**Considering Privacy and Confidentiality in Public Health Assessment Documents**

Office of Community Health Hazard Assessment

Agency for Toxic Substances and Disease Registry

U.S. Department of Health and Human Services

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# 1. Purpose and Introduction

## 1.1. Purpose

To provide methods to Office of Community Health Hazard Assessment (OCHHA) to protect confidentiality and privacy as it relates to agency products (documents, maps, etc.) and public conversations (written, oral, or electronic). Confidentiality is the condition of honoring a request or expectation that information will be protected from unauthorized disclosure. Privacy is an individual's interest in keeping information about himself or herself confidential.

## 1.2. Introduction

Procedures regarding confidentiality requirements generally refer to medical records and similar personal information. However, any information or data that specifically identifies an individual or household can be considered "private."

To the extent possible, ATSDR and its public health partners will make every effort to protect privacy and maintain confidentiality. This document outlines how ATSDR public health scientists and professionals can protect privacy and maintain confidentiality. ATSDR's Partnership to Promote Local Efforts to Reduce Environmental Exposure (APPLETREE) state partners may consider these processes. However, ATSDR advises these partners follow privacy protection rules defined by their respective agencies.

# 2. Definition of Terms and Corresponding Authorities

## 2.1. Formal Definitions

The Office of Science for the Centers for Disease Control and Prevention (CDC) provides the following definitions [CDC 2025]:

**Assurance of Confidentiality:** Provides protection to both individuals and institutions from court-ordered release of identifiable information. This assurance, authorized under Section 308(d) of the Public Health Service (PHS) Act, is used for studies conducted by CDC staff and/or contractors. ATSDR has not requested a delegation of authority to collect data under PHS and has no Assurances of Confidentiality.

**Certificate of Confidentiality:** Protects individuals from court-ordered release of identifiable information (personal identifiers, see below). ATSDR has no Certificates of Confidentiality because ATSDR has not received a delegation under the authorizing section of the Public Health Service Act.

**Personal Identifiers:** Information obtained and recorded in such a manner that human subjects can be recognized, directly or through links to the subjects. Examples include names, social security numbers, and street addresses.

## 2.2. Working Definitions and Authorizations

### 2.2.1. Confidentiality

ATSDR is not authorized to grant an assurance of confidentiality or certificate of confidentiality. Without a certificate of confidentiality, a court could order the release of information that the agency treats as confidential. For example, if a resident decides to send us their personal medical records, we treat the records as confidential, but a court could order ATSDR to release the information.

ATSDR has been able to protect the confidentiality of some kinds of information (medical, legal, trade secret, enforcement, etc.). Using arguments related to exemption clauses under the Freedom of Information Act (FOIA) [DOJ 2022] and other legislation, ATSDR has established processes for the care and control of the "confidential" information it collects.

### 2.2.2. Privacy

The development of the legal right to privacy has generally tended to restrict the government's interference in the lives of individual citizens [Warren and Brandeis, 1890]. The following activities are considered an "invasion of privacy" [Prosser 1960 in Onsrud, Johnson, & Lopez 1994]:

- Intrusion
- Public disclosure of private information (health concerns or problems)
- Appropriation (using a name or likeness for commercial gain)
- Casting the individual in a false light before the public

For public health agencies, the primary area of concern is the public release of private health-related information, such as biological or environmental results that are used in exposure investigations, public health assessments, or health consultations.

#### *2.2.2.1. Historical Perspective on Privacy*

In 1973, the U.S. Department of Health, Education, and Welfare (HEW) included five privacy protection principles in the Code of Fair Information Practices [HHS 1973]:

- There must be no secret personal data recording systems.
- Individuals must have a means of learning about their stored personal information and how it is used.
- Consent is required for secondary uses.
- Individuals must have a means of correcting personal information.
- Data controllers must maintain data and ensure data security.

