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Protecting Privacy and Confidentiality in Environmental Health Research

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Abstract

Environmental health researchers often need to make difficult decisions on how to protect privacy and confidentiality when they conduct research in the home or workplace. These dilemmas are different from those normally encountered in clinical research. Although protecting privacy and confidentiality is one of the most important principles of research involving human subjects, it can be overridden to prevent imminent harm to individuals or if required by law. Investigators should carefully consider the facts and circumstances and use good judgment when deciding whether to breach privacy or confidentiality.

Keywords

privacy; confidentiality; environmental health research; ethics; home; workplace; informed consent

I. INTRODUCTION

Environmental health scientists frequently conduct research on exposures to pesticides, allergens, industrial chemicals, and other substances in the home or workplace, which can provide valuable information for preventing diseases and promoting health.¹ For example, studies of exposure to allergens in the home provide useful information for preventing or managing respiratory diseases such as asthma.² Research on pesticide exposure of agricultural workers can help public health professionals to develop interventions for preventing pesticide poisoning and reducing the risks of developing illnesses (e.g., Parkinson's disease) related to long-term pesticide exposure.³ However, research on domestic and occupational exposures can pose ethical dilemmas related to the protection of research subjects or others, because investigators may ask individuals for information pertaining to private behaviors such as substance abuse or sexuality, or they may collect samples from private areas such as bedrooms, bathrooms, or offices. Investigators may inadvertently discover information related to illegal or illicit conduct such as child abuse or violations of occupational safety laws.¹ Therefore, environmental health researchers often need to make difficult decisions about how to protect privacy when they conduct research in the home or workplace.¹ These dilemmas are different from those normally encountered in clinical research.

II. PRIVACY AND CONFIDENTIALITY

Privacy and confidentiality are related but different concepts. Privacy refers to an individual's interest in controlling access to himself or herself.⁴ There are two distinct types of privacy: informational privacy and physical privacy. Informational privacy refers to the interest in controlling access to private information about one's self, such as data pertaining to medical conditions, sexual practices, income, or social security number. Physical privacy refers to the interest in controlling access to one's body, biological specimens, or personal space. Observing a person undressed without permission would be an invasion of that person's physical privacy but not necessarily his or her informational privacy. Illegally accessing a person's medical records would be an invasion of informational privacy but not necessarily physical privacy. Confidentiality refers to measures that are taken to protect an individual's informational privacy, such as limiting access to medical or research records, data encryption, and secure data storage.⁴ Confidentiality is concerned with informational privacy, not physical privacy.

Many philosophers have examined the moral foundations of privacy interests. Some hold that the obligation to protect privacy is ultimately based on other, more fundamental moral principles such as the right to liberty or autonomy or the duty to not harm others.⁵ For example, breaching medical confidentiality can be regarded as unethical because it can cause harm such as loss of employment, discrimination, legal liability, or embarrassment to the person. Breaching confidentiality may be unethical even if it does not cause any harm because it violates a person's right to control the disclosure of private information. Watching someone undress without permission invades physical privacy; even if it does not cause harm to the person, it violates his or her right to control access to his or her body. Others hold that violations of privacy are wrong because they undermine intimacy, which is necessary for the formation of meaningful human relationships. People develop close relationships by sharing private information, secret dreams and desires, and physical space. Because people cannot form these close relationships unless they have some expectation that their privacy will be protected, society needs laws and ethical rules to protect privacy.⁶

A. Protecting Privacy and Confidentiality in Research Involving Human Subjects

Regardless of how one understands the moral foundations of privacy, it is clear that privacy and confidentiality are important values that should be protected in research with human subjects.⁷ Numerous ethical codes and legal mandates, such as the Declaration of Helsinki,⁸ the Council for the International Organization of Medical Sciences guidelines,⁹ and U.S. federal research regulations,¹⁰ require investigators to protect the privacy and confidentiality of research participants and to explain how privacy and confidentiality will be protected during the informed consent process. Many commentators recommend that investigators should also protect the privacy and confidentiality of third parties who may be directly affected by research but who are not the subjects of research, such as occupants of a home in which data collection takes place, family members identified in genetic research, or communities participating in a study.¹¹ Additionally, state and federal laws that protect the privacy of patients receiving health care, such as the Health Insurance Portability and Accountability Act (HIPAA), also apply to research activities.¹²

