the people's health. In addition, toxicogenomics may improve understanding of such processes as reproductive toxicity and nongenotoxic carcinogenesis, which normally require long-term animal studies.

Toxicogenomics is a highly complicated science and faces a number of challenges, including its relative infancy as a science, the complexities of analyzing and validating the data, and difficulties in using, sharing, and retrieving the data. Dr. Greenlee cautioned that without an understanding of the underlying biologic processes, there is the possibility of overinterpreting toxicogenomic information—for example, a researcher who sees a profile of a gene without an understanding of what it means to fundamental metabolic processes and cell functioning cannot use this information to determine a probable health outcome. In addition, he noted that as toxicogenomics deals with the complex biologic systems, researchers should be careful not to oversell the technology before its applications are well understood.

These challenges make communicating toxicogenomics to the public complicated. The public's general lack of scientific literacy may make it

more difficult for communicators and scientists to design communication strategies. The difficulties of communicating technical information to a nontechnical audience are discussed in further detail in the sections that follow.

RISK COMMUNICATION

Risk is often conceptualized as the probability that an event will result in an adverse outcome and the perceived severity of that event. The National Research Council (NRC 1989) defined risk communication as “an interactive process of exchange of information and opinion among individuals, groups, and institutions. It involves multiple messages about the nature of risk and other messages, not strictly about risk, that express concerns, opinions, or reactions to risk messages or to legal and institutional arrangements for risk management.” As described by the NRC, the risk-communication process can be “considered successful only to the extent that it, first, improves or increases the base of accurate information that decision-makers use, be they government officials, industry managers, or individual citizens, and, second, satisfies those involved that they are adequately informed within the limits of available knowledge.” Thus, helping officials, managers, and citizens to gain sufficient knowledge to make informed decisions about risk has become a key goal of risk communication.

Risk-communication theory deals with aspects of public participation, conflict resolution, risk assessment, and risk management. Effective risk communication is a two-way process involving the participation of and information exchange between the scientist and the nonexpert. The risk-communication process also involves collaboration between technical experts and communication experts to ensure that it truly is an “interactive process of exchange of information and opinion among individuals, groups, and institutions” (NRC 1989).

The following pages discuss tools essential to the risk-communication process, including an analysis of the audiences and the roles of the mass media and the public.

Understanding the Audience

Sharon Dunwoody, University of Wisconsin, noted that scientists routinely ignore the audience in risk-communication campaigns. Dr. Dunwoody discussed the importance of understanding the audience as a

prerequisite for effective risk communication. Understanding the audience requires knowledge of a number of crucial paradigms in thought processes and behavioral research, including the various ways in which people approach decision-making and uncertainty.

Efforts to understand the audience should probably take into account the various ways in which a given audience will seek and process information. Specifically, some of the different ways of information processing and information seeking were discussed. It is critical for communicators to understand the audience's information seeking behavior to determine which channels (types of media) are used by the audience and might most effectively be employed to communicate information. In addition, the ways in which people process information they do receive could impact the audience's attitudes and behaviors.

Information-seeking behavior can be defined as actions taken by individuals to obtain information. Information seeking can be characterized as routine and nonroutine. Routine information seeking includes regular activities that attend to messages in the mass media, such as watching the evening news on television every night. Nonroutine information seeking includes behaviors that go beyond ordinary information channels, such as the mass media, to seek additional information, such as going to speak to a doctor. Information seeking may involve heuristic or systematic processing of the information that has been gathered. Heuristic processing is "a limited mode of information processing that requires less cognitive effort and fewer cognitive resources" than systematic processing (Eagly and Chaiken 1993; Griffin et al. 1999); it uses superficial, learned cues to assess the validity of information uncritically. Systematic processing requires "more comprehensive efforts to analyze and understand information" (Griffin et al. 1999); it requires more cognitive effort to assess the value of information critically and to integrate this new information with current knowledge. However, attitudes and behavior developed through systematic processing may be longer-lasting (Eagly and Chaiken 1993).

We are constantly bombarded with information. To process information, people usually simplify it or make an educated guess that reduces the time spent in analyzing solutions in situations that they understand poorly. Information-processing is defined as mental operations that a person does with the information he or she obtains, such as attending to it, assessing it, drawing inferences from it, combining it with information already known, and remembering or forgetting parts of it. There are four basic methods of processing information (here combined with related information seeking activity): routine heuristic processing, routine systematic processing, non-routine heuristic processing, and nonroutine systematic processing. Routine

heuristic processing, the most common type, occurs when people superficially process risk messages that they encounter through channels that they use routinely or habitually. In routine systematic processing, people use their habitually accessed channels to get risk information but process it in a more critical manner. Nonroutine heuristic processing goes beyond routine information channels to gather information and to process it uncritically. A person may call someone special, such as a highly trusted expert, to seek advice about a risk. Dr. Dunwoody provided an example: “My doctor tells me to do something. That’s good enough for me. I do it. I’m going to minimize the amount of time I spend analyzing the situation.” In the least common method, nonroutine systematic processing, people go beyond their routine information channels to gather information and process it critically. In that case, a person may contact a physician for a second opinion or seek out various experts who may be able to answer questions and then make his or her own decision after weighing and assessing the evidence and the authorities’ possibly differing views.

Using the work of Eagly and Chaiken (1993) and others, Griffin et al. (1999) proposed that three main factors influence the extent to which a person will seek out and process information in a more active way: the desire for information sufficiency, perceived information-gathering capacity, and relevant channel beliefs. Information sufficiency is the amount of information that people believe they need to make informed decisions about a risk. Information seeking and information processing are also moderated by capacity (an individual’s ability to obtain, understand, and use information) and channel beliefs (a person’s everyday beliefs about the channels of information—the belief that one type of media is more biased than another). Perceived information-gathering capacity involves a person’s assessment of his or her ability to gather new information about the risk and evaluate it critically. Relevant channel beliefs are a person’s everyday beliefs about the various channels (media) of communication, such as whether they are biased or contain useful information. For example, people usually favor information that is presented by a particular type of media, such as newspaper, television, or radio. The various ways in which a given audience will seek and process information will reflect the audience’s current beliefs and knowledge about toxicogenomics, cognitive and emotional motivations to overcome information insufficiency, their capacities to seek and process new information, and beliefs about the sources of information and the channels that might be used to gather it.

David Ropeik, Harvard Center for Risk Analysis, stated that to generate effective communication strategies that fit the needs of heuristic processors and encourage more systematic information processing, risk communicators

are encouraged to present information openly. Communicators should also evaluate an audience's possible level of emotional responses (such as worry) to an issue when forming a communication strategy.

Mr. Ropeik explained that, in "framing" a message about toxicogenomics, communicators should also be aware that a person's initial learning experience about a topic will probably help to shape later beliefs about it. "Frames" are cognitive structures that people use to help them to make sense of things and events, including the new and unfamiliar. Frames guide people's choice of what information to pay attention to and emphasize. People often use their understanding of past situations as an initial guide when deciding how to think, behave, or communicate in a new situation. For instance, if a person has an adverse initial experience with a particular technology, such as a specific computer software, it will probably shape all later feelings about that technology, regardless of how it improves. Also, framing can be affected by social forces external to the person—for example, interactions with others and socioeconomic factors. In the case of toxicogenomics, the public may not have any specific knowledge of this technology; however, they may use their previous knowledge of the interaction between the environment, genetics, and toxins to conceptualize an understanding of toxicogenomics data.

