Guidelines for the Management of Inquiries Related to Cancer Concerns or Suspected Cancer Clusters

Maryland Department of Health and Mental Hygiene (DHMH)

October 2015

Larry Hogan, Governor

Boyd Rutherford, Lt. Governor

Van Mitchell, Secretary, DHMH
Maryland Department of Health and Mental Hygiene

Environmental Health Bureau
Prevention and Health Promotion Administration
201 West Preston Street, Room 327
Baltimore, Maryland 21201
410-767-6234   Toll Free 1-866-703-3266
Fax 410-333-5995
http://phpa.dhmh.maryland.gov/SitePages/environmental.aspx

Maryland Cancer Registry
Center for Cancer Prevention and Control
Prevention and Health Promotion Administration
201 West Preston Street, Room 400
Baltimore, MD 21201
410-767-4055   Fax 410-333-5218
http://phpa.dhmh.maryland.gov/cancer/SitePages/mcr_home.aspx

The services and facilities of the Maryland Department of Health and Mental Hygiene (DHMH) are operated on a non-discriminatory basis. This policy prohibits discrimination on the basis of race, color, sex, or national origin, and applies to the provisions of employment and granting of advantages, privileges and accommodations.

The Department, in compliance with the Americans with Disabilities Act, ensures that qualified individuals with disabilities are given an opportunity to participate in and benefit from DHMH services, programs, benefits, and employment opportunities.

The Maryland Cancer Registry is supported by Maryland General Funds, the Maryland Cigarette Restitution Fund, and by contract number U55/CCU321894 from the Centers for Disease Control and Prevention, National Program of Central Registries.

The Environmental Health Bureau is supported in part by Maryland General Funds, and by CDC Cooperative Agreements 2U38EH000944 and 5U60OH009856.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>State And Local Agency Roles In Suspected Cancer Cluster Management</td>
<td>5</td>
</tr>
<tr>
<td>Step 1: Initial Contact And Response (Figure 2)</td>
<td>12</td>
</tr>
<tr>
<td>Step 2: Assessment (Figure 3)</td>
<td>17</td>
</tr>
<tr>
<td>Step 3: Determine Feasibility Of Conducting An Epidemiologic Study</td>
<td>23</td>
</tr>
<tr>
<td>Step 4: Conduct An Epidemiologic Investigation (Figure 5)</td>
<td>25</td>
</tr>
<tr>
<td>Appendix 1. Media Protocol</td>
<td>26</td>
</tr>
<tr>
<td>Appendix 2. Resources</td>
<td>28</td>
</tr>
<tr>
<td>Appendix 3. Data Collection Instruments</td>
<td>31</td>
</tr>
<tr>
<td>Appendix 4. Information About Cancer Clusters And Risk Perception</td>
<td>36</td>
</tr>
<tr>
<td>Appendix 5. References</td>
<td>1</td>
</tr>
</tbody>
</table>

## Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1: Flow of Information and Response to Cancer Concerns</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Figure 2: Step 1 – Initial Contact and Response</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Figure 3: Step 2 – Assessment</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Figure 4: Step 3 – Determine Feasibility of Conducting an Epidemiologic Study</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Figure 5: Step 4 – Epidemiologic Investigation</td>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>
INTRODUCTION

Suspected cancer clusters and questions about the possible relationship between cancer and environmental factors are often reported to health officials by concerned citizens or community groups, and only infrequently identified by analysis of cancer registry data. (CDC, 1990) Local officials at the county level, including Health Officers, Environmental Health Directors, Epidemiologists, and Community Health Nurses, are often the first points of contact for citizen concerns about possible clusters, and as a result, local and state agencies need a coordinated approach in evaluating and responding to these reports.

Purpose

The purpose of this document is to outline the state of Maryland’s approach to suspected cancer clusters. It is meant to guide local and state environmental and public health officials in managing reports of suspected cancer clusters. These revised Guidelines for the Investigation of Suspected Cancer Clusters were derived from the cumulative experience of the Maryland Department of Health and Mental Hygiene, Maryland Department of the Environment, other Maryland state officials, other state health departments, and from guidelines from the U.S. Centers for Disease Control and Prevention (CDC). The recommendations that follow were compiled from guidance documents developed by these agencies and from the advice of Maryland experts with experience in epidemiology, environmental health, toxicology, cancer control, and risk communication.

Background

For the purposes of these guidelines, the term cancer cluster is a greater than expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time (CDC, 2013). In this document the term community will be used to describe any group of people defined by a geographic region, whether through residence, workplace, or recreation. Cancer is not evenly distributed in the population and therefore, the occurrence of cancer cases grouped in place and time is not uncommon.

Cancer Cluster Etiology

Cancer clusters can occur for a variety of reasons:

- Statistically random cancer cases can be grouped in time and space purely by chance
- Cancer cases can occur when individuals from a variety of locations, occupations, and risk factors are diagnosed with cancers at about the same time and within the same geographic area
- In rare instances, cancer cases are caused by common environmental or occupational exposure(s) to cancer-causing agents in a geographic area. These “true” clusters can

occur with a small numbers of cases over long periods of time, making their recognition difficult.

- Since people frequently change residential locations and there is a delay of years or decades between the time of environmental exposure and the development of cancer, it may be very difficult, or at times, impossible to demonstrate a link between a particular exposure or location and specific cancers. Even when they occur, the recognition of cancer clusters from environmental contamination may go undetected since exposures likely occurred years ago.
- On the contrary, childhood cancers have shorter latency periods and a correlation between exposure and cancer development may be detectable (CDC, 2013).

**Inquiries about Suspected Cancer Cluster**

Across the U.S., a state and local health agency receive approximately 1,000 inquiries per year regarding suspected cancer clusters, and in Maryland, the Department of Health and Mental Hygiene receives an average of one inquiry every few months. Nationally, only 2 of every 1,000 reports of suspected clusters are shown to be “true” clusters that have statistically significant elevations in cancer rates that warrant an in-depth epidemiologic study. Numerous state and federal agencies agree that finding a major association between a specific exposure and a specific cancer is rare, and most reports of suspected cancer clusters are usually resolved without a full-scale investigation.

The following considerations should be taken into account when approaching suspected cancer cluster investigations:

1) **Differences exist among cancer types**: Each type of cancer (e.g. lymphomas, breast cancer, or colon cancer) differs in etiology (cause), predisposing factor(s), target organ(s), and rate(s) of occurrence.
2) **Complicated causative factors**: Cancers are usually caused by a combination of factors that interact in ways that are often not fully understood.
3) **Latency Period**: For most cancers, the long latency period (i.e., the time between exposure to a causal agent and the first appearance of cancer symptoms and signs) complicates any attempt to associate cancers occurring at a given time in a community with local environmental contamination.

When excess cancer occurs in a specific group of individuals (bound by a geographic area and time) at a rate that is statistically significantly higher than expected, and cannot be explained by chance it is important to conduct a more detailed cancer cluster investigation. Cancer cluster reports should never be ignored.