These principles were incorporated into the Privacy Act of 1974 and are still relevant to our work today. The Privacy Act allows individuals to gain some control over the use of their personal information by federal and state agencies by requiring the following [Onsrud, Johnson, & Lopez 1994]:

- Enabling individuals to learn what information pertaining to them is being collected and used by the agencies

- Preventing information from being used, except for the purpose for which they gave their consent
- Gaining access to the records and correcting them
- Ensuring use of information that is legal and necessary to deliver services
- Requiring safeguards against misuse

**FOIA:** FOIA was enacted in 1966 and amended in 1974. FOIA allows any person to obtain access to federal agency records. There are nine exemptions to the types of agency records that can be accessed. Two of those exemptions specifically relate to personal privacy issues. A 1999 court case on FOIA found that an individual's home address is protected under exemption 7(C) of FOIA (O' Kane v. United States Customs Service, 169 F.3d 1308, (11th Cir., 1999)).

Later, Congress enacted the Freedom of Information Reform Act of 1986, which amended FOIA to provide broader exemption protection for law enforcement information. It also added special law enforcement record exclusions and created a new fee and fee waiver structure. In October 1996, Congress enacted the Electronic Freedom of Information Act Amendments of 1996, which addressed the subjects of electronic records, FOIA reading rooms, and agency backlogs of FOIA requests [DOJ 2022].

**HIPAA:** The Health Insurance Portability and Accountability Act (HIPAA) became law in October 2000. The regulations pursuant to this law require agencies and organizations that collect personal health-related information to ensure that the privacy of individuals is protected through controls on the use and distribution of that data. HIPAA regulations impact the use of geographic information system (GIS) and mapping by public health agencies and provide certain allowances to support public health activities. The Department of Health and Human Services' Office of Civil Rights (OCR) can answer questions about how HIPAA may affect ATSDR activities. Guidance can also be found at https://www.hhs.gov/hipaa/.

#### *2.2.2.2. ATSDR Consideration of Privacy*

It is ATSDR's practice to protect and respect individual privacy to the fullest extent possible. Again, it is important to recognize that a court could direct ATSDR to release "private" information. For example, we do not release the names of petitioners, but a court could order us to release this information. Similarly, the concentration of a chemical in an individual's private well can be defined as private information. However, ATSDR could be ordered to release this information.

In general, in our public health documents, ATSDR will avoid using names and addresses

- to identify samples and information that we generate and collect
- when using data and information generated by other entities
- when that information is not critical to the public health story

To determine other restrictions and recommendations for data handling, consult data use agreements and consent forms made between the data source and recipient. For example, a consent form may indicate that de-identified data can be released only to other local, state, or federal environmental and health agencies (i.e., a resident does not have access to the data).

# 3. Records Received or Collected as Input to the Assessment Process

## 3.1. Environmental Data

Environmental information (sampling results, location, plans, etc.) may be collected by ATSDR, ATSDR partner agencies, or other sources. Environmental information may include information that we consider private. Address and coordinate information that provide location (spatial) information are important to our work and are generally included in our environmental sampling data. Collecting this information is critical to the health assessment process. Consult with the geospatial research, analysis, and services program (GRASP) on the appropriate collection, use, and storage of spatial data.

Records collected for this purpose that include private information can be stored and maintained as nonconfidential. However, if such materials are requested for release under FOIA, all "private" information should be redacted, with concurrence from the FOIA officer. Do not promise to keep data completely confidential without obtaining approval of formal confidentiality protection, such as that offered by a 301 (d) Confidentiality Certificate.

## 3.2. Geographic Information System Data

OCHHA has established guides and limits for handling personal data in a Geographic Information System (GIS). They include the following provisions.