Various attributes of a person also affect his or her view of a given hazard, including sociocultural and demographic factors, such as sex, age, education, political orientation, income, and ethnicity. Furthermore, a person's perceptions about whether other relevant people believe that he or she should engage in a particular behavior (subjective norms) can be at least as important a predictor of the behavior as the person's own thoughts and attitudes about it (Ajzen 1988).

In risk communication, it is critical to understand that there is never just one audience; rather, there are a variety of audiences that may receive any communication effort. Kasisomayajula Viswanath, Harvard School of Public Health, stated that "risk communication is a product of interactions among different groups, agencies, and institutions, as well as individuals." Each group or public may receive or use risk information in different ways and there are different audiences for different media; for example, some people prefer print media, some people use the Internet, and other people rely on television. "There are differences in media use among people," he said, "as well as in the way they use these media." For instance, information disseminated in one medium, such as television, may be responded to in different ways by different audiences. To be successful, risk communicators should take into account the variety of audiences that exist for toxicogenomics communication and identify their individual risk-information

needs and preferred information channels. The audiences include individuals who receive toxicogenomics information about their health, advocacy groups, and health-care providers, among others.

Developing the theme of understanding differences in potential audiences, Deirdre Lawrence,¹ of the National Cancer Institute, discussed her research on health disparities and smoking. The National Cancer Institute defines health disparities as “differences in incidence, prevalence, mortality and burden of cancer and related adverse health conditions that exist among specific populations” (NCI 2004). Factors that may influence these population disparities for diseases such as cancer include not only race and ethnicity, but also gender, age, sexual orientation, geographic factors, and other sociocultural identifiers. Health disparities may also affect how different audiences perceive and access risk information.

Effective risk-communication strategies must also address other audience concerns, including socioeconomic, educational, and communication disparities, such as the inability to reach some segments of society through specific media. For example, consider the concept of the “digital divide” which refers to the disparate use of the Internet. Research indicates that access to the Internet is not randomly distributed but is closely related to levels of income and education. Communication will be less effective if these concerns are not addressed.

Public Participation and Influence of the Media on Public Awareness

Public participation is defined as “that part of the decision-making process through which responsible officials become aware of public attitudes by providing ample opportunity for interested and affected parties to communicate their views. Public participation includes providing access to the decision-making process, seeking input from and conducting dialogue with the public, assimilating public viewpoints and preferences, and demonstrating that those viewpoints and preferences have been considered by the decision-making official” (CFR 40 § 25 [2000]). Susanna Hornig Priest, University of South Carolina, commented that not including the public in policy and decisions regarding emerging technologies “can be a risk in itself.” It is essential that the public be involved in the early stages of

¹Opinions and statements included in the workshop summary are solely those of the participant and are not necessarily adopted or endorsed or verified as accurate by the National Cancer Institute.

developing any public-health policy, and public participation is an important component of the risk-communication process. Without public input, even the most comprehensive communication strategy may not be effective.

Using genetically modified foods as an example of the need for public participation, Dr. Priest said that in the United States, and particularly in Europe, public opinion regarding research on and use of genetically modified foods has sometimes been negative. She explained that a lack of public participation in the early stages of technologic development may have increased public uncertainty about food safety and contributed to negative opinions about the food. A lack of public participation also diminishes people's feelings of choice and control. Dr. Priest cited the example as one that demonstrates that "people need to be involved in some way in the early stages" of decision-making. A person's beliefs about issues such as biotechnology may be influenced by their trust in the source of the information. Accurate information about the benefits of a technology such as genetically modified foods may play a lesser role in forming a person's opinion than a person's preconceived ideas about the risk. Initial public attitudes about genetically modified foods, in addition to concerns about the broader risks of the technology to ecological systems and species, may have played a role in the public's disapproval of these foods. These initial attitudes are based primarily on the public's trust in the information source rather than factual information, and these attitudes may not change in response to additional information.

Public opinion depends heavily on awareness of the issues and the public's relative trust in the institutions, agencies, scientists, or regulators presenting the information. The mass media can play a large role in creating public awareness and may frame and shape the information on which public opinion is based.

Although the mass media may not play a significant role in telling the public "what to think," they can present issues for the public "to think about"—a concept known in communication research as media "agenda-setting" (Priest 2004). Most mass-media coverage of scientific issues is generated outside the media by interested parties who alert the media and spark interest, thus leading to a story on the subject. The interested parties may include advocates, promoters, opponents, watchdogs, consumer groups, environmental groups, and religious groups, as well as scientists. Providing the mass media with information about a given issue may not be enough, however, to increase public knowledge or involvement. In developing a risk-communication strategy, it is important not only to identify the risks that the public should think about but also to explain why the risks are

important. Although no one wants risks exaggerated, today's public is unlikely to accept claims that only benefits and no risks exist.

Myths of Risk Communication

Many scientists seem to hold a number of myths about providing information to the public. One is that because experts fully understand the risks associated with a technology, they can communicate them to the public effectively. To illustrate the fallacy of that belief, Dr. Dunwoody described a situation in which a scientist was studying the risks that a person might incur by eating contaminated fish caught in the Great Lakes. During a public meeting at which the researcher sought to present the results of his work, he used a risk comparison that he thought would help the public to understand the issue better. He stated that the risks posed by eating contaminated Great Lakes fish were equivalent to those posed by breathing the air in some of the large metropolitan U.S. cities. Later, he found that this message had been seriously misinterpreted, and he was accused of downplaying the risks associated with eating Great Lakes fish. Numerous newspaper editorials from around the state criticized the comparison. Unfortunately, the researcher had not thought about the audience's understanding of his comparison and about what people might take away from his message.

Another common myth of risk communication is that the more the public knows and understands about a technology, the more the technology will be appreciated. Dr. Dunwoody provided an example of this type of misconception by describing public perceptions of a nuclear power plant in Taiwan. Several years ago, an information campaign that cost millions of dollars was designed to educate the Taiwanese public about plans to build a nuclear power plant. The assumption behind the campaign was that "to understand the technology is to like the technology." However, the information campaign failed to change people's opinions about nuclear power. In fact, there were some profound and unintended consequences to public perceptions about nuclear power. People who had little or no previous knowledge about nuclear energy seemed to appreciate the information, found it useful, and subsequently were relatively approving of the plan to build a nuclear power plant. For the segment of the population that had previously held beliefs about nuclear power, however, whether favorable or unfavorable, their beliefs were reinforced by the information campaign. The example shows that knowledge gain does not necessarily predict

whether or how the public's perception of risk will change. Such uncertainty in predicting the results of risk communication permeates the research data.

SUFFICIENCY OF INFORMATION

Information sufficiency can be viewed at the social and the individual levels. At the social level, information sufficiency is the availability of risk-related information sufficient for decision-making on a broad scale, such as a policy on global climate change. At the individual level, information sufficiency is the availability of risk-related information that is sufficient for a person to make a decision, for example, on how to deal with a risk in daily life or whether to support science and public policy related to a risk, such as voting for an environmental referendum.