In most cases, the proper handling of a suspected cancer cluster report usually leads to resolution and can also serve to increase a community’s understanding of the multiple factors involved in a suspected pattern of cancer. As a result, a community is more likely to understand if an investigative agency determines that a suspected cancer cluster investigation is not statistically warranted, or begins to collect additional information for a more detailed study.
These Guidelines outline the ways in which the following *Primary Goals in the Handling of Suspected Cancer Cluster Reports* may be realized.
Primary Goals in the Handling of Suspected Cancer Cluster Reports

- To respond to the concerns of individuals and community groups.
- To identify and characterize cancer cases in geographic and time patterns.
- To efficiently evaluate cancer cluster reports in order to assess whether they require further investigation or necessitate a different response.
- To provide accurate and appropriate information and feedback to citizens, communities, health professionals and other stakeholders. Agency responders should be transparent, openly welcome and receive community input, and explain each decided action to the community (CDC, 2013).
- To raise public awareness about opportunities for cancer prevention and provide information on the many factors that can influence cancer patterns.
- To further investigate reports that may be “true” clusters.
STATE AND LOCAL AGENCY ROLES IN SUSPECTED CANCER CLUSTER MANAGEMENT

Local Health Departments
Local health departments lead the management and investigation of suspected cancer cluster reports, and are typically in the best position to:

- Evaluate geographic, environmental, and socioeconomic factors at the community level
- Utilize community resources for case-finding and health education
- Assess the social and political dimensions of a suspected cluster
- Collaborate with local health care providers
- Identify when and where to provide public communication at the local level

The following individuals at a local health department should strive to work together to handle suspected cancer cluster reports:

- Health Officer
- Environmental Health Director
- Epidemiologist(s)
- Community Health Nurses

State Agencies
The state agencies principally involved in cancer cluster investigations are the:

- Maryland Department of Health and Mental Hygiene (DHMH)
  - Environmental Health Bureau (EHB)
  - Maryland Cancer Registry (MCR) located in the Center for Cancer Prevention and Control (CCPC)
- Maryland Department of the Environment (MDE).

When one of these state agencies receives a request for assistance from a local health department, they will provide consultation and technical support throughout the management of a suspected cancer cluster as follows:

- EHB coordinates activities between local and state agencies.
- MCR provides population-based Maryland and community-level data to investigate the cancer cluster report.
- MDE provides support when cancer-related issues involve environmental contaminants or concerns.
- Other state agencies may be asked to provide information or participate in an investigation including, the Maryland Department of Labor, Licensing, and Regulations (including the Office of Occupational Safety and Health) and the Maryland Department of Agriculture.

Interagency Communication
During all multi-agency cluster investigations, inter-agency communication is essential and objectives and activities should be made clear to all participants. Whenever possible, participants should identify a single spokesperson that is a credible figure with authority to speak on behalf of all agencies to the individual or communities from which the inquiry originated.
Figures 1 through 4 on the following pages provide an overview of the management process for inquiries related to cancer and cancer clusters and the specifics of the four steps involved.
**Figure A: Flow of Information and Response to Cancer Concerns**

- **Request regarding cancer cases or suspected exposures causing cancers**
  - Maryland Cancer Registry (MCR) (DHMH Center for Cancer Prevention and Control)
  - Local Health Department (LHD)
  - Initial assessment of possible exposure/disease relationships
  - LHD
  - Findings communicated to requesting source

- **DHMH Environmental Health Bureau (EHB)**
  - Maryland Department of the Environment
Figure B: STEP 1 – Initial Contact and Response
(Response time: within 2 weeks)

Request regarding cancer cases or suspected exposures causing cancers

From media?
Yes
Refer to public information officer

No
Collect information using appropriate tool (Appendix 3)

What is the concern?

General info about cancer, published data, and sources
Refer to public data sources (e.g. CDC Wonder, state cancer profiles, DHMH data)

Collect information using appropriate tool (Appendix 3)

Refer to EHB and LHD

EHB coordinates with LHD and MCR to determine if additional info is needed about cases and exposure

Yes
Go to STEP 2

No
LHD communicates written feedback to original requestor
Figure C: STEP 2 – Assessment
(Response time: within 1 month)

EHB coordinates approach with LHD and MCR

EHB, LHD, and MCR determine what information is required regarding the cancer, exposures, and other information

LHD
- Gather local environmental data
- Gather info about local population and their health
- Contacts requestor and other potential cases for additional info

EHB
- Create report template
- Contact other DHMH units, as needed
- Contact other agencies (MDE, MOSH, other) as needed

MCR
Evaluate and analyze Maryland cancer registry data

Is a cancer cluster possible, given available statistics, exposures, biology, and population?

No
- LHD communicates written feedback to original requestor

Yes
- Go to STEP 3
**Figure D: STEP 3 – Determine Feasibility of Conducting an Epidemiologic Study**

*Response Time: Within 2 weeks*

- EHB
  - Coordinate joint teleconference and/or meeting with LHD, MCR, other DHMH units, MDE, Centers for Disease Control and Prevention (CDC), as appropriate.
  - Determine what the specific questions are (i.e. type(s) of cancer)

Will the State of Maryland conduct an investigation?

- **Yes**
  - Contract with an entity that will conduct the investigation.
  - Determine whether there are other responsible parties who will conduct the investigation (employer, EPA, etc).
  - If DHMH will conduct an investigation, write investigation protocol for discussion and circulate for approval.

- **No**
  - LHD communicates written feedback to original requestor.

EHB coordinates investigation in collaboration with LHD

Go to STEP 4
Figure E: Step 4 – Epidemiologic Investigation
(Respons e time: months to years)

Epidemiologic Investigation

- Purpose is usually to determine if exposure to a specific risk factor or contaminant is associated with an identified cluster of specific types of cancer.
- Generally a long process involving a study team, study-specific written protocols, and separate funding/resources.
- Often conducted by academic researchers.
- Important for agency, study team, community, and media to have effective communication about expectations, timeline, possible outcomes (particularly inconclusive outcomes), and limitations.
- Decisions regarding possible corrective public health actions may be made independent of epidemiologic investigation.
STEP 1: INITIAL CONTACT AND RESPONSE (FIGURE 2)

The objectives of Step 1 are to:

1) Gather information to understand and establish the nature of the concern
2) Make an initial judgment regarding the need to pursue the issue as a cluster investigation.
3) Begin an investigative process to collect information on the type of cancer, cancer risk factors, and suspected clusters.

The report should be referred quickly to the responsible unit in the health agency and should not be dismissed prematurely. A sound understanding of cancer cluster concepts and investigation methods, as well as good listening and communication skills, are essential for every team member involved in a cancer cluster investigation. All involved staff should be familiar with the definitions, principles and practices presented in Appendix 4.

1. **Before speaking to the public about a suspected cancer cluster, the health agency responder** (henceforth referred to as “Responder”) **should understand the concepts of risk perception and risk communication, and be familiar with the general concepts of cancer cluster investigations.** The Responder should have expertise or training in cancer and/or environmental epidemiology.

2. **DHMH approaches cancer clusters using a team approach that involves epidemiologists, toxicologists, environmental scientists, communication specialists, and other experts.**
   The responder should have training and experience in risk communication and should:
   - Read through this guide, including important concepts and practices in Appendix 1 and 4.
   - Anticipate how media coverage has affected (or will affect) public perceptions.
   - Anticipate how public sentiment may be emotionally weighted.