- **Limit what is accepted or collected:** Before collecting or accepting any personal information, decide what is absolutely necessary to make a public health decision at the site. Only store or maintain information within the GIS that can be released without violating individual privacy rights. When data are collected or received, define the purpose of collecting or using data and notify the relevant parties about your intended use for the data. Subsequent uses should be consistent with what you have stated.
- **Identify who will have access to the data:** Establish security procedures (e.g., password protection) for electronic files. The security procedures should align with security protocols that have been developed for paper files. Include a description of where the files are stored, how the files are secured, and who has access to the files.
- **Properly mark electronic documents according to their status** (i.e., Confidential or For Internal ATSDR Use Only)**:** The intended use should be clearly visible on each page as a watermark, header, or footer. Use appropriate document labels when saving documents (Restricted Use or Highly Sensitive) and allow viewing only on an as-needed basis. DHS provides additional information for safeguarding sensitive personally identifiable information (PII) [2017].
- **Ensure the quality of the data:** Establish a mechanism to ensure that personal data used is accurate, complete, and up to date. For data not collected by ATSDR, obtain information on the quality assurance and quality control procedures used by the collecting group.
- **Limit the release or distribution of personal information:** Do not release information in a form in which the individual could be identified either directly or indirectly (e.g., do not show a map with street addresses and health concerns labeling those addresses). Make every effort to "de-identify" the personal information (e.g., remove the name or address so that it cannot be recombined with other information kept by the Agency to identify an

individual). Use aggregation and other mechanisms to avoid identifying a specific address [Zandbergen 2014].

## 3.3. Background Information

Background information gathered from published sources (reports, etc.) can be stored and maintained without special consideration. However, care should be taken to protect privacy when using the information in products and discussion: See Section (V)(C).

# 4. File Management

## 4.1. Confidential Information

In this section, use the definition of "confidential" from Section (II)(B) of this document. Confidential files at headquarters will be maintained according to the ATSDR Records Management Program Standard Operating Procedure/Quality Control Plan. Hardcopies of ATSDR generated documents and records sent to Records Management are considered originals. ATSDR is in the process of establishing a Virtual File Room (VFR), where scans of documents and records will be archived according to their designated retention period. ATSDR will also keep the hardcopies until the National Archives and Records Administration (NARA) decides to dispose of the scanned paper copies.

If confidential information is to be stored in any other location, the following steps should be followed:

1. Date stamp the records upon receipt (hard copy).
2. Make a copy for the remote file (hard copy). Remote files are hard copies of records that are retained in a designated location offsite from the main ATSDR office facilities.
3. Appropriately maintain hard copies or immediately send the original information with an explanatory email message to the Virtual File Room at Records@cdc.gov. The email should note the confidential nature of the information and the related site information.
4. At the remote location, update the inventory sheet(s) for the site. Note receipt of sensitive records relating to the Site (hard copy).
5. Secure records in a designated, specially locked file cabinet (hard copy).

As soon as possible, shred copies of confidential file information maintained in a location other than the Virtual File Room. If shredding is not possible, ship the confidential records to the Virtual File Room for final disposition.

## 4.2. For "Private" Data

Private information can be stored and managed as a routine document until ATSDR files are

- needed for review by an outside agency or person or
- requested for release under FOIA.

Once files are requested, contact your office director or ATSDR associate director of science to identify private information. Work with them and the FOIA officer to identify information that might be covered under one of the FOIA exemptions. For additional information on this topic, refer to the FOIA guidelines [CDC 2014].

# 5. Documents/Products Generated by ATSDR

## 5.1. Biological Data

### 5.1.1. Biological Data Collected for an Exposure Investigation (EI)

Exposure investigations involving the collection of biological information must be coordinated with and approved by the Exposure Investigation Section of OCHHA. The EI group will submit the project to the Office of Science to determine whether

- IRB (Institutional Review Board) applies to protect human subjects and
- the Paperwork Reduction Act (PRA) applies to ensure that appropriate burden is placed on participants.

For EIs, IRB does not apply since EIs are not studies. PRA does apply since questionnaires are administered to participants. The EI documentation will include the participant's address information, age, sex, etc. The documentation will be protected as personally identifiable information (PII). For further information on the EI process, contact the EI section chief and access the following links for further information on the IRB and PRA process [CDC 2026a, CDC 2026b].

Analytical samples collected during an exposure investigation are identified by a unique, non-personal code. For example, blood lead samples might be identified as BL1, BL2, BL3, etc. During the EI, a key is developed to correlate participants with sample numbers to maintain the confidentiality of participants. Then, you can use the data, absent identifying and private information, to generate a document or work product. The management of confidential records is outlined in Section (IV)(A).

### 5.1.2. Biological or Medical Data Collected for a Health Study

Data collected and generated during health studies will be managed and stored according to the Health Studies Section [ATSDR 2023] guidelines.