The desire to achieve information sufficiency, and confidence in judgment, often motivates people to seek and process information (Eagly and Chaiken 1993). The sufficiency principle "asserts that people will exert whatever effort is required to attain a 'sufficient' degree of confidence that they have accomplished their processing goals" (Eagly and Chaiken 1993). Understanding this principle may assist in developing an appropriate risk-communication strategy.

A fundamental goal of risk communication is to provide information to the audience that is based primarily on what the audience identifies as its information needs, taking into account the audience's knowledge base and misperceptions that some or all may have. In the case of toxicogenomics, it is critical to understand the following: What do the audience members know, or think they know, about toxicogenomics? What are their levels of uncertainty? What will they want and need to know about the use of toxicogenomics technology and data? How will the audience respond to and use the information they receive about toxicogenomics?

What Does the Audience Know or Think It Knows?

David Ropeik acknowledged that most people do not have a fundamental understanding about toxicogenomics. A participant noted, that although the scientific community is probably being reached through the scientific process by publishing in journals, a large segment of the population does not receive toxicogenomics information. In fact, only sparse information about toxicogenomics is available to the public or nonexperts. Most avail-

able information is designed primarily to be used by technical audiences. Therefore, there is an opportunity for scientists and risk communicators to frame the issue in the developmental phase and help to provide information that will set the base for initial public awareness of toxicogenomics and attitudes about it.

Some audiences might interpret information about toxicogenomics, in part, on the basis of their understanding of toxicology. People have always been intuitive toxicologists; that is, they rely on their senses to detect harmful or unsafe food, water, and air. The sciences of toxicology and risk assessment have emerged to improve detection of harmful chemicals. According to Mr. Ropeik, research has determined that much of the public is excessively health protective in its assessment of the toxic effects of chemicals. Public reactions to questions about toxicity usually yield a dichotomous response: a substance is considered either good or bad. That response highlights two common misconceptions that the public has about toxicology: *dose confusion*, a prominent misconception that any chemical that is harmful to human health is harmful at any dose; and *the usefulness of animal data to infer human toxic responses*—that is, the public is often overconfident about the utility of extrapolating accurately from an animal's response to a toxicant to a human's response to the same toxicant.

Craig Trumbo, University of Vermont, discussed those misconceptions in greater detail. He described surveys conducted to gauge public understanding of the science of toxicology by analyzing the public's reactions to the following questions: If you are exposed to a chemical in any way, are you going to suffer an adverse effect? Do you understand the concept of dose-response? The results indicate that most people will be overcautious in their responses. Most people believe that an adverse health effect is always the outcome of an exposure to a chemical, regardless of the dose.

Scientific uncertainty about extrapolating from animal data to human response is underestimated by the public (Trumbo 2004). Although most scientific analyses rely heavily on such extrapolations and expert judgment to understand how toxic effects in animals could be related to human responses, the public is more likely than toxicologists to believe that an animal's response to a toxicant is equivalent to a human response.

The term "lay" or "popular" epidemiology refers to public perceptions about health risks (Davison et al. 1991). People interpret health risks on the basis of observations of everyday events, discussions of disease prevalence within the community, and other sources, such as the mass media. Dr. Trumbo's work with cancer clusters is an example of lay epidemiology at work. The involvement of communities in self-reported cancer-cluster investigations can have both unfavorable and favorable aspects. On the

unfavorable side, communities that identify cancer clusters may be considered highly risk sensitive, and may interfere with scientific investigations, and demand verification of their initial beliefs, despite scientific findings that do not support their assertions. On the favorable side, the community can become actively involved in its own health issues, and community members may act as alert clinicians. Regardless of whether a cancer cluster is real or imagined, the community will tend to develop a common perspective, organize, seek an official investigation, and become involved in assessing the credibility of sources of information. Dr. Trumbo recommended that epidemiologists, toxicologists, and other scientists recognize that public involvement is inevitable in potential cancer-cluster conditions. He went on to state that scientists should become involved at the very beginning of such investigations to encourage the public to participate in the scientific process and to guide and inform the public along the way.

What Is the Audience's Level of Uncertainty?

A person's uncertainty about an issue can be a primary determinant of his or her response to a risk. Mr. Ropeik noted that uncertainty is inherent in virtually any risk, and the more uncertain a person is, the more likely that he or she may protect himself or herself with an emotional response, such as caution, worry, fear, or even anger. Research on uncertainty has shown that where scientific uncertainty or ambiguity is accentuated, a person's comfort with the information communicated may be substantially decreased. Understanding the individual's or audience's level of uncertainty is one way to shape effective risk-communication strategies. Mr. Ropeik added that emotional responses to uncertainty should not be considered irrational by scientists. Instead, scientists should strive to understand and respect those responses.

What Will the Audience Want and Need to Know?

Developing messages that take into account people's beliefs is a vitally important aspect of communicating toxicogenomics information to the public. Scientists involved in toxicogenomics research have a good opportunity to help frame the science for the public by emphasizing information about the technologies and data that they conclude would be beneficial for the public to understand and consider.

Risk communicators sometimes use a “mental-models” approach in designing an effective communication strategy (Figure 2 is a graphical representation of a mental model of decisions regarding infectious-disease transmission). The figure depicts individuals making decisions leading to actions that might expose them to a disease carried by others whose health has already been compromised (Fischhoff et al. 1998). This approach facilitates the integration of relevant information into an expert model and provides a structured process for the measurement of public perceptions. Julie Downs, Carnegie Mellon University, discussed the use of mental models to assess systematically what kinds of information are needed by the public and then to create messages to meet those needs. The mental-models approach has five steps: design integrated assessments of all the possible variables involved in the issue based on information from topic experts; gather information from the chosen audience; identify gaps, misconceptions, and critical problems in the audience’s comprehension; develop interventions to correct problems (to present information relevant to decisions in a nonjudgmental tone); and evaluate the communication outcomes. Mr. Ropeik noted that an important part of the process is identifying gaps in the target audience’s knowledge. They should be identified at the outset of the modeling process because the gaps need to be addressed to gain effective communication with the audience.

First, an integrative assessment or an “influence diagram” is developed to include all the variables that the experts have identified as important. An influence diagram is a simple visual representation of all the variables used by the audience to make a decision about a risk. It also includes the essential elements of the decision, such as uncertainties, different ways of approaching the decision, and how these influence each other. Experts elaborate on the influence diagram to determine the relevance of each variable. Figure 2 depicts a simple influence diagram that models the relationship between fertility and sexually transmitted diseases (Fischhoff et al. 1998).

Figure 2 is representative of a simple influence diagram related to teenage sexuality. The unshaded boxes represent chance variables, and the shaded box represents actions. An arrow indicates that the value of a box depends on the value of the preceding box. The solid lines represent the factors affecting an initial decision. The dashed lines represent the consequences of that decision. One example of a decision discussed in Fischhoff et al. (1998) includes an individual who believes that he or she is infertile, and this information influences the probability of unsafe sex (link a). Unsafe sex should affect the probability of a disease such as, chlamydia (link b). Actually having the disease changes the probability of the health states, including fertility (link c).