3. **During the first conversation with the community member or group reporting a suspected cancer cluster, the Responder should introduce him/herself and establish their expertise.** The Responder should convey their competence by stating their background and telling the inquirer why it is their role to speak with them. The Responder should be knowledgeable about cancer, cancer prevention, and guidelines on investigating suspect cancer clusters; and be able to offer the inquirer easily accessible resources. The Responder should:
   - Understand the context of the inquirer’s concern, the nature of the perceived problem, the history of whether it has been reported to authorities, and, if applicable, how authorities have responded to date.
   - Demonstrate to the inquirer that he/she cares about the issue by carefully and patiently listening and questioning to clarify concerns. Understand that inquirers will not trust individuals they perceive are not listening to them so be open, transparent, and thorough with respect to the evaluation of information and actions taken, and very mindful to be sensitive and responsive to the inquirer’s concerns.
- Speak clearly and compassionately.
- Tell the inquirer if an answer to a question is not known and indicate that the answer will be found and communicated.
- Determine whether the person is simply requesting information or requesting a cancer cluster investigation.
- Take detailed notes including, names, times, dates of the call(s).

4. **During the first phone call, the Responder should collect as much comprehensive information as possible from the inquirer.** The Responder should:

   - Collect general information from the inquirer on the age, type of cancer, date of diagnosis, place of residence at the time of diagnosis, and geographic area of concern. This information will be used to determine if the preliminary data meet the statistical and other characteristics of a “true” cancer cluster. (See Appendix 3)
   - Ask the inquirer to provide detailed information (such as names, ages, cancer types, dates of diagnosis, addresses, risk factors of cases) if available.
   - Tell the inquirer that the information s/he gives to the health department, such as individual names, diagnoses, and risk factor information will be treated in a confidential manner—per Maryland law. Information about the health of other community member(s) should not be shared with the inquirer, nor should information about other reports or other cases of cancer be disclosed. Any release of information from the MCR must be in aggregate form and meet the MCR Data Use Manual and Procedures [http://phpa.dhmh.maryland.gov/cancer/SitePages/mcr_data.aspx](http://phpa.dhmh.maryland.gov/cancer/SitePages/mcr_data.aspx).
   - Evaluate the inquirer’s information keeping in mind that it can be difficult to assess accuracy and completeness. It is inappropriate to ask the inquirer to collect additional confidential medical information from persons outside of his/her own family and doing so, may place the inquirer in the position of risk communicator, creating the potential to provoke unjustified alarm in the community. The Responder may however, ask the inquirer to refer other concerned citizens, or those with cancer, to the health department so that they can be interviewed separately.
   - Listen carefully to the inquirer’s theories about the cluster and address them in follow-up discussions with the inquirer.
   - Describe the steps that will be taken to handle the suspected cancer cluster.

5. **If the inquirer is only requesting information such as the rate of cancer in the county or zip code area, the Responders should attempt to identify and supply available information.**
- County-level and state-level cancer rates are available for local health departments and state agencies.

The Responder should:

- Consult with the MCR to determine whether data at the zip code, census tract, city, sub-county, or neighborhood level is required. Zip code and census tract level data can be used to compare rates across different zip codes and/or larger geographic areas, and may be available upon request from the MCR. If the specifics of the data request are known, the Responders should complete a MCR data request form available at http://phpa.dhmh.maryland.gov/cancer/Documents/mcr_DataRequestForm_DHMH4663.pdf

- Obtain and attempt to check the accuracy of information intended to be conveyed to the inquirer and determine what data can be legally released based on the MCR Data Use Manual and Procedures (http://phpa.dhmh.maryland.gov/cancer/SiteAssets/SitePages/mcr_data/MCR%20DataUse%20Manual%20and%20Procedures%20102012.pdf).

- Know the material well enough to speak authoritatively and generate confidence.

- Attempt to explain numbers and statistics in understandable lay terms, in particular, explanation of rates, standardized rate ratios, and confidence intervals may require additional resources or examples.

- Do not hide or “sugarcoat” relevant data.

- Be, or strive to become, relatively familiar with the geographic area of concern, its demographic profile, and its history (e.g., industrial and residential development) in order to understand the health and environmental concerns of the community.

6. If the inquirer is still expressing concern about cancer or exposures in a particular location, or requests further investigation after the initial discussion, the Responder should collect and evaluate any additional information the inquirer offers. (See Appendix 3)

7. The Responder should not prematurely judge whether the suspected cancer cluster can be reasonably excluded as a cluster or should be investigated in more detail.

- A suspected cancer cluster is more likely to be a “true” cluster if it involves any of the following:
  - Cases of a single cancer type (rather than several types)
  - Three or more cases of a rare cancer type
- An unusual number of cases in individuals at an early age at diagnosis
- A sudden appearance of cases
- A type not usually diagnosed in a certain demographic group.

- The Responder should explain to the inquirer that a list of individuals with cancer does not constitute a cluster on its own. For example, “true” clusters may be the result of non-environmental factors such as clusters within a family result from genetic factors.

- Before a decision can be made to exclude a report as a cancer cluster or continue with an investigation, the Responder should ensure that the Health Officer and DHMH staff concurs with the decision.

- It is strongly advised that trying to establish or hypothesize causes for the individual cancer cases reported and described by the inquirer is avoided.

  - Attempting to establish a cause for each case may lead the inquirer to believe that all cancer cases have an identifiable cause which is often not the case. A few cancers are clearly associated with environmental or occupational exposures (e.g., some skin cancers, mesothelioma, and angiosarcoma of the liver), but in most cases, it is difficult to attribute individual cancers to specific exposures.
  - If the investigation ultimately cannot identify an environmental cause of the case(s), the investigator’s credibility will be diminished and the inquirer will turn to other agency representatives for answers.

- A decision at Step 1 not to pursue an investigation is based on the determination that the reported cases are unlikely to comprise a cancer cluster and therefore, conducting a statistical assessment to determine whether an excess of cancer cases exists might be unsuccessful because the cancers are not likely to share a common, environmental etiology. This determination might involve multiple communications with the inquirer, as well as additional data-gathering.

8. If the inquirer acknowledges and is satisfied with the decision not to move forward, the inquiry can be closed.

9. If further steps are anticipated, the Responder should tell the inquirer how and when he/she will get back to them and proceed to Step 2: Preliminary Investigation. The Responder should:

  - Collect address and contact information of the inquirer. (See Appendix 3)

Send the document entitled, *Q&A: Cancer Causes and Clusters* from the Maryland Department of Health and Mental Hygiene to the inquirer as soon as possible (found here: [http://phpa.dhmh.maryland.gov/cancer/SitePages/Cancer%20Clusters.aspx](http://phpa.dhmh.maryland.gov/cancer/SitePages/Cancer%20Clusters.aspx)).
- Communicate a summary of the specific situation and any next steps if this may be helpful to the inquirer.
STEP 2: ASSESSMENT (FIGURE C)

Step 1 focused on understanding the inquirer’s concerns, gathering information, and conveying information about cancer, its risk factors, and suspected cancer clusters. A second step is needed if the possibility of a cluster cannot be reasonably excluded.

The objectives of Step 2 are to:
1. Collect and review readily available information; and
2. Provide an estimate of the likelihood that a cancer excess has occurred by reviewing the types of cancer, age, possible common exposures, and by comparing observed and expected rates in the geographic area. (Note: Clusters reported at worksites will require different methods.)