## 5.2. Environmental Data

Environmental sampling data are collected by ATSDR and its partners as part of a health study or as an exposure investigation activity. PII collected during an environmental EI will be treated the same as that collected for a biological EI.

All data collected under a health study should be maintained in accordance with guidance provided by the Health Studies Section. Environmental data obtained from other federal, state, tribal, territorial, or local agencies (e.g., EPA) will be managed in accordance with applicable data sharing agreements, agency-specific confidentiality requirements, and federal information protection policies.

## 5.3. Spatial Data and Maps

### 5.3.1. Background Information

Maps are effective devices for recording, analyzing, and communicating information about the environment. Maps can show the location and the spatial extent of features. They can also illustrate distance and direction between locations. Patterns of distribution can be determined and analysis conducted to generate hypotheses on why the patterns exist.

GIS can be defined as a computer system that stores and links nongraphic attributes or geographically referenced data with graphic map features to allow a wide range of information processing and display operations, as well as map production, analysis, and modeling. GIS provides ATSDR with a valuable way to integrate data gathered from a wide variety of sources into one comprehensive data set. Additional information on developing maps that complement our work is included in Appendix B.

In environmental public health, we must take particular care to not substitute the map for reality. Remember that a dot on a map represents a person who has cancer or is drinking contaminated water. That person's privacy must be respected. If public health practitioners view and use a map as a collection of symbols without connection to the underlying personal reality, adverse consequences are possible.

### 5.3.2. Guide for the Use of Maps in ATSDR Products

#### *5.3.2.1. Define the purpose of using the data on the map*

Examine what information is needed on the map to convey the message. The purpose of the map is to support the conclusions and discussion in the document, not to replace it.

Determine the scale needed to convey the public health message and use the most abstract scale possible. To protect privacy, the health assessor may need to generalize data depicted on maps that will be included in public documents. Health assessors should not include more detail in maps than is needed, even when the information is available. For example, using digital maps that clearly indicate every home may be appropriate for depicting site boundaries or other public information, but not individual home sampling results. Pictures that are not to scale (as opposed to detailed maps) are preferred when there is a need to display the geographic relationship of private sampling results.

Do not include more detail than is necessary for the purpose of the maps. It is not necessary to include all maps created for a project in the final project report (i.e., the public health assessment, health consultation, etc.). Just include the maps needed to support your conclusion.

#### *5.3.2.2. Other considerations*

Take steps to ensure the quality of the data used in maps and to limit the release or distribution of personal information, as discussed in Section IIIC.

## 5.4. Background and Historic Information

In describing the land use near a site and the history of a site, staff are encouraged to limit the use of specific addresses, locations, and personal names.

### 5.4.1. Location and Address Information

In gathering and reporting background information on a site, staff are encouraged to avoid using specific address information for everything except the subject facility. For example, if there is a school within two blocks of the site, avoid naming it unless it is critical. It is sufficient to simply indicate that a school is located near the site.

### 5.4.2. Personal Names

Do not include personal names in the document unless it is critical to the public health story being told. Potentially responsible parties can be identified by name, but even that can be avoided in many instances.

Similarly, employees of public agencies and elected officials can be identified by name, but this level of detail is often not crucial to the document and can be eliminated. For example, instead of saying, “Mary Swift, of State Agency A, indicated....” the text could simply say, “State Agency A staff indicated.”

# 6. Discussing a Person's Health Symptoms and Conditions

## 6.1. One-on-one Discussions and Public Availability or Phone Conversations

When speaking privately with a person about their health concerns, ATSDR staff should listen but clearly explain that ATSDR cannot offer individual diagnosis or treatment recommendations. Rather, we use the individual's health experience as an indicator of issues that concern the community as a whole.

It is also important to identify and clarify your credentials before information is shared. Individuals may consider you a physician or other healthcare provider. If you are a physician, it’s important to clearly state that your role at ATSDR is not medical diagnosis or treatment recommendations. Suggest the individual share their health concerns and site- or incident-related fact sheets with their healthcare providers.

