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

Maryland Department of Health and Mental Hygiene

January 2010

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INTRODUCTION

Suspected cancer clusters 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. The local and state agencies need a coordinated approach in evaluating and responding to these reports.

Purpose

The purpose of this document is to outline 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 *Guidelines for the Investigation of Suspected Cancer Clusters* were derived from the cumulative experience of other state health departments and officials from the Centers for Disease Control and Prevention (CDC). The recommendations that follow were compiled from the guidance documents developed for these agencies and the advice of Maryland officials with experience in epidemiology, environmental health, toxicology, cancer control, and risk communication.

Background

For the purposes of these guidelines, the term "cluster" is an unusual aggregation, real or perceived, of health events that are grouped together in time and space and that are reported to a health agency. (CDC, 1990)

Cancer is not evenly distributed in the population, and therefore, the occurrence of cancer cases grouped in time is not uncommon. Cancer clusters can occur for a variety of reasons:

- random cancer cases that are grouped in time and space purely by chance;
- cancer cases that 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; and
- rarely, cancer cases caused by common environmental or occupational exposure(s) to cancer-causing agents in a geographic area. These "true" clusters can occur with small numbers of cases over long periods of time, making their recognition difficult.

Numerous state and federal agencies agree that finding a major association between a specific exposure and a specific cancer is rare, and that reports of suspected cancer clusters are usually resolved *without* a full-scale investigation. Nationally, only about 2 of every 1,000 reports of suspected clusters are shown to be "true" clusters that have statistically significant elevations in cancer rates warranting an in-depth epidemiologic study. However, when excess cancers are observed in certain groups, are statistically significantly higher than expected, and cannot be explained by chance, it is important to try to identify common factors among the cancer cases, and to conduct a more detailed cancer cluster investigation. **No cancer cluster report should be ignored**.

The proper handling of a suspected cancer cluster report usually leads to resolution of the report and increases community understanding of the multiple factors involved in that community's pattern of cancer. With this understanding, the community is more likely to understand the outcome of the report when the agency either closes the file or begins to collect additional information for a more detailed investigation.

These Guidelines outline the ways in which the following Primary Goals 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 the cancer cases in geographic and time patterns.
- To efficiently evaluate reports in order to assess whether they represent potential clusters requiring further investigation, or concerns that need a different response.
- To provide accurate, appropriate information and feedback to citizens, the community, and health professionals**.**
- To raise public awareness regarding 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 are key agencies in the management and investigation of suspected cancer cluster reports. Local health departments are typically in the best position:

- To evaluate geographic, environmental, and socioeconomic factors at the community level;
- To utilize community resources for case-finding and health education;
- To assess the social and political dimensions of a suspected cluster;
- To utilize relationships with local health care providers; and
- To utilize the occasion to provide public communication at the local level.

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

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

Upon request, the State will provide consultation and technical support. The State agencies/units principally involved in cancer cluster investigations are: the Maryland Department of Health and Mental Hygiene (DHMH) Center for Environmental Health Coordination (CEHC); the DHMH Maryland Cancer Registry (MCR) in the Center for Cancer Surveillance and Control; and the Maryland Department of the Environment (MDE).

When a local health department needs assistance,

- The DHMH CEHC coordinates activities between the local and state agencies;
- The MCR provides population-based Maryland and local data to investigate the cancer cluster report;
- The MDE provides support when cancer-related issues involve environmental contaminants or concerns; and
- Other agencies may play a role in providing information or participating in investigations such as the Maryland Department of Labor, Licensing, and Regulations (including the Office of Occupational Safety and Health), or the Maryland Department of Agriculture.

During all multi-agency cluster investigations, inter-agency communication is essential. 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 for the agencies involved. Figures 1-4 provide an overview of the management process for inquiries related to cancer and cancer clusters and the specifics of the three Phases.