In clinical research, investigators collect private information such as a person's medical and family history, sexual behaviors, alcohol and drug use, diet, exercise, clinical laboratory test results, genetics, and environmental exposures. Because clinical investigators rarely need to enter a person's home or office to collect this information, most of the privacy issues in clinical research center on safeguarding confidentiality.¹³ To be sure, difficult ethical dilemmas can arise when deciding how to protect confidentiality in the clinical setting, such as deciding whether to disclose a person's HIV status to affected parties, but these ethical

dilemmas are different from those that arise in health research conducted in the home or workplace environment, because clinical researchers usually obtain this private information as part of their study, not inadvertently during data collection in a private area.^{1,14,15}

B. Protecting Privacy and Confidentiality in Environmental Health Research

When investigators conduct research in the home or workplace, they may request private information from research subjects, such as medical history, daily activities, diet, and drug and alcohol use. The ethical dilemmas concerning the protection of private information obtained as part of the study are similar to those encountered in clinical research. However, investigators may also discover private information that is not being collected as part of the study when they enter a home or workplace.^{1,14} For example, in a study of how allergens in the home affect asthma, investigators may collect dust samples from bedrooms, bathrooms, recreation rooms, dining rooms, hallways, kitchens, and basements. When investigators enter these areas, they may observe evidence of illicit drug use or other illegal activities, building code violations, dangerous conditions in the home, domestic violence, and child or elder abuse/neglect. In a study of how chemical exposure in the factory affect health, investigators may collect samples from offices, assembly lines, bathrooms, dining areas, locker rooms, waiting rooms, and hallways. When investigators enter these areas, they may observe evidence of illicit drug use, alcohol use, or violations of environmental and occupational safety laws.

Ethical dilemmas arise when investigators have to decide what, if anything, they should do with the private information that they inadvertently discover in a home or workplace. As we have seen, ethical guidelines and regulations require investigators to take steps to protect private information. However, investigators may sometimes have good reasons to override these obligations and disclose private information obtained in the home or workplace. The most compelling reason to disclose private information is to protect individuals, especially children or vulnerable adults, from harm. Most ethical theories hold that we should help other people when it is reasonable to do so, including taking appropriate measures to rescue people who face imminent harm.¹⁶ For example, if we see someone drowning in a pool, we should throw in a life preserver, call a lifeguard, or take some other measure to save the person's life. We need not jump into the pool to save the person unless we are trained in water safety because this would risk our own lives, but we should not stand by idly.

If an investigator discovers evidence of child abuse/neglect while collecting samples in the home, he or she would have a strong moral obligation to report that information to the relevant authorities to protect the child from harm. The investigator may also have a legal obligation to report evidence of child abuse/neglect, because many jurisdictions have laws requiring educators, health care workers, and members of certain professions to report child abuse/neglect.¹ However, there may also be reasons not to report suspected child abuse/neglect, such as in cases where the evidence may be inconclusive and reporting the situation to the authorities may cause unnecessary harm to the child or other family members.¹⁴ Investigators should carefully consider these and other facts and circumstances when deciding whether to report. They may also discuss the situation with the parents or guardians prior to taking any action if they believe there has been some misunderstanding.

Investigators may encounter reporting dilemmas when they collect samples in the workplace environment. For example, suppose that investigators observe significant violations of occupational safety laws in a factory that place workers in imminent danger. They would have a strong ethical obligation to report these violations to the appropriate authorities to protect the factory workers from harm. However, similar to the child abuse/neglect example, there may be reasons not to report workplace safety issues: the evidence may be inconclusive, the potential harm to employees may be minimal, some workers may be fired

if a safety report is made, and the entire research project may be jeopardized if the employer decides to no longer cooperate with the researchers. To deal with these and other contingencies, investigators should discuss safety violations with the management before contacting outside authorities, because the information that is disclosed may be harmful or embarrassing to employers. It may be possible to resolve these issues in a way that protects workers but also does not harm the employer or undermine the study. Investigators should use good judgment when deciding how to approach workplace safety issues that they discover while conducting a study.