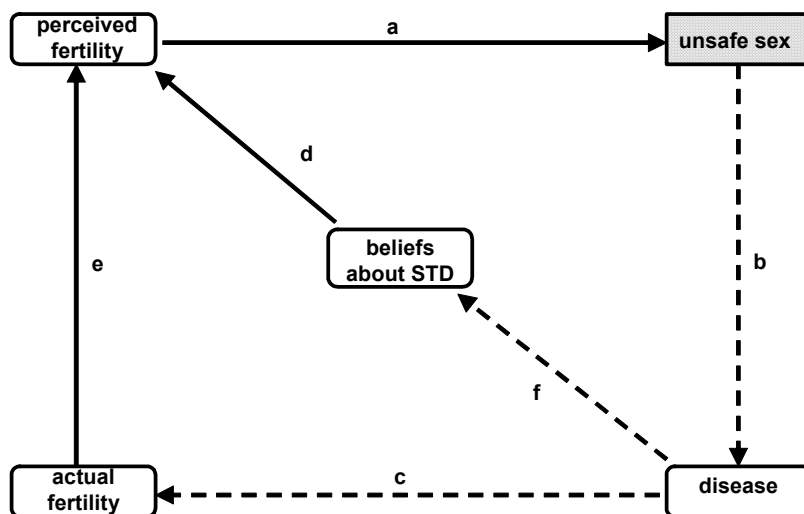


FIGURE 2 Influence diagram depicting a model of the relationship between fertility and sexually transmitted diseases. Source: Fischhoff et al. 1998. Reprinted with permission; copyright 1998, Elsevier.

The second step in mental modeling is to conduct pilot testing of the material to learn what the audience knows and how they think and talk about the risk. Typically, the risk communicator evaluates what the public knows in a systematic and open-ended manner, for example, using in-depth interviews. During the interviews, important misconceptions are identified, and basic understanding of concepts is evaluated. A communication message is developed to flesh out people's understanding of the issue, address their misconceptions, and try to bring their mental model of the issue into line with that of the experts. The communication message is evaluated after being presented to a test audience to determine whether it has led to improvements in audience understanding or changes in behavior. The risk communicator should now understand better what information needs to be provided on the basis of what the public already knows and how it conceptualizes the issues. Finally, an evaluation of the overall model should be conducted to determine whether people's knowledge or behavior changed following the communication (Downs 2004).

How Will the Audience Respond To and Use the Information?

It is critical to understand the audience's current knowledge about toxicogenomics to assess future responses to further information about toxicogenomics. No relevant examples of toxicogenomics communication are available at present, but research on communicating other scientific issues may provide useful examples. Dr. Downs extrapolated from her work regarding efforts to influence adolescent sexual behavior. Using the example of safe-sex messages related to adolescent sexual behavior, Dr. Downs discussed how people can misunderstand messages. For example, to encourage abstinence, students are told that having unprotected sex even once can result in pregnancy. However, students may decide that because they did not become pregnant after one unprotected sexual encounter, they can continue to have unprotected sex without becoming pregnant in the future. The students are using the information that has been provided to them and are doing their best to make sense of it. However, because the message has been designed to help "control" adolescents' behavior, but is not intended to inform them, the messages given to them may not address the information gaps they have about risky sexual behaviors. When designing risk-communication strategies, the risk communicator should know what information the audience lacks and what information the audience would want and need to know to make the best decisions. The risk communicator should not try to control behavior through a specific but limited message.

At the societal level, there are many factors to consider in assessing how audiences might respond to and make use of toxicogenomics information. Health disparities and environmental-justice issues are of primary concern because they shape how information is received by specific groups and how it should be presented to be communicated effectively.

According to Deirdre Lawrence, research on health disparities in populations, such as low-income populations and nonwhite communities, is relevant to toxicogenomics communication. In developing communication strategies to discuss toxicogenomics with various groups, it is important for researchers to understand that different socioeconomic groups may perceive information about risk in general and information about their own health differently, particularly if the information pertains to possible differences in their genetic susceptibility to disease (Lawrence 2004).

A concrete example of health disparities in the United States involves lung cancer rates among African Americans. Lung cancer is the leading cause of cancer death in the total U.S. population. Smoking causes about

80% of lung cancer, and tobacco is related to at least 30% of the other cancer deaths in the United States. Thus, the leading cause of preventable deaths in the United States is tobacco use. An analysis of racial and ethnic differences in cancer outcomes finds that African Americans are more likely than persons of other racial and ethnic groups to die of eight types of cancers: pancreas, lung and bronchus, prostate, mouth, pharynx, esophagus, liver, and cervix. Most of these cancers are related to tobacco use. Studies have found that American Indian populations have the highest smoking rates, and rates of smoking in both white Americans and African Americans are similar. African Americans are more likely to smoke “lightly” (less than 15 cigarettes per day); however, they are also less likely to quit smoking and more likely to die from lung cancer. Researchers have tried to determine the reason for those differences, including studying genetic differences between groups. One possible reason for the difference in lung cancer deaths is that about 75% of African American smokers use menthol cigarettes. Menthol cigarettes may increase exposure to the toxic components of cigarette smoke (Lawrence 2004).

Although they are still in the early stages of development, smoking-cessation programs that are based on finding a nicotine-dependence gene provide an example of the complexities of risk communication in populations that face health disparities. Some studies have demonstrated both genetic and environmental influences on smoking initiation and cessation (Lerman et al. 1999, Hall et al. 2002). Other studies are being conducted to determine the candidate genes (a gene that researchers think may be linked to a particular disease or condition) for nicotine dependence and to consider how this information can be used to develop a smoking-cessation treatment or intervention program. One such study is looking at polymorphisms (the physical quality or character occurring in different forms) of nicotine metabolism to determine whether a person who has a particular allele (one member of a pair or series of genes that occupy a specific position on a specific chromosome) is more at risk for developing the smoking habit than a person who lacks the allele. A challenge is how to communicate with people about the variation in their genes and how it may be related to their smoking patterns (Lawrence 2004).

Researchers looking at tobacco and genetics research are also trying to determine whether and how people’s knowledge of their genetic susceptibility may modify or change their behavior. If an individual knows that he has an allele that increases their risk, will he be more likely or less likely to try to change his smoking behaviors? Researchers are struggling with how to determine and address the heterogeneity within groups and between groups.

Other potential societal health and communication issues that need to be addressed include discrimination, tailored informed consents, and the potential adverse psychological outcomes that may result when some people get information about their genetic susceptibility to disease (Lawrence 2004).

CAPACITY TO ACCESS AND UNDERSTAND INFORMATION

It is important to examine how individuals and particular populations access risk information. In particular, traditionally disadvantaged groups may access risk information differently, an important consideration given that they also may face health disparities that are informed by toxicogenomics information.

Some Social Contexts

Risk communicators must know how different audiences access various forms of mass communication, such as newspapers, magazines, direct mail, radio, television, and the Internet. In addition to the mass media, toxicogenomics information may be accessed through other interpersonal channels of information, such as communication from health care providers and community networks. Dr. Viswanath discussed the use of different media as an indicator of differences among educational, social, and ethnic groups. An understanding of the appropriate use of various media is crucial to reaching an intended audience. Information presented in one medium, such as newspapers, is likely to reach only particular socioeconomic groups. Many people do not or cannot access information via television or the Internet. People use the Internet and other forms of electronic media to different degrees.