Figure 1. Flow of Information and Response to Cancer Concerns

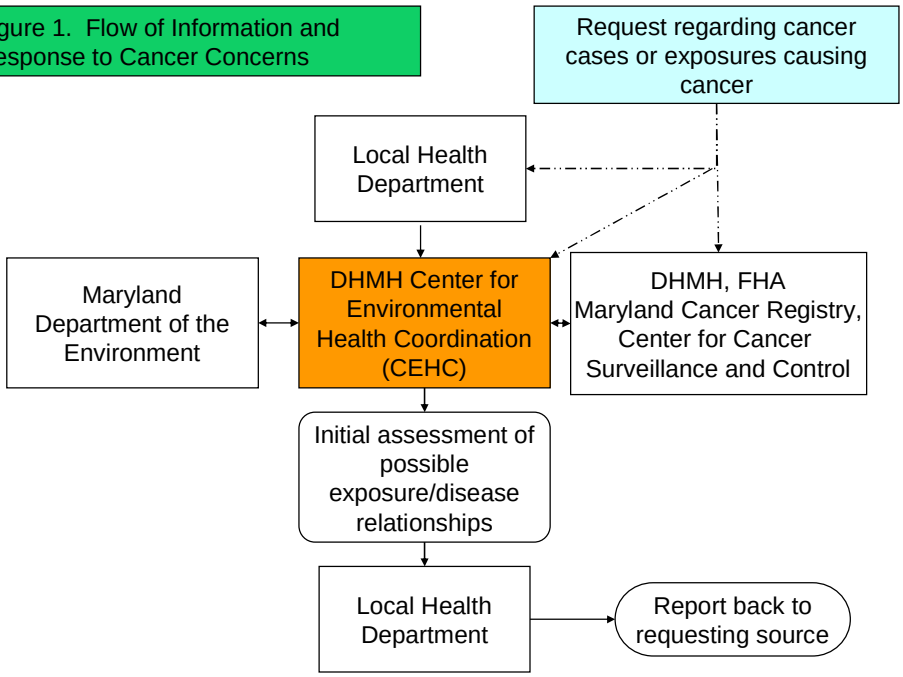
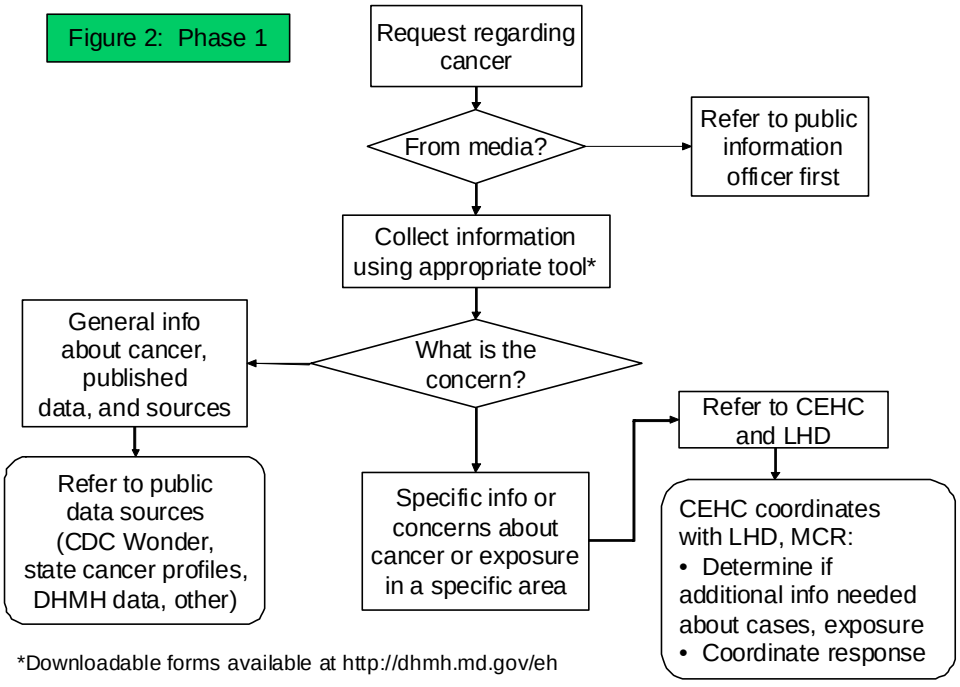


