

Rhabdomyosarcoma (RMS) and Cancer Cluster Overview

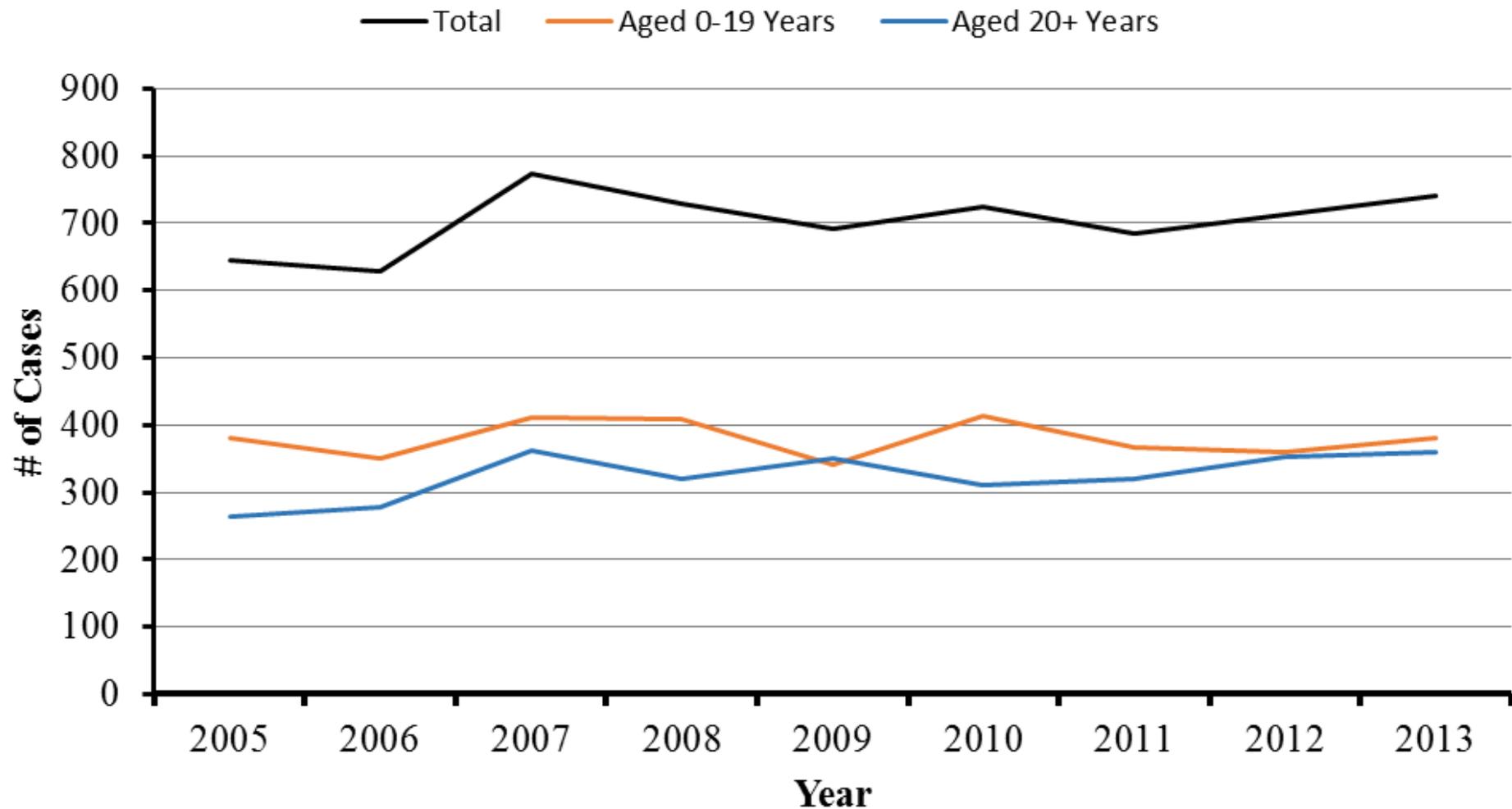
NH Dept of Health & Human Services
Governor's Task Force Seacoast meeting
September 14, 2016

Rhabdomyosarcoma (RMS)