Dr. Viswanath discussed the use of computers and the Internet as an example of the unequal use of various media by different populations. The use of the Internet is still limited: 48% of the U.S. population does not yet have access to it. These people must rely on many different media for their information. In his research, Dr. Viswanath has found that a variety of factors—such as age, education, socioeconomic status, income, geography, and sex—determine whether and how people use the Internet to obtain information. These socioeconomic factors also affect the use of newspapers, television, and magazines as information sources.

People's access to information and to health care is a primary issue in communities that face health disparities. Many factors need to be considered when communicating about risk to these communities, including access to genetic counseling, the audience's literacy rates, and the presenters' ability to be culturally sensitive when providing information (Lawrence 2004). Dr. Lawrence noted that communicators should determine how different racial and ethnic groups access information and tailor their message accordingly. For example, communicators of smoking cessation programs would need to determine the most effective way to deliver this information to individuals as well as determine who is not being reached by the program (Lawrence 2004).

Dr. Lawrence continued by stating that communicators should also work to develop strategies that show sensitivity to the history of people who experience health disparities. Senator Edward M. Kennedy stated that "those who have borne the principal brunt of research, whether it is drugs or experimental surgery, have been the more disadvantaged people within our society, have been the institutionalized, the poor, and minority members" (Senator Edward Kennedy, Congressional Hearings, February 1973).

Trust is an important issue in groups that have been subjected to discrimination. Research on lung cancer and smoking in these groups has found that these groups perceive genetic information and counseling differently from other groups. For example, preliminary research has shown that African Americans often believe that genetic information is going to be harmful, whether or not they are familiar with it, whereas for white Americans, the more familiar they were with genetic information, the more receptive they were to genetic counseling (Furr 2002). It would be beneficial for genetic counselors and other health professionals who deal with genetic information to have training in cultural competency. Cultural competency requires an ability to understand and appreciate cultural differences between groups.

Some Individual Contexts

The public's general lack of scientific understanding needs to be considered in designing an effective toxicogenomics message. The low level of understanding of probabilistic information and low numeracy (basic understanding of numerical relationships) by most people may also have profound effects on how a message is perceived by the public. Sharon Dunwoody discussed research on numeracy. Researchers have found that most people cannot correctly answer the question, "If someone tosses a coin

1,000 times, on the average how many of those tosses should turn up heads?”

The likelihood that rare events, such as diseases and accidents, could co-occur is routinely misunderstood or underestimated by the general public and may explain some of the strong concerns about disease clusters, particularly cancer. This basic cognitive problem of underestimating the likelihood of co-occurrence of rare events is common in lay epidemiology. Dose confusion, as discussed by Dr. Trumbo, is another example of a public misconception of a scientific concept. Dose confusion is the belief that nearly everyone who is exposed to a carcinogen or other hazardous chemical, regardless of how small the amount, will develop a disease.

EMOTIONAL RESPONSES TO RISKS²

A person's emotional response to risk—such as worry, fear, anger, or even hope—can be an important determinant of how he or she will respond to risk messages. Worry or fear, for example, can increase attention unless the message produces a noxious level of fear (see, for example, Witte 1994). A fear appeal message (a message designed to channel fear of an adverse consequence to motivate behavior change in the target population) will not be effective if the person who gets the message believes that he or she cannot do anything to reduce risk and therefore reduce fear. Some factors that are important for predicting affective responses to risk information include a sense of dread about the risk (which includes perceptions that it is uncontrollable, deadly, catastrophic, involuntary, and so forth) and the feeling that it is unknowable (not observable, has delayed effects, and so forth) (for example, Slovic 1987).

A person's strength of beliefs regarding a particular issue can be a strong determinant of his or her response to information about the issue. Robust beliefs can be one of the “most important predictors of risk-communication outcomes because robust beliefs are extremely resistant to change” (Dunwoody 2004). Knowledge and personal frames about a risk are also important in determining how new information about the risk will be perceived in the future (Ropeik 2004).

Uncertainty can also play an important role in a person's response to risk. In many cases, the more a person knows about a risk, the more comfortable he or she is likely to be with it. As the uncertainty and level of harm associated with the risk increase, a person's comfort level tends to

²Applicable at the individual level.

decrease (Dunwoody 2004). “Self inflicted risks,” such as the risk associated with voluntarily driving a car, may be viewed very differently and elicit different emotional responses than risks imposed by others or by the environment, such as the risk from consuming contaminated drinking water. People are more suspicious of risks that are imposed on them by others or that they feel they cannot control.

TRUST IN SCIENTIFIC AND GOVERNMENT AGENCIES AND MASS-MEDIA ORGANIZATIONS

Effective risk communication often depends on the audience’s trust in scientific organizations, government agencies, and mass-media channels. The level of trust in and the credibility of the source of a message has been found to depend on three factors: audience perceptions of the source’s knowledge and expertise, perceptions of openness and honesty, and perceptions of concern and care (Peters et al. 1997). For example, studies of public perception of food safety have shown that several factors are consistently predictive of higher perceptions of food safety risk, including feelings of distrust toward regulatory agencies and poor consumer confidence in the adequacy of government regulations on pesticide use (Williams and Hammitt 2001). Communicators should understand that trust is easier to destroy than to build and that a person’s level of trust in an information source may be topic-specific.

A person’s view of the mass media can also affect how the person processes information. Studies have found that people tend to have negative perceptions of mass-media information when they believe that the source is of low quality (such as a tabloid), when the media are perceived to be too powerful, or when they have unfavorable feelings toward the source (Griffin et al. 1999).

William Freudenburg, University of California, Santa Barbara, discussed current public opinion and trust in technology. People today probably know less than past generations did about the technologies that they used in their everyday lives. Previously, many people were aware of how a plow worked, but today it seems that proportionately fewer people understand how a computer works—that is, today we are more dependent on technologies that fewer of us understand. Along with the growing dependence on technology, there has been a parallel increase in uncertainty about the agencies that regulate the technology and the information they disseminate. A participant noted that the public will often gauge its trust in the government’s information based on whether the information released is

positive or negative. In other words, if a government agency makes a statement that a chemical has toxic effects in humans, the public may be less skeptical of this information than if the agency stated that the chemical is not harmful to human health. Dr. Freudenburg noted that these feelings and perceptions about the government should be considered in designing a toxicogenomics communication strategy.

WRAP UP: DEVELOPING TOOLS FOR EFFECTIVE TOXICOGENOMICS COMMUNICATION

The following is a summary of future research areas developed by the workshop discussants during their presentations and in group discussion. The concepts build on the theory and practice of risk communication presented earlier in the workshop. The focus is primarily on ways to develop a communication strategy that incorporates understanding of the relevant audience, takes into account current knowledge of toxicogenomics, and sends a clear message about the advantages and disadvantages of the technology (see Figure 3).

Focus on the Audience

In general, an audience-based approach to communication is useful when selecting a specific communication goal, when considering multiple audiences, and when framing appropriate messages for each audience. The importance of openness, honesty, and building trust with the public is also important to effective communication. Communicators need to keep in mind that it is easier to lose the public's trust than to establish it. For any message, there are a variety of audiences, and there is no specific method or medium that will adequately reach all of them. As Dr. Viswanath noted, risk communicators should recognize that there are different publics for different media, and people vary in choice and use of media. Dr. Lawrence stated that using resources wisely is necessary to develop effective communication for the "hardly reached" populations.