Figure 2: Phase 1



*Downloadable forms available at http://dhmh.md.gov/eh

Figure 3: Phase 2

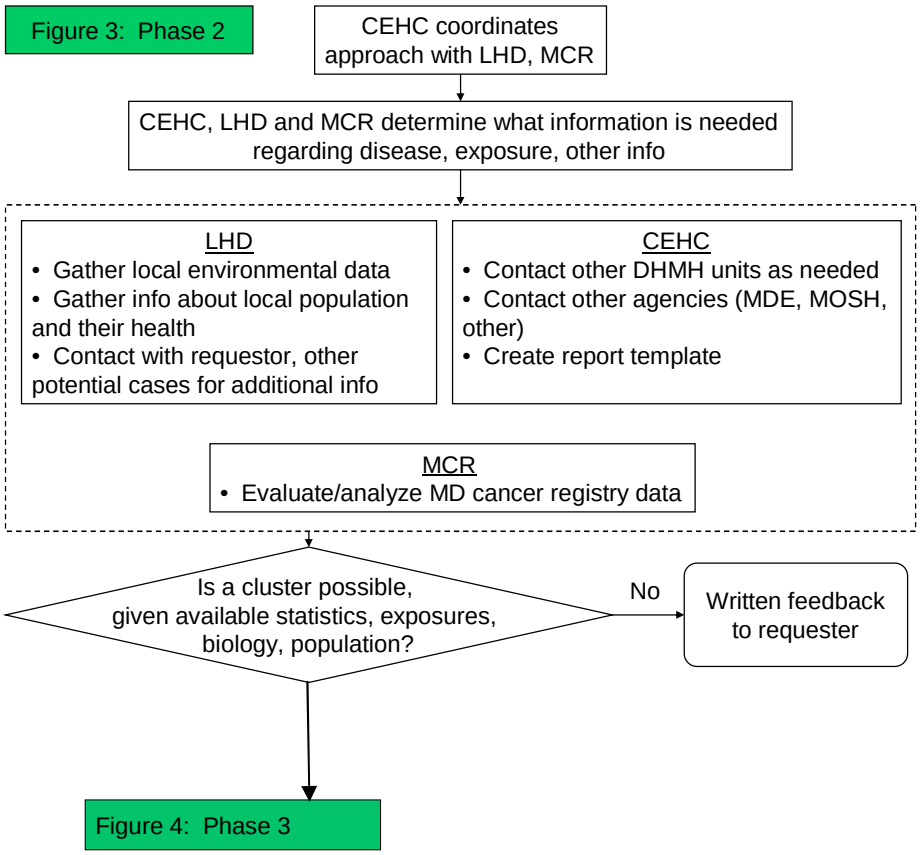


Figure 4: Phase 3

CEHC

• Coordinate joint teleconference/meeting with LHD, MCR, other DHMH staff/units, MDE, Centers for Disease Control and Prevention (CDC), as appropriate

• Determine whether the State of Maryland will conduct the investigation, contract with an entity to conduct the investigation, or whether there are other responsible parties who will conduct the investigation (employer, EPA, etc.)

• If DHMH will conduct investigation, write protocol for Phase 3 investigation for discussion and circulate for approval

• Coordinate investigation in collaboration with LHD

PHASE 1: INITIAL INFORMATION COLLECTION (FIGURE 2)

The objectives of Phase 1 are:

1) To gather information, understand and establish the nature of the concern;
2) To make an initial judgment regarding the need to pursue the issue as a cluster investigation; and
3) To begin an educational process about cancer, cancer risk factors, and suspected clusters.

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 these principles and practices, presented in Appendix 4.

1. Before speaking with someone requesting information, understand the concepts of risk perception and risk communication; familiarize yourself with the general concepts of cancer cluster investigations.

- 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.

2. During the first conversation, introduce yourself and determine the requester's basic concerns and informational needs.