Consider a case where a resident at a public availability session is concerned that the site could be related to rashes she has had. ATSDR staff would listen to her concerns and note that rashes are a community concern. The written notes of the conversation should not include personal identifiers. If there is a need to link the person's name with the specific individual health information they provide, treat the written information confidentially and store it as indicated in Section IV of this document.

ATSDR, The Association of Occupational Environmental Clinic (AOEC), or Pediatric Environmental Health Specialty Unit (PEHSU) may have publicly available information that individuals can share with their healthcare providers. ATSDR staff should clearly identify themselves, their credentials, role, and the limitations of what they can provide regarding individual health concerns. Consider the following illustrative statements from ATSDR’s ToxFAQs: ATSDR can also tell you publicly available information on the location of occupational and environmental health clinics. These clinics specialize in recognizing, evaluating, and treating illnesses resulting from exposure to hazardous substances. If you think you have been exposed to this or any other chemical, talk to your doctor or nurse or call 1-800-222-1222 to be connected to your local poison control center.

## 6.2. Discussing a Person's Health Symptoms and Conditions in a Public Forum

ATSDR staff should not encourage an individual to share personal information about their health in a public forum or meeting. If a person wants to share, ATSDR staff should respectfully suggest a one-on-one conversation be held at the break or after the meeting. It’s important to have strong meeting facilitation skills to move the conversation away from individual health conditions.

If the person is insistent on telling his or her health story in a public forum, there is very little to do except be empathetic and listen. After the speaker finishes, ATSDR staff should use appropriate risk communication techniques and rephrase the issue in general terms. They should indicate that we can certainly include the general issue as a community concern.

# 7. Commonly Asked Questions

**What should I do if data from an environmental agency uses personal information (address or name) to identify sampling locations?**

Generate a new sample identification scheme that does not rely on personal identifiers (soil sample 1, 2, 3, etc.). Then create a document to serve as a key to the new coding system. Specifically, the key should identify the original sample identification (often address or resident name AND the newly created identification number). Treat the original data and key as confidential information. The data with the new, non-personal identification numbers should be used for generating all agency documents.

If the source agency has publicized the private information (e.g., discussed or presented in a public forum), it may be possible to use the information in an ATSDR product. However, this situation should be an exception. Discuss this situation with your supervisor or technical project officer as appropriate.

**Is it ok to include the potentially responsible party's (PRP) name in the document?**

Yes, if the PRP has been identified in a source document, their identity is not protected (private or confidential) information. However, if the PRP is an individual person, as opposed to a corporation or agency, it is frequently possible to avoid using the person's name. The preferred approach is to avoid using the person's name. Remember, if the PII is not needed to tell the public health story, leave it out.

**If I have a map from EPA that has specific addresses or family names listed, can I use that in my document?**

We should avoid using personal information to the extent possible, but it may be possible to include the map. It might have been released in a public forum (e.g., public meeting, poster session, printed in the paper, etc.) or been part of an administrative record that is readily available to the community (e.g., in the local library). View these situations as exceptions and discuss them with your supervisor.

**Is there a way to summarize health concerns collected from public availability sessions or individual conversations without giving too many identifiers?**

Yes, the best way to accomplish this is to take only general notes about health effects and to group similar comments together. For example, if resident #1 complains of miscarriages, and resident #2 voices concern about low birth weights, in summarizing the community concerns you might list something like "concern for reproductive outcomes" (i.e., low birth weight, miscarriages, etc.).

Unless there is a need to contact a resident again, name and address are not needed. If you are trying to understand whether there may be a geographic component to the complaints, consider having a map available. It should have enough detail for residents to find the approximate location of their home, but not the exact location. This will be a site-specific determination.

**Is there any way to generate detailed maps that illustrate the spatial relationship between sampling points for publication and public communication purposes without violating privacy considerations?**

Yes, choose a scale for your map that shows major landmarks, but not specific addresses. You can use it to show the relative location of sampling points. Another alternative is to offset the sampling results. GIS gives us the ability to generate very specific figures to describe aspects of a site. In generating figures, it is important to remember the point that we are trying to highlight. We can show exact locations, but we don't need to include that level of detail in our reports. Health assessors should note the difference between internal visualization for health assessments and maps published as communication tools in documents and meetings. Maps for internal visualization may provide a high level of detail and spatial context for the site team or health assessor's understanding. The expectation is that internal maps will not be used in public health documents.