Important components include the study design as well as the collection, analysis, and interpretation of relevant data. Decisions must be made concerning the case definition, how the population of concern (the study population) is defined, the choice of comparison cancer rates, and the choice of statistical methods.

The information below identifies important aspects of this process.

Review the literature for risk factors and the expected epidemiological patterns for the cancer(s) or risk factor(s) in question.

- DHMH EHB and MCR have information from the National Cancer Institute on the epidemiology of various types of cancer available upon request.

1. Complete the collection and review of information from the inquirer.

- Use the provisional information from the inquirer and other sources in the community to establish limits for the investigation, including, a case definition, geographic boundaries, and a time period of investigation (i.e., new cases of specific type(s) of cancer in a specific census tract during specific years).
  Define the study population, by:
  o Demographic characteristics,
  o Geographical area, and
  o Time period of concern.
  The case definition, study population, study area, and period of interest will require justification.

- Check the names and diagnoses the inquirer reported against information contained in the MCR database. The MCR data are the best information available to confirm the inquirer’s information however, the MCR may not have recently diagnosed cancer cases because they have not yet been reported.

- The investigator should understand community concerns and identify facts about local environmental factors by: (1) reviewing the literature on risk factors for the types of cancers of concern to the inquirer (e.g., environmental,
occupational, genetic, infectious); and (2) consulting with local environmental health officials and MDE where appropriate, regarding potential environmental exposures or community concerns (e.g., hazardous waste sites, industries, and other potential sources of exposure. It is important during this process to recognize that proximity to a potential source is not necessarily the same thing as exposure, though in many cases it may serve as a proxy for exposure. Often the most difficult part of any investigation is the determination of whether and how exposure to an environmental hazard may have occurred.

- Contact the original inquirer if there are additional questions and provide a status report. Remind the inquirer that information given to the health department, such as names, diagnoses, risk factor information will be treated in a confidential manner. Information about one community member may not be shared with others in order to prevent the release of information that may lead to the identification of a person with cancer. It means that additional information you obtain will not be shared back with the person making the request if he or she asks.

- Be available to personally visit the inquirer and community members in order to facilitate the exchange of information; schools and workplaces are often neutral meeting places. Community risk communication events (for example, a town meeting to discuss the issues) usually require expertise and serious planning and you may consider asking DHMH to participate in the meeting. Consult someone with experience in these events before scheduling. The EHB, MCR, and MDE can assist with this step. Creating a comprehensive communication plan is important in order to identify audiences, communication needs, and communication channels.

2. **Contact the MCR if needed**, and ask for cancer incidence rate(s) for the population of concern compared to the rate(s) from an appropriate comparison population (or observed number of cases compared to expected number).

- The MCR may be able to perform census tracts-, county-, and state-level cancer rates with statistical comparisons. MCR data are complete enough to permit comparisons of rates in different census tracts and larger geographic areas.
  - Realize that the population of a census tract may not reasonably represent the population of concern (e.g., a housing development, a water district) in terms of its demographics, risk factors, and environmental conditions.
  - Remember that the smaller the population under consideration, the less stable the calculated rate will be. Consult with MCR or EHB for these special analyses.

---

2 Need to contact MCT for additional information will be determined based on the number of cases, geography, type(s) of cancer, age(s) at onset, onset date(s), setting(s), and biologic feasibility.
To receive data from the MCR, complete an MCR Data Request Form for information needed from the MCR available at:

A simple count of the number of cases is usually not sufficient to identify whether cancer is elevated in the area. Age-adjusted comparisons to other areas, such as the county or Maryland are needed.

- **Standardized incidence ratios (SIRs)** compare the observed number of cases to the “expected” number of cases in that area over a specific time period.
  - The expected number is based on age-specific rates of the cancer(s) in comparison areas. If the observed number of cancer cases is not statistically significantly greater than the number of cases that are expected to occur, then there is no cluster and the investigation can usually be closed.

If statistical analyses determine that the observed number of cases significantly exceeds the expected number, then the possibility of a cluster cannot be ruled out and a more detailed investigation may be necessary. MCR and EHB can assist with this step.

3. **Identify any major limitations in SIR calculations, such as:**

- The observed number of cases may be too small for meaningful statistical comparisons.

- The population of concern may not be well defined and its boundaries may have been artificially drawn to fit only the identified cases. The correct base population that reflects the population at risk may not be known at the time.

- The typical process by which clusters are recognized often combines cancer cases that are not causally related (different sites or types of cancer).

- The choice of a comparison population can significantly affect the results. Ideally, the comparison population should be demographically similar to the population of concern. Age-, race-, or gender-adjustment of rates may be indicated.

- Cluster investigations must look back in time for information and as a result, pieces of necessary information may often be missing. Therefore, the investigation may be open to errors in the discovery of cases, the boundaries for study, the timing of events, and details about risk factors (age, family history, medical history, personal behaviors, occupations, and exposures).

- The continual movement of people in and out of an area makes the collection and interpretation of data difficult. Cancers that develop after people move out of the area will not be included, and cancers that develop in people who recently moved into the area cannot be attributed to local exposure(s).
4. **If there is insufficient information to calculate a cancer rate for the affected population, then other rates or comparisons may be used.**

- It may be appropriate to use census tract or county-level rates (from MCR) as surrogates for the affected population. In this case, compare these rates with other readily available county-, state-, or national-level rates.

5. **Report back to the inquirer.**

- After discussion among those people and agencies responding to the concern, determine who will report back to the inquirer by telephone and/or written response.
- Telephone the inquirer and describe the results of your comparison.
- Write a summary of your findings and send it to the inquirer. It is important to respond to the caller in writing, explaining the process and results including the determination that the cases likely do not comprise a cancer cluster. The inquiry should then be closed with appropriate documentation. Offer to visit in person and discuss your findings with the inquirer, interested persons, or with a community group (after careful thought and planning).

6. **Close the case if the presence of a cluster is not supported by the available information.**

- The following situations suggest that continued study is *unwarranted*:
  
  - The cancer incidence rates calculated for the population of interest and/or the census tract suggest that the cancer observed in the area is within expected values.
  
  - The number of cases reported in the cluster may be so small that they negate the possibility of statistical significance.
  
  - The information needed to answer pertinent questions may not be obtainable.
  
  - The facts discovered may not present a cohesive picture of common exposure and disease. This occurs when a variety of cancers are found that have distinctly different causes and risk factors.
  
  - The original question has been answered and the reporting party’s concerns have been satisfied.

- **Questions/Issues to consider:**
o Are there enough cases and a large enough population for statistical stability?

o Has there been an increase in the incidence rate of the specific cancer over time?

o How many more observed cases are there than expected (the number of excess cases)?

o Are the demographic characteristics of these cases unusual for the type of cancer (e.g., in a younger population)

o Have reports of water, air, soil testing occurred and been reviewed? (If an ongoing community concern; test regularly.)

o All reports should be clear about any assumptions that have been made regarding latency period, that is, the time interval between when exposure is thought to have occurred, and when the cancer(s) may have become clinically detectable. This information will be helpful to readers, and will also help to clarify whether there is value in looking at additional cases in the future in the same area.