Other rationales for compromising privacy are less compelling than protecting people from imminent harm. For example, suppose that investigators discover evidence of illegal drugs in a home. One could argue that they should report this illicit activity to the police to help enforce the drug laws and protect residents of the home from the potential harm associated with drug use. However, reporting the presence of illegal drugs in the home could do more harm than good, because making a report may undermine the research subjects' trust in the investigators, the evidence may be inconclusive, and the police may decide not to investigate the complaint anyway. A great deal depends on the circumstances of the situation. For example, if the investigators discover only a small amount of marijuana on a shelf where they are collecting dust samples, perhaps they should not say anything. However, if the investigators discover a large cache of various illegal substances, which would indicate that someone is selling drugs on the premises, and there are children in the home who may be in danger as a result of this illegal activity, then they should consider making a report. Once again, investigators should use good judgment when deciding whether to report illegal drugs (or other illicit activities) in the home and they should carefully consider the relevant facts. They may also discuss these issues with occupants, if appropriate.

Investigators may also encounter situations in the workplace that do not necessarily require them to make a report to the relevant authorities. For example, suppose investigators discover potential violations of environmental laws when collecting data in a workplace. If these violations do not place people in imminent danger or pose significant, imminent risks to the environment, then they may decide to discuss the issue with the management rather than making a report to the authorities. Other illegal activities discovered in the workplace, such as evidence of alcohol/drug abuse, sexual harassment, or fraud/embezzlement, may be treated in a similar fashion.

The informed consent process can play a critical role in addressing issues related to privacy, confidentiality, and reporting illegal or dangerous activities to authorities.¹ Federal research regulations¹⁰ and other ethics rules⁹ require investigators to inform research subjects about how confidentiality and privacy will be protected. Investigators should not only notify subjects about measures that will be taken to safeguard confidentiality and privacy, but they should also inform them about circumstances in which they are obligated to breach confidentiality or privacy, such as reporting child neglect/abuse. Because it will not be possible to anticipate every situation in which it may be appropriate to breach confidentiality or privacy, a generic statement such as “privacy or confidentiality may be breached to protect people from imminent harm or if required by law” may be appropriate. Investigators should also discuss potential privacy/confidentiality issues with employers when conducting a study at a worksite. Talking about these issues with research subjects and other affected parties can help to promote trust and cooperation and avoid misunderstandings.

Investigators should also address privacy and confidentiality issues when planning a research project and developing a protocol. They should clearly describe the steps they will take to protect privacy and confidentiality, and how they will handle situations in which they may have an ethical or legal obligation to breach privacy or confidentiality. They should

describe these issues in sufficient detail so that an institutional review board or other ethical review committee can understand how the proposed research project will affect the rights and welfare of human subjects and other affected parties, and how the investigators plan to protect them.

Finally, it is important for investigators to train research staff about privacy and confidentiality issues that may arise when collecting data in a home or workplace.¹⁴ They should inform research staff about the measures that will be taken to protect privacy and confidentiality, such as secure storage of research records, limited access to data, and encryption, and instruct research staff on the importance of avoiding unnecessary invasions of privacy in the home or workplace. For example, research staff should not open drawers or closets without permission, and they should not snoop around the home or workplace. They should collect samples only in pre-approved, designated areas. They should also be instructed on what to do if they inadvertently discover illegal or dangerous activities. Training may need to be revised as investigators acquire more experience in conducting research in the home or workplace.

III. CONCLUSION

Protecting privacy and confidentiality presents some unique—and often difficult—ethical dilemmas for investigators who are collecting data in the home or workplace environment. Privacy and confidentiality can be breached to protect people from imminent harm or if required by law. Investigators should carefully consider the relevant facts and use good judgment when deciding whether to compromise privacy or confidentiality. They should also address these issues when developing a research protocol and during the informed consent process, and should train research staff on confidentiality and privacy protections and concerns.

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