**Can we share the results of biological testing with other agencies and entities (e.g., EPA, an individual's personal physician)?**

It is important that our agency partners understand from the outset that we will not share individual testing information without a signed release from the individual participant. This provision can, on a site-specific basis, be built into the standard consent form.

Individuals who participate in an EI receive a copy of their personal testing results. Each person can choose to share their data with the interested agency or entity.

Collective data, with personal identifiers removed, is often shared with other entities and made part of the final EI report. For EIs, ATSDR will identify the intention to share data with other entities in the consent form. The participant may agree to sharing at their discretion. The EI participant doesn't have to allow their data to be shared with any entity in the consent form.

# Appendices

## Appendix A. Sample Letters and Memos

**Example 1a. Letter for Returning Unsolicited Hard Copy Medical Records to Private Resident**

Dear *[insert Name]*:

Enclosed are the documents that you mailed to the Agency for Toxic Substances and Disease Registry (ATSDR) on [*insert date]*. The information you provided contains your personal medical information. ATSDR cannot protect the information. Therefore, to ensure your privacy, I am returning the documents to you.

ATSDR cannot offer medical diagnosis for individuals, but we can respond to generalized health issues. I have made note of your concerns that chemicals from the *[insert name of site/spill]* could cause health effects such as *[insert general description of health concerns e.g., rashes, cancer, birth defects, etc.]*

*If information is available on the site or chemical, add the following paragraph:* I have included some information on the effects of chemicals that may help answer your questions. If you need additional information, please contact me.

*If a PHA/consult is being prepared, add the following:* ATSDR is currently developing a public health assessment. We will include responses to concerns voiced by the community, including yours, in that document. You will not be individually identified in the concerns or responses included.

Thank you for your interest in ATSDR's activities. If you need additional information, or if I can be of assistance, please contact me at *[insert phone/email*].

enclosure (s)

cc: site file

**Example 1b. Letter to Resident, Requesting Release Form**

Dear *[insert name]*:

The Agency for Toxic Substances and Disease Registry (ATSDR) has received the medical information that you mailed on *[insert date]*. The materials you provided contain confidential information. In order for ATSDR to make use of the information, we need a signed release form from you. I have enclosed a form with this letter. Please read it. If you agree with us using the information as described, sign and return the form to ATSDR in the envelope provided. If you have any questions regarding the content of the form, please contact me at *[insert phone/email].* If we do not receive a signed release form from you by *[insert date],* we will return your records to you.

While we are waiting to hear from you, the records you provided have been marked “confidential” and are being handled accordingly (kept in a secure file cabinet with limited access). If you request it, ATSDR will provide you with additional information on the storage of those files.

Please note that ATSDR cannot offer a medical diagnosis for individuals, but we can respond to generalized health issues. The information you have provided will be used to identify general public health issues, like rashes or birth defects, that ATSDR can address in future documents.

Thank you for your interest in ATSDR's activities. I look forward to receiving your completed release form. Please contact me at *[insert phone/email]* if you have any questions or if I can be of assistance.

Enclosure

cc Release form

**Example 1c. Release Form to Accompany Letter**

Release Form for Medical Records Provided to ATSDR by a Private Person

I elected to share medical records for myself or for my dependent(s) with the Agency for Toxic Substances and Disease Registry (ATSDR). I provided the information for ATSDR to use as it sees fit in evaluating possible health impacts of exposure from *[insert name of site/spill]* and in responding to generalized community concerns.

Benefits and Limitations

I understand that ATSDR cannot provide a clinical diagnosis, offer medical treatment suggestions, conduct formal medical referrals, or provide direct clinical care services for me or my dependents. However, I will benefit from sharing my records by enabling ATSDR to provide chemical specific information that may be of use to me or my health care provider.