7. **If the presence of a cancer cluster is not supported by the available information and the inquirer’s concerns are NOT satisfied, then the situation requires careful consideration.**

This is perhaps the most difficult circumstance encountered while managing a cluster report. It points out the value of a team approach to the problem. In this situation, it is important to understand the local strengths and limitations with regard to risk communication and to identify resources available to your agency as backup.

- Try to identify the cause for dissatisfaction; often it stems from a feeling of helplessness, mistrust, or confusion.

**Helplessness:**
- Suggest ways of becoming involved with cancer prevention or advocacy. The American Cancer Society offers a number of ways to become active.

**Mistrust:**
- A third party, “neutral source,” or a person with more expertise may be needed to convey or reinforce what is known. See the appendix for resources.

- A face-to-face meeting to explain the available information may be useful. Suggest that the inquirer invite a knowledgeable and trusted guest. These
meetings require preparation, skills and experience in risk communication—good intentions will not be enough.

Confusion:
- The inquirer may need more time to absorb and consider the information provided. Suggest a date and time in the near future for further discussion.
- An experienced spokesperson may be effective. Consider a Health Officer, Community Health Nurse, Environmental Health Director, Epidemiologist or Social Worker.

8. **If the presence of a cluster cannot be ruled out, continue with a more detailed investigation (Step 3).**
   - Notify the DHMH EHB, MCR, and/or the MDE if a further investigation appears warranted.
   - After discussion with these parties, contact the inquirer and tell them the outcome of the conversation, such as whether a detailed investigation may be conducted.
   - If a decision is made to move forward, the health agency should provide a written report to the caller, as well as to any partners contacted. This report should include a description of the results of the preliminary analyses and circumstances, carefully articulating what is known and not known at this point. Finally, the report should describe the health agency’s plan (i.e., next steps).

9. **Even if further steps are not anticipated, it is still important to follow-up with the inquirer to solidify your interest in their concerns. If you have not already done so:**
   - Collect address and telephone information from the inquirer. (See Appendix 3)
   - Send the document entitled *Q&A: Cancer Causes and Clusters* found at: [http://phpa.dhmh.maryland.gov/cancer/SitePages/Cancer%20Clusters.aspx](http://phpa.dhmh.maryland.gov/cancer/SitePages/Cancer%20Clusters.aspx) to the inquirer.
   - Include a cover letter that summarizes the specific situation.
STEP 3: DETERMINE FEASIBILITY OF CONDUCTING AN EPIDEMIOLOGIC STUDY (FIGURE 4)

Up to this point, the investigation has relied upon data that are readily available through existing surveillance systems and more rigorous case finding; case verification; and/or comprehensive demographic, occupational, and behavioral data on each reported case have not been conducted. The time and space boundaries of the suspect cluster may still be unclear. Please note that the link to a causative agent has not been formally studied, and will not be studied using epidemiological methods until the existence of an elevated cancer rate or the existence of a small number of similar rare cancers has been demonstrated. Most state health departments report that less than 0.5% of cancer cluster investigations reach Step 3.

Step 3 investigation occurs when the following three are observed:
1) Preliminary data suggests the existence of a cluster resulting from:
   - An aggregate of one type of cancer, or more than one type that are closely related to the suggested agent
   - Suspected exposure to an agent that has been scientifically linked as a causative agent to the observed cancer(s) (e.g. benzene and leukemia, or asbestos fibers and mesotheliomas)
2) Measurement of exposure can be obtained on an individual level; and
3) Adequate high-quality information and data exists to allow for a well-designed epidemiologic study, and the number of individuals studied is at a number that provides sufficient power for an epidemiologic study.

The investigation must be planned carefully, and a major feasibility study (see guidance below) may be needed to determine whether an investigation is warranted since an inadequately data supported study will not bear results that are valid and scientifically defensible. It is strongly suggested that the Step 3 portion of the investigation should occur in consultation with DHMH EHB, MCR, and MDE.

Major Feasibility Study

Purpose: to objectively uncover whether a proposed epidemiologic study linking a health event and a putative exposure is scientifically appropriate.

When conducting a comprehensive feasibility study, the following should be considered:

1) **Hypothesis Development and Research**: Develop the proposed epidemiological study hypothesis and review scientific literature and past health agency reports to determine whether the same type of cancer has led to other inquiries and investigations.
2) **Stakeholder Involvement**: Community stakeholders (environmental, business, local health departments, medical centers, community groups, etc.) should be involved in order to collect critical information, such as, community concerns (to determine whether they can be adequately addressed through an epidemiological study), possible environmental risk factors in the area, and potential issues of cultural sensitivity to consider when planning an investigation.
3) Despite a significantly elevated SIR, a feasibility assessment might indicate that further epidemiological study may be unable to determine the cause of the elevated rate.

4) Possible outcomes of a major feasibility study are:
   a. A major epidemiological investigation is not feasible
   b. An investigation is possible but may not answer specific concerns raised by the cluster
   c. An investigation is both feasible and can be accomplished

5) If a feasibility study determines that an epidemiologic study is scientifically warranted, investigators should provide a recommended study design and proceed to Step 4.
   a. Conducting epidemiologic investigations can take several years so the health agency should consider what can be done in the interim to protect the community’s health and keep members informed.
   b. Often, community members may respond negatively to this timeline and consider this level of investigation as research that does not benefit community members rather than a concerted public health response to a genuine community concern. To overcome this perception, it is important for investigators to provide periodic progress reports to the community.

STEP 4: CONDUCT AN EPIDEMIOLOGIC INVESTIGATION (FIGURE 5)

Epidemiologic Investigation

Purpose: to perform an etiologic investigation of a potential cancer-exposure relationship.

The primary purpose of this step is to pursue the epidemiologic and public health issues that the cluster generated--not necessarily to investigate a specific cluster.

Points to keep in mind:

- Even if a cancer cluster and an environmental exposure are identified, an epidemiologic investigation may not demonstrate a conclusive association between the two. Other risk factors such as those that are genetic, occupational, infectious, or behavioral may complicate findings making it difficult to demonstrate a statistically significant association.

- If an investigation does not identify an association between a particular suspected environmental exposure and cancer cluster, the exposure may still be linked to the cluster. In such cases, more scientific information might be required (e.g., toxicologic and clinical data) to establish an association.

Step 4 also provides the opportunity to evaluate whether additional public health measures are necessary, such as implementing community smoking cessation programs, cancer screenings, health risk assessments, removing environmental hazards, and/or other activities. If beneficial to public health, these measures should not be delayed pending a decision to conduct or complete an epidemiologic study to assess a potential cancer-exposure relationship.

At this stage, regardless of the findings, care must be taken when communicating to the public about the results, their interpretation, and how they were derived. Emphasis on behalf of the investigator and responder (if they are not the same), should be conducted through continuous and open communication, community involvement, and ensuring that effective public health actions are not delayed or dependent on the results of the investigation.
Appendix 1. Media Protocol

STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene
Larry Hogan, Governor - Boyd Rutherford, Lt. Governor - Van Mitchell, Secretary

Office of Communications
Christopher Garrett
Karen Black
410-767-6490

FOR IMMEDIATE RELEASE:

MEDIA PROTOCOL

It is the protocol of the Maryland Department of Health and Mental Hygiene that all media inquiries be cleared through the DHMH Office of Communications prior to conducting interviews with reporters. This protocol is not to be interpreted as a means of censorship, but rather as a policy to coordinate communication. *NOTE: this protocol does not apply to media inquiries regarding employees’ personal views on any particular subject -- only to those soliciting information or an official response on behalf of the Department.