- Establish your expertise and convey your competence by stating your background and telling the requester why it is your role to speak with them.
- Demonstrate to the requester that you care about the issue. This requires careful listening and questioning. Requesters will not have confidence in people who do not listen to them.
- Speak clearly and compassionately.
- If you do not know an answer, say so. If possible, tell the requester that you will find the answers and get back to them.
- If you are unsure of a question, repeat or paraphrase it to be certain you understand the meaning or the question.
- Determine whether the person is simply requesting information or requesting a cancer cluster investigation.
- Take detailed notes, noting names, times, dates of the call(s).

3. **If the person is only requesting information, such as the rate of cancer in the county or Zip code area, attempt to identify and supply available information.**

   - County-level and state-level cancer rates are available to local health departments and State agencies. Zip code or census tract level data may be available upon request from the MCR. These allow for comparisons of rates in different Zip codes and larger geographic area.

   - Consult with the MCR to obtain data at the Zip code, census tract, city, sub-county, or neighborhood level. A data request form should be completed (available at http://fha.maryland.gov/cancer/mcr_data.cfm).

   - Obtain and attempt to check the accuracy of information that you intend to convey; determine what data can be released based on the MCR Data Use Policy and Procedures (http://fha.maryland.gov/cancer/mcr_data.cfm).

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

   - Simplify the information as much as possible. Avoid technical jargon.

   - Attempt to explain the numbers in understandable terms.

   - Do not hide or "sugarcoat" relevant data.

4. **If the requester is still expressing concern about cancer or exposures in a particular location or requesting further investigation after your initial discussion, collect and evaluate the information the requester offers.**

   - Collect general information from the requester 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.

   - If the requester has detailed information (such as names, ages, cancer types, dates of diagnosis, addresses, risk factors of cases), you may ask the requester to give you the available information.

   - Tell the requester 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—it is the law in Maryland. Do not share information that you have about health of other community member(s) with the requester; you may not disclose information you have about other reports or other cases of cancer. Any release of information from the MCR must be in aggregate form and meet the MCR Data Use Policy and Procedures (http://fha.maryland.gov/cancer/mcr_data.cfm).

- Evaluate the requester's information. It is difficult to asses the accuracy and completeness of the requester's information. Asking the requester to collect additional confidential medical information from persons outside of his/her own family is inappropriate and may place the requester in the position of risk communicator, creating the potential to provoke unjustified alarm in the community. The requester may, however, be asked to refer other concerned citizens or those with cancer to the health department so that you may interview them directly.

- Listen carefully to the requester's theories about the cluster. Address them in follow-up discussions.

- Describe the steps that will be taken to handle the suspected cancer cluster.

5. Judge whether the reported 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);

    - A rare type of cancer (rather than common types). For rare cancer types, three or more cases may be sufficient to signal a cluster;

    - An unusual number of cases at early age at diagnosis; or

    - A sudden appearance of cases.

- Help bring the requester to an understanding that a list of people with cancer does not alone constitute a cluster.

- Before a decision is made either to exclude the report as a cancer cluster or to continue with the investigation, make certain that the Health Officer and the DHMH staff concur with the decision.

- Avoid trying to establish or hypothesize causes for the individual cancer cases reported and described by the requester, especially early on. Attempting to establish a cause for each case may lead the requester to believe that all cancer cases have an identifiable cause, which is often not the case. There are a few cancers associated with environmental or occupational exposures (for example, some skin cancers, mesothelioma, or 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 requester will turn to other agency representatives for answers.

6. **If further steps are anticipated, tell the person requesting information how and when you will get back to him/her, and proceed to Phase 2: Preliminary Investigation.**

    - Collect address and contact information of the person making the request.

    - Send the brochure, entitled *Questions and Answers about Cancer Clusters* from the Maryland Department of Health and Mental Hygiene, to the requester as soon as possible (http://fha.maryland.gov/pdf/cancer/combined_cancer_cluster.pdf).

    - Send a letter that summarizes the specific situation and next steps if you believe this may be helpful to the requester.