Study the Audience

Studying and understanding the audience is critical for effective communication of useful information. The communicator needs to take into

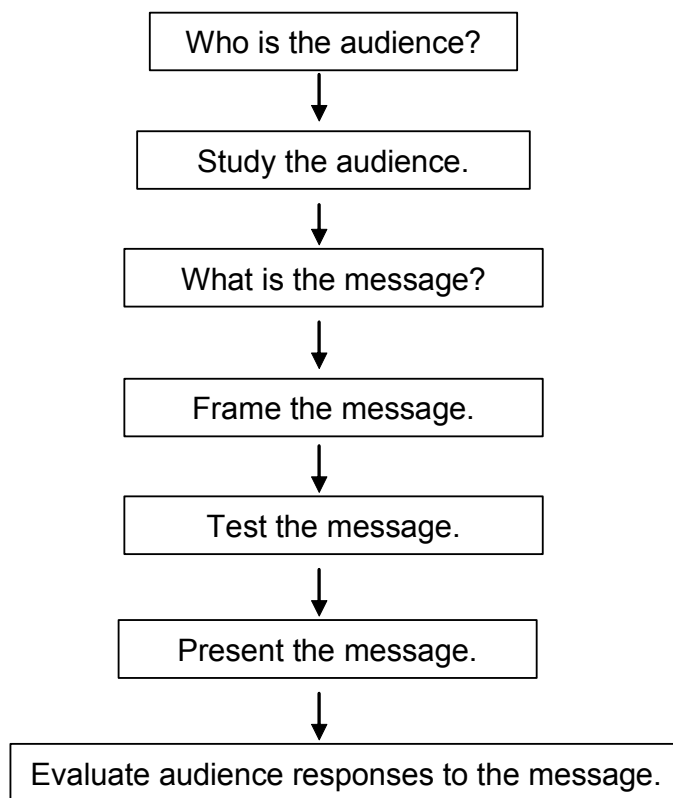


FIGURE 3 Toxicogenomics risk communication: Steps to communicate science effectively.

account factors such as the members' interests, knowledge, capacities, and needs. It is important that communicators also evaluate an audience's possible emotional responses (such as worry, fear, anger, and hope) to an issue when forming a communication strategy. Some critical questions to be considered when developing a research agenda for toxicogenomics communication are the following:

- What do various groups of people know already about toxicogenomics? This information would help in gauging baseline public knowledge.
- What do the experts think the public should know about toxicogenomics?

- What do members of the public say they need or want to know about toxicogenomics?
- What are the different audiences' capacities to access, process, interpret, and use toxicogenomics information, and how might these capacities vary from one social group to another?
- What are the audiences' levels of trust in institutions that develop and manage toxicogenomics technology and information?
- What kinds of emotional responses might toxicogenomics elicit from nonexperts?
- What messages are useful and effective? Testing these messages with the intended audiences and adjusting them according to their responses is necessary.

Dr. Lawrence noted that resources devoted to the following area would help reduce communication barriers and would assist in making toxicogenomics information more accessible to diverse populations: reducing health disparities; determining the best way to make new information accessible to diverse populations; and integrating cross-disciplinary training in epidemiology, statistical genetics, risk assessment, and other related fields.

Dr. Lawrence also emphasized that communicators would benefit from being especially sensitive to the historical context of medical research in vulnerable populations, such as the Tuskegee syphilis study and earlier studies on the elderly, retarded, prisoners, and children. Such studies have led to distrust among these populations and their advocates about the intent of scientific research. She noted that it would be beneficial for genetic counselors and other health professionals who deal with genetic information to have training in cultural competency.

What Is the Message?

In defining a communication strategy, it is vitally important that researchers identify the information that they would like to present to the public about toxicogenomics and tailor it based on their understanding of the audience and its current knowledge base. Dr. Lawrence noted that caution is advisable when describing the promise of this technology; both the potential benefits and the potential drawbacks of toxicogenomics need to be communicated. Describing the promise of the technology in a realistic manner may help to improve public understanding of and opinions about the technology. She also stated that it is not appropriate to promote the idea that information from toxicogenomics studies is useful at the individual

decision-making level, because the data that have been generated thus far need to be validated. A participant added that as toxicogenomics is still in its infancy and its implications are still unknown, it might be helpful to design interim messages about the technology. Mr. Ropeik emphasized that the science of toxicogenomics is relatively unknown to the public, so researchers and communicators have an opportunity to explain what they believe the technology will accomplish.

Frame the Message

Although most toxicogenomics communication efforts will occur in the future, this may be an ideal time to begin to frame the toxicogenomics message for the nonexpert audience. Mr. Ropeik noted that in framing the message, it is important that communicators define toxicogenomics to shape initial public awareness of the science. He added that communicators should be aware that a person's initial learning experience about a topic is likely to shape all later beliefs about it. In establishing a definition, the use of clear and unambiguous language is valuable so that it is understandable to the appropriate audience. The public may also encounter various kinds of information about toxicogenomics that is not connected to the communication efforts coordinated by the scientific community. This knowledge may also influence the public's understanding of the science. Dr. Dunwoody reinforced this idea: "In any area of science and technology, [communicators] won't control the landscape. Instead, [the communicator is] a participant in the landscape trying to anticipate the kinds of variables, the kinds of forces that will come out, and communicators will work to manage those as best as they can."

Dr. Trumbo added that research has shown that hope can motivate people to seek more information about an unknown topic. If toxicogenomics is framed in a manner that highlights the applications of the technology as a potential disease-prevention or public-health tool, a favorable public response to the technology may result. An effective communication strategy may depend on the communicator's awareness that a person's initial experience with an issue is likely to shape all his or her later beliefs about it. Mr. Ropeik noted that communicators should also understand that, in framing a risk message, a person's experience with a risk can affect how strongly he or she will feel about the message.

Mr. Ropeik discussed the importance of promoting the role of the National Center for Toxicogenomics (NCT). The mission of the NCT, a part of the National Institute of Environmental Health Sciences, is "to

coordinate a nationwide research effort for the development of a toxicogenomics knowledge base.” Establishing public awareness of the role of NCT would be beneficial in encouraging public trust in the government institution directly involved in the research and in informing the public of a credible information resource.

Test the Message

Dr. Trumbo noted that it is essential to test the message to gauge how people will probably respond to and use it. For example, toxicogenomics may prove to be an inherently frightening word to the public. The public response to the term may make it difficult to promote the technology. A survey could be constructed in advance of communication efforts to gauge general reactions to the term. A survey might help to determine whether an alternative term would be more appropriate for use by the research community. A survey might also help to inform communicators about the initial interpretations people make about toxicogenomics based on their inferences from other sources of information and their existing knowledge of areas related to toxicogenomics.

Present the Message

Dr. Viswanath observed that risk communicators should recognize that there are different publics for different media, and people vary in choice and use of media. Successful risk communication provides information via media that the intended audience can access readily and that meets the audience’s needs for information to help them evaluate and deal with risks. Dr. Lawrence reiterated that communicators should note that access to health information is a primary issue in vulnerable communities that face health disparities.

Dr. Downs discussed the application of the mental-models approach in communicating risk. She noted that the mental-models approach may be a useful tool for gauging the audience’s perception of the technology. It can provide information relevant to the decision-making process and can be useful for determining the audience’s existing knowledge and understanding of the topic. The mental-models approach could assist in designing a process to build a foundation of public knowledge so that future information about toxicogenomics, when available, would make sense to the public.