The Department has an obligation to provide consistent and factual information to the media. In order for this to occur, the Office of Communications must be informed proactively about issues or incidents that may attract media attention. This notification can be done by telephone (410-767-6490) or e-mail. This is necessary so that the Office of Communications may respond in a timely manner and maintain consistency regarding matters of DHMH or Administration policy.

After the Secretary of Health and Mental Hygiene, the Director of Communications is designated as the Department’s chief spokesperson. When appropriate, the Director will assign responsibility to those staff members with particular expertise needed to provide information or technical support.

When contacted by the media, ascertain the issue, and then advise the reporter that an appropriate party will make contact. All media contacts, no matter to whom they are directed, are to be forwarded to the Office of Communications where a decision will be made in concert with appropriate Administration Directors, etc., as to what, if any, information will be released, by whom and in what format. Health professional boards, commissions and local health departments are asked to provide follow-up information to the Office of Communications when appropriate.

All media calls are returned and all requests for information are responded to in a timely manner. Under some circumstances, it may be necessary and appropriate to require reporters to file a Public Information Act request and pay a reasonable fee for copies of documents.
Program personnel unable to obtain prior approval from the Office of Communications should use their best judgment in granting an interview or providing written information. This especially applies when programs are contacted by the media in response to hearings, presentations, press releases or advisories issued by the Department. If information is released, please notify the Office of Communications afterwards with a phone call or e-mail.

The scope of responsibility encompassed by the Department makes it essential that media contacts be handled in a prompt and professional manner. In addition to its coordinating function, programs are encouraged to use the Office of Communications as a resource in preparing for media contacts. The Office of Communications must be contacted regarding information to be distributed via press release or through a media event or outlet. The Office of Communications is able to provide assistance in the distribution of press releases and/or other information to the media, and in coordinating press conferences, special events, etc.

**Office of Communications Staff:**
D. Christopher Garrett, Director of Communications, christopher.garrett@maryland.gov
Karen Black, Director of Media Relations, karen.black@maryland.gov
Jacqueline Campbell, Management Associate, jacqueline.campbell@maryland.gov

###
Appendix 2. Resources

Reporting suspected cancer cluster concerns in Maryland
All suspected cancer cluster concerns in Maryland should be reported to a resident’s local health department. Local health department contact information can be found online in a document titled, *Local Health Department Contact Information for Maryland Residents* which is located here: http://phpa.dhmh.maryland.gov/cancer/SitePages/Cancer.aspx

Point of contact for information and for official Maryland cancer statistics:
Maryland Cancer Registry  
Center for Cancer Prevention and Control,  
Prevention and Health Promotion Administration  
Maryland Department of Health and Mental Hygiene  
201 West Preston Street, Room 400  
Baltimore, MD  21201  
(410) 767-4055  
Fax: (410) 333-5218  
http://phpa.dhmh.maryland.gov/cancer/SitePages/mcr_home.aspx

For guidance on risk communication and conducting cancer cluster investigations:
Environmental Health Bureau  
Maryland Department of Health and Mental Hygiene  
Prevention and Health Promotion Administration  
201 W. Preston Street, Room 327  
Baltimore, MD  21201  
(410)-767-6234  
Toll Free 1-866-703-3266  
Fax: (410) 333-5995  
http://phpa.dhmh.maryland.gov/SitePages/environmental.aspx

Maryland Department of the Environment  
Science Services Administration  
1800 Washington Blvd.  
Baltimore, MD  21230  
(410)-537-3572  
Fax: (410) 537-3873

Agency for Toxic Substances and Disease Registry  
U.S. Department of Health and Human Services  
*Chemicals, Cancer, and You*  
A Primer on Health Risk Communication
http://www.atsdr.cdc.gov/risk/riskprimer/

Centers for Disease Control and Prevention
Environmental Hazards and Health Effects - Cancer Clusters
http://www.cdc.gov/nceh/clusters/default.htm

For information on cancer control programs and activities in Maryland:

Maryland Department of Health and Mental Hygiene
Center for Cancer Prevention and Control
201 West Preston Street, Room 303
Baltimore, MD 21201
410-767-5281
http://phpa.dhmh.maryland.gov/cancer/SitePages/Home.aspx

Maryland Department of Health and Mental Hygiene
Maryland State Council on Cancer Control
201 W. Preston Street, 3rd Floor
Baltimore, MD 21201
(410) 767-5641
http://phpa.dhmh.maryland.gov/cancer/SitePages/sccc_home.aspx

To report occupational-related health hazards, injuries, or illness:

Maryland Department of Labor, Licensing and Regulation,
Division of Labor and Industry
Maryland Occupational Safety and Health
10946 Golden West Drive
Suite 160
Hunt Valley, MD 21031
Phone: 410-527-4499
Fax: 410-527-4481
http://www.dllr.state.md.us/labor/mosh/
For information on pesticides, including safe pest management techniques, pesticide handling and disposal, and health hazards:

Maryland Department of Agriculture
Pesticide Regulation Section
50 Harry Truman Parkway
Annapolis, MD 21401-7080
410-841-5700
http://mda.maryland.gov/plants-pests/Pages/citizens_guide_pesticide_enforcement_complaints.aspx

To report pesticide related illnesses:

Environmental Health Bureau
Maryland Department of Health and Mental Hygiene
Prevention and Health Promotion Administration
201 W. Preston Street, Room 327
Baltimore, MD 21201
(410)-767-6234 Toll Free 1-866-703-3266
Fax: (410) 333-5995
http://phpa.dhmh.maryland.gov/SitePages/environmental.aspx
Appendix 3. Data Collection Instruments

Report of Cancer Concern

Name and Title of Individual Taking Report:

Unit: □ Local Health Dept. □ DHMH Environ PH Coord □ MD Cancer Registry

Date of Initial Report:

Name of Reporter:

Address:

City:

Phone:
Fax:
E-Mail:

Summary of Concern:

Initial Response/Resolution:

Reported to Env. PH: To Whom:_________________________ Date: __________________

Reported to LHD: To Whom: ________________________________
Jurisdiction_________________________ Date_________________
Copy this page as many times as needed to collect information

**Case Information:**

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>Sex (M/F)</td>
<td></td>
</tr>
<tr>
<td>Date of Birth</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>City/Town of Residence</td>
<td></td>
</tr>
<tr>
<td>County of Residence</td>
<td></td>
</tr>
<tr>
<td>Length of Time at Current Residence</td>
<td></td>
</tr>
<tr>
<td>Cancer Site/Type</td>
<td></td>
</tr>
<tr>
<td>Date of Diagnosis</td>
<td>Date of Death</td>
</tr>
<tr>
<td>Place of Diagnosis (Hospital, Doctor’s Office, State, etc.)</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>For how long?</td>
</tr>
<tr>
<td>Smoking History</td>
<td>Never Smoked, Former Smoker, Current Smoker</td>
</tr>
<tr>
<td>Other Information</td>
<td></td>
</tr>
</tbody>
</table>