PHASE 2: PRELIMINARY INVESTIGATION (FIGURE 3)

Phase 1 focused on understanding the requester'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 Phase 2 are:

1) To collect and review readily available information; and
2) To provide an estimate of the likelihood that a cancer excess has occurred by reviewing the types of cancer, ages, possible common exposures, and by comparing observed and expected rates in the geographic area. (Note: Clusters reported at worksites will require different methods.)

The information below identifies important aspects of this process.

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

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

2. Complete the collection and review of information from the requester.

- Use the provisional information from the requester and other sources in the community to establish some 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 Zip code during specific years).

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

- Contact the original requester if there are additional questions and provide a status report. Remind the requester 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 requester and community members in order to facilitate the exchange of information; schools and workplaces often are 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 ask DHMH to participate in the meeting. Consult

someone with experience in these events before scheduling. The CEHC, MCR, and MDE can assist with this step.

3. **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 Zip code, city/town, county, and state-level cancer rates with statistical comparisons. MCR data are complete enough to permit comparisons of rates in different Zip codes and larger geographic areas. Realize that the population of a Zip code 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, the smaller the population under consideration, the less stable the calculated rate will be. Consult with MCR or CEHC for these special analyses.

   - Complete an MCR Data Request Form for information needed from the MCR available at:
     http://fha.maryland.gov/pdf/cancer/mcr_DataRequestForm_DHMH4663.pdf

   - 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 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. However, 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 CEHC can assist with this step.

4. **Identify any major limitations in this comparison, 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).

*Need for additional information will be determined based on the number of cases, geography, type(s) of cancer, ages at onset, onset dates, setting, and biologic feasibility

- 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. Pieces of necessary information are often missing; therefore, the investigation is 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; cancers that develop in people who recently moved into the area cannot be attributed to local exposure(s).

5. 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 historical Zip code- 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.

6. Report back to the requester.

- After discussion among those people and agencies responding to the concern, determine who will report back to the requester by telephone and/or written response.

- Telephone the requester and describe the results of your comparison.

- Write a summary of your findings and send it to the requester.

- Offer to visit and discuss your findings with the requester, interested persons, or with a community group (after careful thought and planning).

7. 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 local Zip code 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.

8. If the presence of a cancer cluster is not supported by the available information and the requester'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 requester invite a knowledgeable and trusted guest. These meetings require preparation, skills and experience in risk communication—good intentions will not be enough.

Confusion:

- The requester 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.

9. **If the presence of a cluster cannot be ruled out, continue with a more detailed investigation (Phase 3)**.

   - Notify the DHMH CEHC, MCR, and/or the MDE if a further investigation appears warranted.
   - After discussion with these parties, contact the requester and tell them the outcome of the conversation, such as whether a detailed investigation may be conducted.

10. Even if further steps are *not* anticipated, it is still important to follow-up with the requester to solidify your interest in their concerns. **If you have not already done so:**

   - Collect address and telephone information from the requester.
   - Send the brochure entitled *Questions and Answers about Cancer Clusters* from the Maryland Department of Health and Mental Hygiene to the requester.
   - Include a cover letter that summarizes the specific situation.

PHASE 3: FURTHER INVESTIGATION (FIGURE 4)

Up to this point, the investigation has relied upon data that are readily available. No one has performed more rigorous case finding or case verification and comprehensive demographic, occupational, and behavioral data on each reported case have not been collected. The time and space boundaries of the suspect cluster may still be unclear. 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 Phase 3.

Phase 3 investigation occurs when:
1) preliminary data suggest that the cluster may be real:
   - one type of cancer (or more than one type that are closely related to the suggested agent),
   - a likely exposure to an agent with biological plausibility of causing the cancer (often an occupational setting) as well as some scientific research suggesting that the agent in question may cause the cancer of concern (e.g. benzene and leukemia, or asbestos fibers and mesotheliomas);
2) there exists the ability to obtain some measurement of exposure on an individual level; and
3) there is enough high quality information to allow a well designed epidemiologic study individuals involved that would provide sufficient power to justify an epidemiologic study.

The investigation must be planned carefully and a feasibility study may be needed. An inadequately supported study will not bear results that are valid and scientifically defensible. Phase 3 investigation, therefore, should occur in consultation with DHMH CEHC, the MCR, and the MDE.