Dr. Priest added that ensuring that information is provided to the

appropriate mass-media sources will encourage journalists to become interested parties and thus more likely to cover the technology as it develops.

Study Audience Use of the Message

Dr. Trumbo stated that studies could be conducted to evaluate how the audience has accessed, processed, interpreted, and used the message. He added that longitudinal studies can capture periodic changes in perception of toxicogenomics. Public awareness of, trust in, and response to toxicogenomics technology and the handling of toxicogenomics data also need to be tracked and compared over time. It would be wise to start the tracking surveys soon to establish a baseline of public reactions to toxicogenomics and toxicogenomics information before much communication activity takes place.

Challenges

This workshop was not an exhaustive examination of all the relevant psychological and social factors involved in lay persons' access, use, and interpretation of toxicogenomics information. It was designed to identify broad themes for further investigation. However, two challenges for the near future surfaced during the workshop: (1) investigating how to initially frame toxicogenomics for various nonexpert audiences, working through such methods as focus groups and surveys, and (2) conducting a survey to establish a baseline for future tracking of public responses to toxicogenomics before much more information is released.

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Appendix A

STATEMENT OF TASK

| | |
|------------------------------------|---|
| Major Unit: | Division on Earth and Life Studies |
| Division, Office, or Board: | Board on Environmental Studies and Toxicology, Board on Life Sciences |
| Subject Committee: | Communicating Toxicogenomics Information to Nonexperts: A Workshop |
| Staff Officer Name: | Roberta Wedge (BEST), Marilee Shelton-Davenport (BLS) |

Statement of Task:

An ad hoc committee will be appointed under the auspices of the standing Committee on Emerging Issues and Data on Environmental Contaminants to plan a 1-2 day workshop on communicating toxicogenomics information. In particular, the workshop will consider communication about toxicogenomics information with the public and other nonexpert audiences (workers, lawyers, health professionals, policy makers); communication surrounding some key social, ethical, and legal issues related to toxicogenomics and its

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eventual application; and how information related to toxicogenomics research and its social implications may be perceived by nonexperts and used to make decisions about risk. Following the workshop, the committee will prepare a short report of the workshop. This workshop will help identify where and what resources should be applied to improve communication between and among various public sectors and scientists working in toxicogenomics.

Sponsor: National Institute of Environmental Health

Date of Statement: December 22, 2003

Appendix B

COMMITTEE ON EMERGING ISSUES AND DATA ON ENVIRONMENTAL CONTAMINANTS

Sixth Meeting - April 22-23, 2004
National Academy of Sciences
2100 C St., NW
Washington, DC 20418

AGENDA

Communicating Toxicogenomics Information to Nonexperts: A Workshop

Thursday, April 22nd

OPEN SESSION, Lecture Room

9:00–9:30 a.m. Introduction to Risk Communication Workshop
Mark A. Rothstein, committee chair, University of
Louisville School of Medicine and Robert Griffin,
committee member, Marquette University
(outline objectives of workshop)

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9:30–9:45 a.m. Overview of toxicogenomics: William Greenlee, committee member, CIIT Centers for Health Research

Panel 1: Toxicogenomics communication and individual decision-making (committee member leads: Robert Griffin, Patricia Buffler)

9:45–10:15 a.m. Speaker: Sharon Dunwoody, University of Wisconsin (Perceptual communication issues; what an individual might perceive as issues in decision making; information needs; psychological factors such as variability in perception, discuss what kinds of information are used by public in making risk decisions and risk perceptions; how info gets to public and how public reactions get back to scientists/regulatory agencies)

10:15–10:30 a.m. **BREAK**

10:30–11:15 a.m. Panel Speakers (~15 minutes each):
Julie Downs, Carnegie Mellon University
Craig Trumbo, University of Vermont
David Ropeik, Harvard University

11:15–12:00 p.m. Panel Discussion with audience participation

12:00–1:00 p.m. **LUNCH available in basement cafeteria**

Panel 2: Toxicogenomics communication and social deliberations (committee member leads: Linda Fentiman, William Greenlee)

OPEN SESSION Continued, Lecture Room

1:00–1:30 p.m. Speaker: William Freudenburg, University of California, Santa Barbara (How to translate reality of individual risk perception to societal decision making arena; inequality issues related to access to toxicogenomic technologies and information)

1:30–2:15 pm Panel speakers (~15 minutes each):
Deirdre Lawrence, National Cancer Institute

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K. Viswanath, Harvard School of Public Health
Susanna Hornig Priest, Texas A&M University

2:15–3:00 p.m. Panel Discussion with audience participation

3:00–3:15 p.m. ***BREAK***

3:15–4:30 p.m. Summary Discussion with all panel members

4:30–5:00 p.m. Open discussion with audience participation

5:00 p.m. ***ADJOURN***

Appendix C

BIOGRAPHICAL INFORMATION ON THE COMMITTEE ON COMMUNICATING TOXICOGENOMICS INFORMATION TO NONEXPERTS: A WORKSHOP SUMMARY

MARK A. ROTHSTEIN (*Chair*) is the chair of law and medicine and the director of the Institute for Bioethics, Health Policy, and Law at the University of Louisville. He has appointments in the Departments of Medicine and Family and Community Medicine at the School of Medicine and at the Louis D. Brandeis School of Law. He earned a J.D. from Georgetown University. Mr. Rothstein's interests include the ethical, legal, and social implications of genetics, privacy, health policy, and employment law. He is chair of the Privacy and Confidentiality Committee of the National Committee on Vital and Health Statistics, the federal advisory committee that advises the secretary of health and human services on health information policy, including the privacy regulations of the Health Insurance Portability and Accountability Act. He has served on the NRC Committee on Assessing Genetic Risks: Issues and Implications for Health.

PATRICIA A. BUFFLER is professor of epidemiology at the School of Public Health at University of California, Berkeley. She received a Ph.D. in epidemiology from the University of California, Berkeley. Dr. Buffler's research interests include the environmental causes of cancer, especially

gene-environment interaction and childhood cancer, lung cancer, leukemia, brain cancer, and breast cancer; epidemiologic research methods; and the uses of epidemiologic data in health policy. She has served on numerous NRC committees including the Committee on Health Effects Associated with Exposure During the Persian Gulf War; Committee to Review the Hanford Thyroid Disease Study Final Results and Report; Committee on Environmental Justice: Research, Education, and Health Policy Needs; National Forum on Science and Technology Goals: Environment; HHMI Predoctoral Fellowships Panel on Epidemiology and Biostatistics; Steering Committee on Valuing Health Risks, Benefits, and Costs for Environmental Decisions; Committee on Chemical Toxicity and Aging; Committee on Passive Smoking; Committee on Non-Occupational Health Risks of Asbestiform Fibers; and Committee on Priority Mechanisms for Research Agents Potentially Hazardous to Human Health. She currently serves on the Committee on Health Risks from Exposure to Low Levels of Ionizing Radiation (BEIR VII Phase 2). Dr. Buffler was elected to the Institute of Medicine in 1994.