Confidentiality

I understand that my confidential information will be protected to the fullest extent possible, according to state and federal laws. Any reports produced from this information will provide only group information and not identify specific individuals. I understand that if I participate in a confidential manner, any forms containing my name or address will be kept in locked cabinets at ATSDR. Further, ATSDR will take every reasonable precaution to keep my records confidential. Test results may be released only to other federal, state, and local public health and environmental agencies with my consent.

Contact

If I have any additional questions about how my records will be used or stored, I may contact *[insert name]* of the *[insert Federal/State/Local agency name] at [insert phone/email]*.

Consent

I fully understand the benefits and limitations of sharing my medical records as explained to me in this document. All my questions have been satisfactorily answered. I hereby freely and voluntarily give my signed consent for use of the information I have provided as described above.

I, (print)_____, the undersigned, agree to ATSDR staff use of medical records that I provided for: (_) Myself (_) My child/ward, _____ age_____

Signature: _____ Date: _____

Address: _____

_____

_____

Phone #: _____

Witness: _____ _____

(print name) (signature)

Example 2. Letter for Returning Unsolicited Electronic Medical Records to Private Resident

(**NOTE**: in your response, redact the original email to minimize additional transmittal of the PII; any health concerns pertaining to the site may be retained in a separate file without retaining any PII; do not save the PII in any electronic or hard copy format).

Dear Name:

The Agency for Toxic Substances and Disease Registry (ATSDR) received your email on [*insert date*]. The information you provided contains your personal medical information. ATSDR cannot protect the information. Therefore, to ensure your privacy, ATSDR is taking the following steps:

- deleting any record of your personal information in the original email and its attachments, from both the email's inbox and the email's deleted message folders, and
- refraining from saving any record of your personal information in any electronic or hard copy format.

ATSDR cannot offer medical diagnosis, direct clinical care services, formal clinical referrals, or treatment recommendations for individuals, but we can respond to generalized health issues. I have made separate note of your concerns that chemicals from the [*insert name of xyz site/spill*] could cause health effects such as [*insert general description of health concerns e.g., rashes, cancer, birth defects, etc.].*

*If information is available on the site or chemical, add the following paragraph:* I have included some information on the effects of chemicals that may help answer your questions. If you need additional information, please contact me.

*If a PHA/consult is being prepared, add:* ATSDR is currently developing a public health assessment. We will include responses to concerns voiced by the community, including yours, in that document. You will not be individually identified in the concerns or responses included.

Thank you for your interest in ATSDR's activities. If you need additional information, or if I can be of assistance, please contact me at [*insert email*] or [*insert phone*].

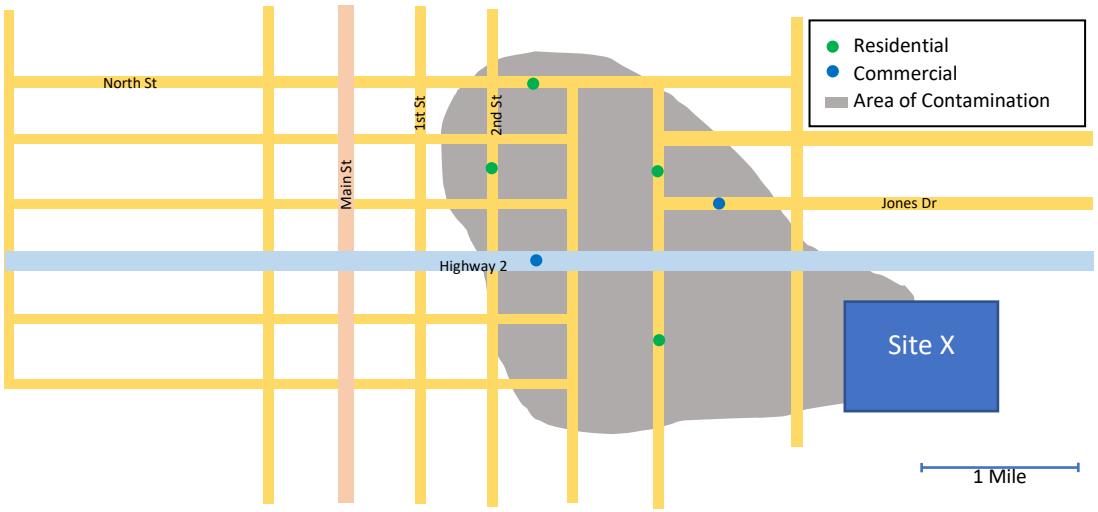
enclosure(s)