**Confirmed in MCR or other registry:**

---

**Case Information:**

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>Sex (M/F)</td>
<td></td>
</tr>
<tr>
<td>Date of Birth</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>City/Town of Residence</td>
<td></td>
</tr>
<tr>
<td>County of Residence</td>
<td></td>
</tr>
<tr>
<td>Length of Time at Current Residence</td>
<td></td>
</tr>
<tr>
<td>Cancer Site/Type</td>
<td></td>
</tr>
<tr>
<td>Date of Diagnosis</td>
<td>Date of Death</td>
</tr>
<tr>
<td>Place of Diagnosis (Hospital, Doctor’s Office, State, etc.)</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>For how long?</td>
</tr>
<tr>
<td>Smoking History</td>
<td>Never Smoked, Former Smoker, Current Smoker</td>
</tr>
<tr>
<td>Other Information</td>
<td></td>
</tr>
</tbody>
</table>

**Confirmed in MCR or other registry:**
Cancer Concern--Information Summary

Local Health Department staff responsible:
DHMH staff responsible:
City:
County:
Other Geographic Boundary:
Perceived Cause (if any):

Date Reported to Environmental Health Coordination Program:

Date Reported to the Maryland Cancer Registry:
Date reported to the Local Health Dept (and to whom):

Case Information Summary:

Steps Taken:

Date of Resolution:

Resolution:
Confidential Report of Occupational/Environmental Disease

Available at:
http://phpa.dhmh.maryland.gov/SitePages/environmental.aspx

Note: The form itself is located at:
http://phpa.dhmh.maryland.gov/OEHFP/EH/Shared%20Documents/Occupational%20Reporting%20Form%20MD%20v1.pdf
# Maryland Department of Health and Mental Hygiene
## Environmental Health Coordination Program
### CONFIDENTIAL REPORT OF OCCUPATIONAL/ENVIRONMENTAL DISEASE

**INSTRUCTIONS:** In accordance with Maryland Code, the following conditions must be reported to the Department of Health and Mental Hygiene: (1) Pesticide-related exposures and illnesses; and (2) occupational illnesses.

<table>
<thead>
<tr>
<th>Reporting Source Information</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Reporting Physician:</td>
<td></td>
</tr>
<tr>
<td>Name of Institution/Clinic:</td>
<td></td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Telephone:</td>
<td></td>
</tr>
<tr>
<td>Medical Specialty:</td>
<td></td>
</tr>
<tr>
<td>Fax:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient Information</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s Name:</td>
<td></td>
</tr>
<tr>
<td>Last</td>
<td></td>
</tr>
<tr>
<td>First</td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td></td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Street</td>
<td></td>
</tr>
<tr>
<td>City</td>
<td></td>
</tr>
<tr>
<td>State</td>
<td></td>
</tr>
<tr>
<td>Zip Code</td>
<td></td>
</tr>
<tr>
<td>Home Telephone:</td>
<td></td>
</tr>
<tr>
<td>Date of Birth:</td>
<td></td>
</tr>
<tr>
<td>Sex: Male [ ] Female [ ]</td>
<td></td>
</tr>
<tr>
<td>Hispanic: [ ] Yes [ ] No [ ]</td>
<td></td>
</tr>
<tr>
<td>Race (check all that apply): [ ] American Indian/Alaska Native [ ] Black/African American [ ] Asian [ ] Native Hawaiian or Pacific Islander</td>
<td></td>
</tr>
<tr>
<td>Other Race (specify):</td>
<td></td>
</tr>
</tbody>
</table>

- [ ] Is this exposure/illness possibly work-related? [ ] Yes [ ] No [ ]
  If so, please provide information on the workplace:
  - Occupation or type of work performed by patient: ____________________________
  - Company where exposure/injury reportedly occurred: _________________________
  - Type of Business or Industry: __________________________
  - Is patient still employed at company? [ ] Yes [ ] No [ ]

<table>
<thead>
<tr>
<th>Diagnosis Information</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis: [ ] confirmed [ ] suspected</td>
<td></td>
</tr>
<tr>
<td>Date of Diagnosis:</td>
<td></td>
</tr>
<tr>
<td>Work-related asthma (if checked, please complete the following information)</td>
<td></td>
</tr>
<tr>
<td>Suspected Agent:</td>
<td></td>
</tr>
<tr>
<td>[ ] New-onset asthma (due to workplace exposure)</td>
<td></td>
</tr>
<tr>
<td>[ ] Work-aggravated asthma (pre-existing asthma aggravated by workplace exposure)</td>
<td></td>
</tr>
<tr>
<td>[ ] Reactive Airways Dysfunction Syndrome (RADS) (asthma resulting from a one-time acute exposure at work)</td>
<td></td>
</tr>
<tr>
<td>Other lung disease (if checked, please complete the following information)</td>
<td></td>
</tr>
<tr>
<td>Asbestosis [ ] Chemical pneumonitis (suspected agent: ________________________ )</td>
<td></td>
</tr>
<tr>
<td>Silicosis [ ] Chemical pneumonitis (suspected agent: ________________________ )</td>
<td></td>
</tr>
<tr>
<td>Beryllium disease [ ]</td>
<td></td>
</tr>
<tr>
<td>Work-related carpal tunnel syndrome [ ]</td>
<td></td>
</tr>
<tr>
<td>Serious work-related traumatic injury to person &lt;15-years-old (if checked, please complete the following information)</td>
<td></td>
</tr>
<tr>
<td>Cause of injury, if known</td>
<td></td>
</tr>
<tr>
<td>Acute chemical poisoning (if checked, please complete the following information)</td>
<td></td>
</tr>
<tr>
<td>Carbon monoxide poisoning [ ]</td>
<td></td>
</tr>
<tr>
<td>Pesticide poisoning Suspected Pesticide: ____________________________</td>
<td></td>
</tr>
<tr>
<td>[ ] Other: [ ]</td>
<td></td>
</tr>
<tr>
<td>Heavy metal exposure (if checked, please complete the following information)</td>
<td></td>
</tr>
<tr>
<td>Mercury level: __________ date of test: __________</td>
<td></td>
</tr>
<tr>
<td>Cadmium level: __________ date of test: __________</td>
<td></td>
</tr>
</tbody>
</table>

**Remarks:** __________________________________________________________________________

---

**Please return this report to Environmental Health Coordination Program, 201 West Preston Street, Baltimore, MD 21201.**
**FAX: (410) 333-5995.**
**For more information or to file a report by phone, call: (866) 703-3346. Voicemail is in operation after hours. THANK YOU.**
**Please note: Disease outbreaks/cluster should be reported by phone.**

See back for Reporting Guidelines

---

October 2008
Appendix 4. Information About Cancer Clusters And Risk Perception

1. Risk Perception and Risk Communication: Points to consider when communicating risk to the public.

   See ATSDR Risk Communication Primer [http://www.atsdr.cdc.gov/risk/riskprimer/]

   - **Risk** means “probability”, or the chance that something may occur. **Cancer risk** is the probability that any person or category of people will develop cancer.
   - A list of individuals with cancer in a specified geographic and time period may not constitute a cluster.
   - Risk estimated by the public may differ from the risk estimated by scientific assessments. This difference in risk estimation is not because the community is unable to apply statistical reasoning but rather, is the result of the community factoring in the following **qualitative** measures into a risk equation:
     - Whether the risk or perceived risk is voluntary or involuntary (smoking vs. drinking water)
     - The degree of control the community or individual has over the source of the risk or perceived risk
     - Potential social and economic ramifications associated with the risk or perceived risk such as, social justice concerns regarding sources of emissions or neighborhood environmental contamination
     - A perceived bias by the community on behalf of the investigation agency
     - Community concerns about suspected cancer clusters usually begin when a relative, friend, neighbor and/or coworker is diagnosed with cancer. This close contact with someone diagnosed with cancer often brings an emotional connection to others who have been similarly diagnosed and a strong desire to identify a common cause.