LINDA C. FENTIMAN is professor of law at Pace University. She earned a J.D. from the State University of New York (SUNY) Buffalo School of Law and an L.L.M. from Harvard University School of Law. Ms. Fentiman has practiced and taught criminal law, environmental law, and health law, concentrating on bioethics, health care access, public health law, and mental disability law, including the insanity defense and competency to stand trial. She has chaired the Health Law Committee of the Association of the Bar of the City of New York and the Section on Mental Disability and the Law of the Association of American Law Schools, and is a member of the Health Law Section of the New York State Bar.

WILLIAM F. GREENLEE is president of CIIT Centers for Health Research. He received a Ph.D. in pharmacology from the University of Rochester. His research interests include the toxicity and carcinogenicity of polybrominated biphenyls and related compounds, neurotoxicity risk assessment, molecular toxicology, and the molecular basis of dioxin toxicity to human keratinocytes. Dr. Greenlee is the current president of the Society for Toxicology.

ROBERT J. GRIFFIN is professor and director of the Center for Mass Media Research at Marquette University. He earned a Ph.D. in mass communication from the University of Wisconsin-Madison. His interests include environmental issues, health, science, risk communication, and new tech-

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nologies. Dr. Griffin teaches statistical reasoning and has written on interpretation of public issues, including perception of scientific issues.

Appendix D

BIOGRAPHICAL INFORMATION ON THE WORKSHOP SPEAKERS

SHARON DUNWOODY is Evjue-Bascom Professor of Journalism and Mass Communication at the University of Wisconsin-Madison. She also serves as chair of academic programs for the University's Institute for Environmental Studies and as head of the Center for Environmental Communication and Education Studies (CECES). Dr. Dunwoody studies the role of the mass media in public understanding of science and has authored numerous journal articles, book chapters and books on the topic. She is a member of the Committee on the Public Understanding of Science and Technology of the American Association for the Advancement of Science. Dr. Dunwoody has served on numerous NRC committees and boards including the Board on Radiation Effects Research, Communications Advisory Committee, Commission on Life Sciences, Committee on Exposure of American People to I-131 from Nevada Atomic Bomb Tests: Implications for Public Health. She earned her Ph.D. in mass communication at Indiana University before moving to University of Wisconsin-Madison in 1981.

JULIE DOWNS is research scientist in the Department of Social and Decision Sciences at Carnegie Mellon University. Her research interests include how social influences affect decision-making and how people can make better decisions by understanding the nature of these influences. One goal

of her research is to implement interventions aimed at helping people make better decisions in the face of often unseen social influences. Dr. Downs earned her Ph.D. from Princeton University.

WILLIAM R. FREUDENBURG is Dehlsen Professor of Environmental Studies at the University of California at Santa Barbara. He is a specialist on the human aspects of risk assessment and risk management and has done extensive research on nuclear and other energy technologies. He has served as chair of Section K (social, economic, and political sciences) of the American Association for the Advancement of Science. He has served on several NRC committees and federal advisory committees relating to energy and waste management issues. He was the first congressional fellow from the American Sociological Association to serve in the U.S. House of Representatives. Dr. Freudenburg received his Ph.D. in sociology from Yale University in 1979.

DEIRDRE LAWRENCE is an epidemiologist in the Risk Factor Monitoring and Methods Branch in the Division of Cancer Control and Population Sciences at the National Cancer Institute (NCI). Her current research interests include applying surveillance, statistical and epidemiologic research concepts to monitor trends of tobacco use in the United States, and analyzing disparities in predictors and patterns of cancer-related risk factors. At NCI, her current responsibilities include planning, initiating, coordinating, and conducting research related to the surveillance of tobacco use, particularly among U.S. population subgroups. In addition, Dr. Lawrence is a member of the NCI Special Studies Institutional Review Board (IRB), and she reviews and contributes to technical reports and conference planning activities relevant to improving tobacco surveillance and reducing cancer-related health disparities. Dr. Lawrence earned her Ph.D. in toxicology from the Massachusetts Institute of Technology and an M.P.H. from the Harvard School of Public Health.

SUSANNA HORNIG PRIEST is director of research for the College of Mass Communications and Information Studies at the University of South Carolina. Formerly, she served as associate professor and director of the Texas A&M University M.S. Program in Science and Technology Journalism. She is the author of a book, *A Grain of Truth*, and a number of other published studies of the relationship between media coverage, public opinion formation, and public policy development for biotechnology. In collaboration with colleagues across Europe and North America, she has also been involved in recent years in a major comparative study of how these dynam-

ics “play out” across national boundaries. Dr. Priest earned a Ph.D. in communications from the University of Washington.

DAVID ROPEIK is director of risk communication at the Harvard Center for Risk Analysis. Mr. Ropeik is responsible for communicating the center’s approach of keeping risk in perspective to the press, policy makers, and the public. He teaches risk communication at the Harvard School of Public Health. He is a commentator on risk issues for National Public Radio’s Morning Edition program. He has written extensively on risk perception and risk communication. He has lectured on these topics at the White House and to numerous government, corporate, and consumer groups worldwide. He served for 9 years on the Board of Directors of the Society of Environmental Journalists. Mr. Ropeik has been a visiting lecturer in journalism at Boston University and Tufts University. He received a B.A. in journalism in 1972 and an M.A. in journalism in 1973 from Northwestern University, Medill School of Journalism.

CRAIG TRUMBO is associate research professor in the Department of Family Practice, College of Medicine, at the University of Vermont. His research focuses on public understanding of science and health-risk communication. He has programs of research on news media representation of climate change, risk communication, and cancer epidemiology, and information effects on water conservation behavior. His research has received nearly \$1 million in support from the National Science Foundation, the U.S. Environmental Protection Agency, the National Institutes of Health, the American Cancer Society, the U.S. Department of Agriculture, and the U.S. Department of Energy. His work has been published in a range of journals, including *Journalism and Communication Monographs*, *Journal of Communication*, *The Journal of Computer Mediated Communication*, *Science Communication*, *Public Understanding of Science*, *Water Resources Research*, *Risk Analysis*, the *American Journal of Public Health*, and the *Encyclopedia of Library and Information Science*. Dr. Trumbo holds an M.S. (1993) in journalism and mass communication from Iowa State University, and a Ph.D. (1997) in mass communication from the University of Wisconsin-Madison.

KASISOMAYAJULA VISWANATH is associate professor of society, human development, and health in the Department of Society, Human Development, and Health at the Harvard School of Public Health. Formerly, he was the acting associate director of the Behavioral Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute. He

came to the National Cancer Institute from Ohio State University, where he was a tenured faculty member in the School of Journalism and Communication with an adjunct appointment in the School of Public Health. Dr. Viswanath was also a center scholar with Ohio State's Center for Health Outcomes, Policy, and Evaluation Studies. His research interest is in using a macro-social approach to the study of communication, his most recent work focusing on mass communication and social change and health communication in national and international contexts with particular focus on communication inequities and disparities. Dr. Viswanath has published on such topics as communication and health campaigns, diffusion of new communication technologies, international communication, and women and media in different journals, including *Gazette*, *Media Culture and Society*, *Health Communication*, *Journalism Quarterly*, *Communication Research*, *American Behavioral Scientist*, *Health Education Research*, and chapters in a number of books. He has also co-edited the book *Mass Media, Social Control and Social Change* with David Demers. Dr. Viswanath received his Ph.D. in mass communication from the University of Minnesota.