cc: site file

# Appendix B. General Information on Maps

Maps are powerful communication devices that lend credibility to health assessment documents and public interactions. Figure B.1 demonstrates a method of generally showing data locations without identifying specific addresses or identifiers. Note that it is sometimes important to show general areas of private and commercial property to communicate locations of concern and demonstrate transparency. Maps should release as little information as is needed to communicate the public health message. Individuals that allowed testing on their properties will have been provided their individual results. People in the general area may wish to know the general extent of contamination based on existing data, to decide their level of health concern and if they should take actions to protect their health.

**Figure B.1. Example figure showing general locations without revealing specific addresses or identifiers**




# Appendix C. Decision-Making Checklist

Things to consider before determining to include private information in a public document or an ATSDR file:

If you answer “no” or “I don't know” to ANY of the bulleted items below, reconsider the need for including private information in your site file or written evaluation and consult with your supervisor.

- Is the private information critical to making a health determination for the site?
- Does the private information help tell the PUBLIC health story?
- Do I know how to use and report the private information without violating privacy considerations?
- Is there an appropriate place for me to store the private records?
- Does the resident or source of records understand how their information will be used?

- Does the resident or source of records understand that ATSDR will NOT be undertaking individual medical diagnosis, direct clinical care services, formal clinical referrals, or treatment recommendations?

## Appendix D. References


[ATSDR] Agency for Toxic Substances and Disease Registry. 2023. Health Studies. Available at https://intranet.cdc.gov/nceh-atsdr/ochha/Health-Studies.html

Campbell, John. Map Use & Analysis. Dubuque, IA: William C. Brown Publishers, 1991, pages 281-289.

[CDC] Center for Disease Control and Prevention. 2014. Freedom of Information Act. Office of the Chief Information Officer. Available at https://intranet.cdc.gov/nccdphp/pdfs/opel/freedom-information-act.pdf

[CDC] Center for Disease Control and Prevention. 2025. Privacy and Confidentiality Unit. Available at https://intranet.cdc.gov/os/osi/pcu/

[CDC] Center for Disease Control and Prevention. 2026a. NCEH/ATSDR Human Research Protections. Available at https://intranet.cdc.gov/nceh-atsdr/os2/human_subjects.html

[CDC] Center for Disease Control and Prevention. 2026b. OMB Paperwork Reduction Act (PRA) Process at NCEH/ATSDR. Available at https://intranet.cdc.gov/nceh-atsdr/os2/omb_overview.html

[HHS] U.S. Department of Health and Human Services. 1973. Records, Computers and the Rights of Citizens. Office of the Assistant Secretary for Planning and Evaluation. Available at https://aspe.hhs.gov/reports/records-computers-rights-citizens

[DHS] Department of Homeland Security. 2017. Handbook for Safeguarding Sensitive PII. Available at https://www.dhs.gov/sites/default/files/publications/dhs%20policy%20directive%20047-01-007%20handbook%20for%20safeguarding%20sensitive%20PII%2012-4-2017.pdf

[DOJ] Department of Justice. The Freedom of Information Act, 2022. Available at https://www.justice.gov/oip/freedom-information-act-5-usc-552

Onsrud HJ, Johnson JP, and X Lopez. Protecting Personal Privacy in Using Geographic Information Systems. Photogrammetric Engineering and Remote Sensing, Vol. 60, No. 9, September 1994, pages 1083-1095.

Warren SD and L Brandeis. The Right to Privacy. Harvard Law Review 4.5:1890, pages 193-220.

Zandbergen, P. A. (2014). Ensuring Confidentiality of Geocoded Health Data: Assessing Geographic Masking Strategies for Individual-Level Data. Advances in Medicine, 2014, Article ID 567049. https://doi.org/10.1155/2014/567049