For further guidance, a complete protocol for the investigation of clusters has been prepared by the Centers for Disease Control and Prevention (Guidelines for Investigating Clusters of Health Events. MMWR 1990; 39 (RR-11):1-16.) These next steps may include:

Major Feasibility Study

Purpose: to determine the feasibility of performing an epidemiologic study linking the health event and a putative exposure. The major feasibility study examines the potential for relating the cluster to some exposure.

Etiologic Investigation

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

The primary purpose of the study is to pursue the epidemiologic and public health issues that the cluster generated--not necessarily to investigate a specific cluster. While describing all of the elements involved in a major feasibility is beyond the scope of this document, the possible outcomes of a major feasibility study may range all the way from a finding that a major study is

not technically feasible, to a finding that such a study can be done but might still not answer the specific concerns raised in the cluster that originally generated the question, to a finding that a major study is both feasible and could be accomplished. Whatever the finding, the results will require care and thoughtfulness in how they are communicated, and stakeholders should understand exactly how the findings were arrived at.

Appendix 1. Media Protocol

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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 Public Relations 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.

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Appendix 2. REFERENCES

American Cancer Society (ACS). Personal behaviors are what really matters when it comes to avoiding cancer. (News Release). March 22, 1997.

Baptiste, M., Rothenberg, R., Nasca, P., et al. Health effects associated with exposure to radioactively contaminated gold rings. *J Amer Acad Dematol* 1984, 10:1019-23.

Bender AP, Williams AN, Johnson RA, Jagger HG. Appropriate public health responses to clusters: the art of being responsibly responsive. *Amer J Epdemiol 1990, 132; Suppl 1: S48-S62.*

Kingsley, B, Schmeikel M, and Rubin C. An update on cancer cluster activities at the Centers for Disease Control and Prevention. *Environ Health Perspect* 2007, 115: 165-171.

Centers for Disease Control and Prevention (CDC). Guidelines for investigating clusters of health events. *MMWR July 27, 1990, 39; RR-11: 1-23.*
http://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm

Council of State and Territorial Epidemiologists (CSTE). Cancer Cluster Workshop Summary, Annual Meeting, June 15-16, 1997, Saratoga Springs, NY.

Herbst, A., Ulfelder, H., Poskanzer, D. Adenocarcinoma of the vagina: association of maternal stillbesterol therapy with tumor appearances in young females. *N Engl J Med 1971, 284:878-81.*

Appendix 3. RESOURCES

Central point of contact for initial information and for official Maryland cancer statistics:

Maryland Cancer Registry
Center for Cancer Surveillance and Control, Family Health 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://www.fha.state.md.us/cancer/registry

For guidance on risk communication and other aspects of conducting cancer cluster investigations:

Center for Environmental Health Coordination
Maryland Department of Health and Mental Hygiene
Infectious Disease and Environmental Health Administration
201 W. Preston Street, Room 327
Baltimore, MD 21201
(410)-767-6234 Toll Free 1-866-703-3266
Fax: (410) 333-5995
http://dhmh.md.gov/eh

Maryland Department of the Environment
Technical and Regulatory Services Administration
1800 Washington Blvd.
Baltimore, MD 21230
(410)-537-3572
Fax: (410) 537-3873
http://www.mde.state.md.us/CitizensInfoCenter/index.asp

Agency for Toxic Substances and Disease Registry
U.S. Department of Health and Human Services
Disease Clusters: Case Studies in Environmental Medicine (2002)
http://www.atsdr.cdc.gov/csem/cluster/index.html

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 Surveillance and Control
201 West Preston Street, Room 303
Baltimore, MD 21201
410-767-5281
Fax: 410-333-7279
http://www.fha.state.md.us/cancer/

Maryland Department of Health and Mental Hygiene
Maryland State Council on Cancer Control
201 West Preston Street, Suite 400
Baltimore, MD 21201
410-767-4055
Fax: 410-333-5218
http://www.fha.state.md.us/cancer/council