   The responding agency should address these concerns with sensitivity to the concerns of community members, a willingness to discuss both the approach to the questions raised and the ultimate findings, and a recognition that honest dialogue with the inquirer is most likely to lead to a satisfactory resolution of the concerns.

2. Understand and be prepared to explain common misconceptions about cancer and cancer clusters.

   Individuals reporting suspected cancer clusters often seek information to confirm an unusual burden of cancer or understand cancer risks. They are generally surprised by actual cancer rates and will benefit from a conversation about cancer, its patterns of occurrence, and major risk factors. Relaying the following information is a good way to begin this discussion (see also *Questions and Answers about Cancer Clusters*, a pamphlet for the public).
Cancer is not just one disease.
The term “cancer” refers to a group of over one hundred diseases that result from the abnormal growth of cells.

Different types of cancer usually have different causes or risk factors, for example, smoking is a known cause of lung cancer. Radiation and benzene are risk factors for certain types of leukemia but not for colon cancer, therefore, it cannot immediately assumed that different types of cancer occurring in one place or at one time share a common cause.

Cancer is more common than most people realize.
Cancer is the second leading cause of death in the United States and Maryland, and 23% of deaths in Maryland in 2011 resulted from cancer. According to the American Cancer Society, about half of all men and one-third of all women in the U.S. will develop cancer during their lifetimes (this does not include risk of the relatively common squamous and basal skin cancers). Four types of cancer account for 51% of all newly diagnosed cancers in Maryland—cancers of the breast, prostate, lung and bronchus, and colon and rectum.

Given these statistics, it is not unusual to learn that several people in a single neighborhood or workplace have cancer.

The risk of cancer increases with age.
Age is the most important risk factor for developing cancer. About 78% of all cancers diagnoses are in people 55 years of age or older, and therefore, a community of older adults is expected to have more cancer cases than a community of younger people or one with a range of age groups.

Most cancers are related to lifestyle factors.
Medical researchers believe that most cancers are related to how we live. Lifestyle factors such as, tobacco use, alcohol use, diet, radiation exposures and obesity are avoidable risk factors for cancers.

Toxic substances in the environment account for a relatively small percentage of cancer deaths in the U.S.
Some individuals in the public believe that cancer is usually caused by exposure to toxic substances in the environment, however, researchers believe that environmental exposures, other than tobacco smoke, likely account for less than

---

10% of all cancers. Many studies have shown that exposure to asbestos, benzene, benzidine, cadmium, nickel, or vinyl chloride in the workplace can cause cancer, but these exposures are rare. Following instructions and safety tips to avoid or reduce contact with harmful substances both at work and at home is important. Although the risk is highest for workers with years of exposure, it makes sense to be careful at home when handling pesticides, used engine oil, paint, solvents, and other chemicals.

http://www.cancer.gov/cancertopics/factsheet/Risk

**Cancers that are diagnosed today are usually related to events that happened many years ago.**

Cancer is caused by both internal factors (i.e., inherited gene mutations, gene mutations acquired later in life, hormones, age, and immune conditions) and external factors (i.e., exposures to tobacco, sun and other ultraviolet radiation, chemicals, X-rays, and infectious organisms). These factors may act together or in sequence to initiate or promote the development of cancer. Ten or more years often pass between the development of mutations or exposure to an external agent and detectable cancer. This long period makes it very difficult to pinpoint the specific causes of many cancers.

**Cancer clusters can occur by chance.**

For some cancer types and some geographic areas, a small number of cases may be enough to change an area’s cancer rate from below average to above average. While the increase may be real, the above average number of cancer cases may simply be the result of variations that occur randomly or by chance and may not be due to a single cause.

3. **Understand and be prepared to explain the following information about environmental contaminants and how they relate to cancer.**

See ATSDR Case Study on Disease Clusters

- The environment presents many potential contributors to cancer, both man-made and naturally occurring, including chemicals, radiation, and infectious agents. In order for these agents to contribute to cancer, a person must have a significant *exposure*.

- **Exposure** is a central concept in toxicology and risk science. An exposure of significance requires that an agent be:
  1) present in the local environment,
  2) transferred from its location in the environment into the body via ingestion, inhalation, and/or absorption through the skin,
  3) metabolized in ways that preserve toxicity,
  4) sufficiently retained in the body, and
  5) delivered to susceptible cells.
It can be very difficult to estimate exposures and their potential role in the development of cancer, and this is particularly true when looking back in time because of 1) the lack of data on existing environmental levels (in most cases), 2) difficulty accurately estimating individual exposure levels, 3) the latency period between exposure and the development of cancer, and 4) the multiple steps and factors potentially involved in the development of a cancer.

- In general, to elevate cancer rates above the expected value in a population, a cancer-causing agent must damage cells in many people. Exposures to cancer-causing agents, wherever they occur, may be too low, too short in duration, or too recent to allow for the development and discovery of cancer.

- The exposures most capable of causing clusters have been much more common in workplaces than in neighborhoods or schools. This is because 1) high levels of substances that cause cancer are more commonly found in industrial environments, 2) if cancers develop, the people with cancer may believe their cancer is related to others with similar cancers in the workplace, and 3) the cluster may be reported to health authorities for investigation.

- Concerns about cancer are often tied to fears about a particular toxic agent or pollution source. In these cases, it is helpful to provide background information about the potential agent or pollution source and it may be necessary to inspect the potential contamination site or check historical monitoring data. That said, it is important to consider the following limitations:
  - The boundaries of the contamination may be unclear.
  - Current samples may not reflect conditions as they existed in the past when exposure may have occurred (that led to the current detectable cancer).
  - Laboratory costs can seriously limit the number of samples that can be tested.

Therefore, even after sampling, the degree of actual exposure to individual community members may be difficult to estimate.
Appendix 5. References


Centers for Disease Control and Prevention (CDC). Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists *MMWR September 27, 2013, 62; RR-8 : 1-14*. http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm?s_cid=rr6208a1_1


The services and facilities of the Maryland Department of Health and Mental Hygiene (DHMH) are operated on a non-discriminatory basis. This policy prohibits discrimination on the basis of race, color, sex, or national origin, and applies to the provisions of employment and granting of advantages, privileges and accommodations.

The Department, in compliance with the Americans with Disabilities Act, ensures that qualified individuals with disabilities are given an opportunity to participate in and benefit from DHMH services, programs, benefits, and employment opportunities.