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
1101 North Eutaw Street, Room 600
Baltimore, MD 21201
410-767-2189
Fax: 410-767-2189
http://www.dllr.state.md.us/labor/mosh.html

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- 841-5710
Fax: 410-841-2765
http://www.mda.state.md.us/

To report pesticide related illnesses:

Center for Environmental Health Coordination
Maryland Department of Health and Mental Hygiene
Infectious Disease and Environmental Health Administration
201 W. Preston Street, Room 327
Baltimore, MD 21201
(410)-767-6234 Toll Free 1-866-703-3266
Fax: (410) 333-5995
http://dhmh.md.gov/eh

Appendix 4. Information about cancer clusters and risk perception

1. Understand the concepts of risk perception and risk communication.

(See also the ATSDR Risk Communication Primer
http://www.atsdr.cdc.gov/risk/riskprimer/)

- Risk means "probability." Cancer risk is the probability of getting cancer or getting specific type of cancer.
- 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. Rather, it is a result of the community factoring in the following ***qualitative*** measures into its risk equation:
  - Whether the risk/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/perceived risk; and
  - Potential social and economic ramifications associated with the risk/perceived risk (such as issues of social justice regarding sources of emissions or environmental contamination).
- The requesters' 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 awareness of many others who have cancer and a strong desire to identify a common cause.
- A list of people with cancer does not alone constitute a cluster.
- The community may perceive the investigating agency as biased.
- The community may make unrealistic demands on agency resources and schedules.

The responding agency should address these concerns with sensitivity to the concerns of the individual(s) requesting information, a willingness to discuss both the approach to the questions raised and the ultimate findings, and a recognition that honest dialogue with the requester is most likely to lead to a satisfactory resolution of the concerns.

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

Those who are requesting information are often seeking information to confirm an unusual burden of cancer or to 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 all start because abnormal cells grow out of control.

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, we cannot immediately assume 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 in Maryland. Cancer was the cause of death for 24% of Marylanders in 2006[1]. According to the American Cancer Society, men have a little less than 1 in 2 lifetime risk of developing some type of cancer; for women the risk is a little more than 1 in 3[2] (and this does **not** include the risk of the common squamous and basal skin cancers). This means that cancer will strike about three out of four families. At least four types of cancer are very common—cancer of the breast, prostate, lung and bronchus, and colon and rectum account for approximately 58% of all newly diagnosed cancers in Maryland[3].

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

The risk of cancer increases with age.

Age is the most important risk factor for developing cancer. About 3 out of 4 people diagnosed with cancer in the United States are age 55 years or older.[2] Therefore, a community of older adults is expected to have more cancer cases than a community with younger people or 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 smoking or other tobacco use, diet, obesity, and lack of exercise are believed to account for approximately 65% of all cancer deaths in the US[3]. Drinking alcohol, skin exposure to the sun, and exposure to certain viruses are other lifestyle factors that cause cancer.

Toxic substances in the environment account for a relatively small percentage of cancer deaths in the U.S.

Some people believe that cancer is **usually** caused by exposure to toxic substances in the environment. However, researchers believe that environmental exposures, *other than tobacco smoke*, probably 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. (ref What you need to know about cancer. NCI. NIH Publication No. 06–1566; Revised February 2005) http://www.cancer.gov/pdf/WYNTK/WYNTK_Cancer.pdf

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

Cancer is caused by both internal factors (such as inherited gene mutations, gene mutations acquired later in life, hormones, age, and immune conditions) and external factors (such as 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 mutations or exposure 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 additional cases may simply be the result of variations that occur randomly or by chance and 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
http://www.atsdr.cdc.gov/csem/cluster/index.html

- The environment presents us with 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 cancer cases. 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 multiple 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 think that their cancer is related to others with the same cancer in the workplace who still work there, 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. It may be necessary to inspect the site or check historical monitoring data; however, 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.
    - 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.

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Maryland Cancer Registry
Center for Cancer Surveillance and Control
Family Health Administration
201 West Preston Street, Room 400
Baltimore, MD 21201
410-767-4055 Fax 410-333-5218
http://www.fha.state.md.us/cancer/registry

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