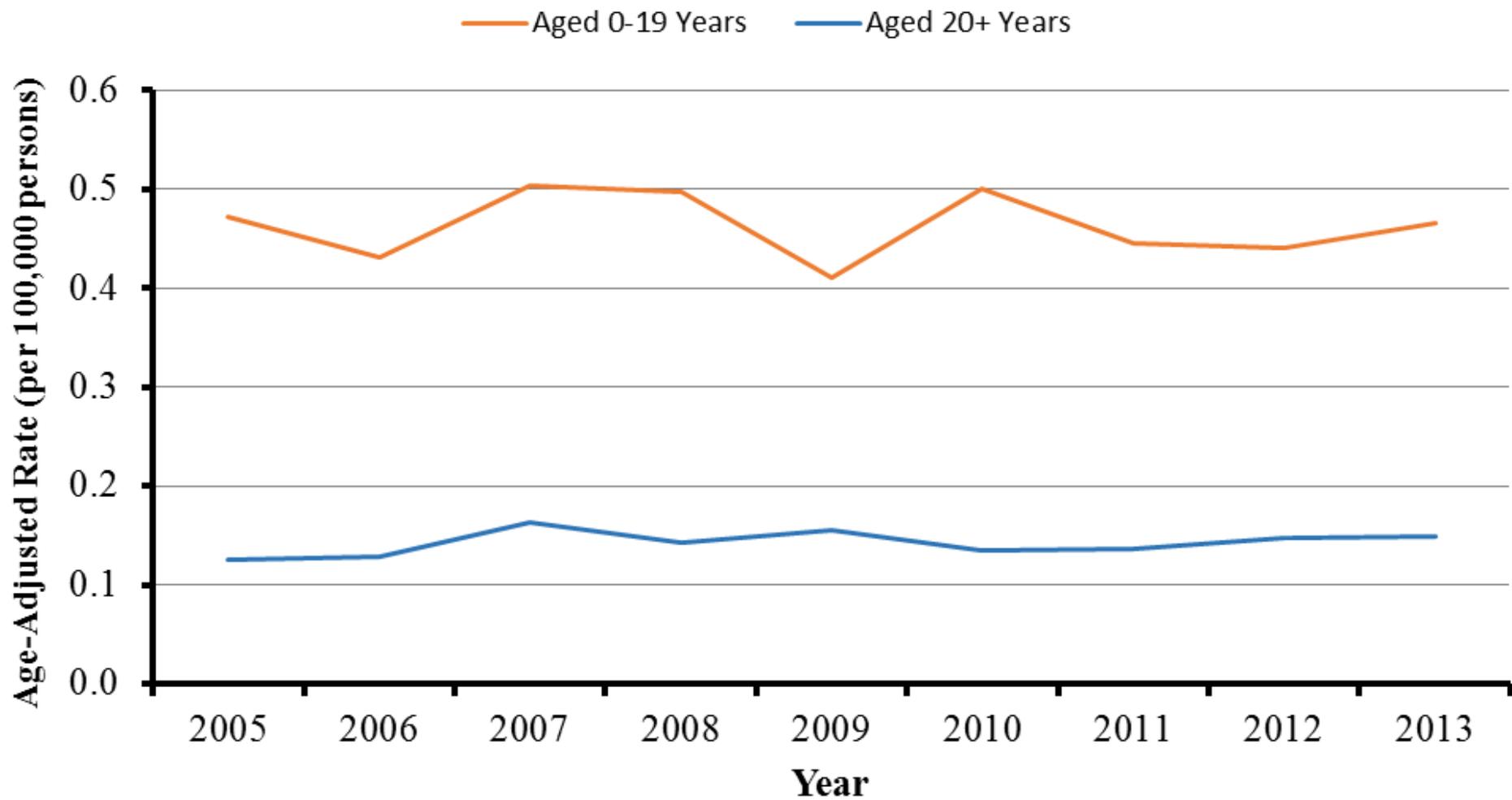
- Sarcomas are malignant tumors that arise from cells that often develop into connective tissue (fat, muscle, bone, cartilage)
- RMS is a type of soft tissue “sarcoma” of developing skeletal muscle
- Can arise in many locations of the body
 - Head and neck
 - Genitourinary system
 - Extremities

- Represent 3-4% of all pediatric cancers
- Most are sporadic without any identifiable cause
- Can be associated with familial cancer syndromes (i.e. neurofibromatosis)
- Individuals at risk for PPB because of underlying genetic conditions are also at increased risk for RMS

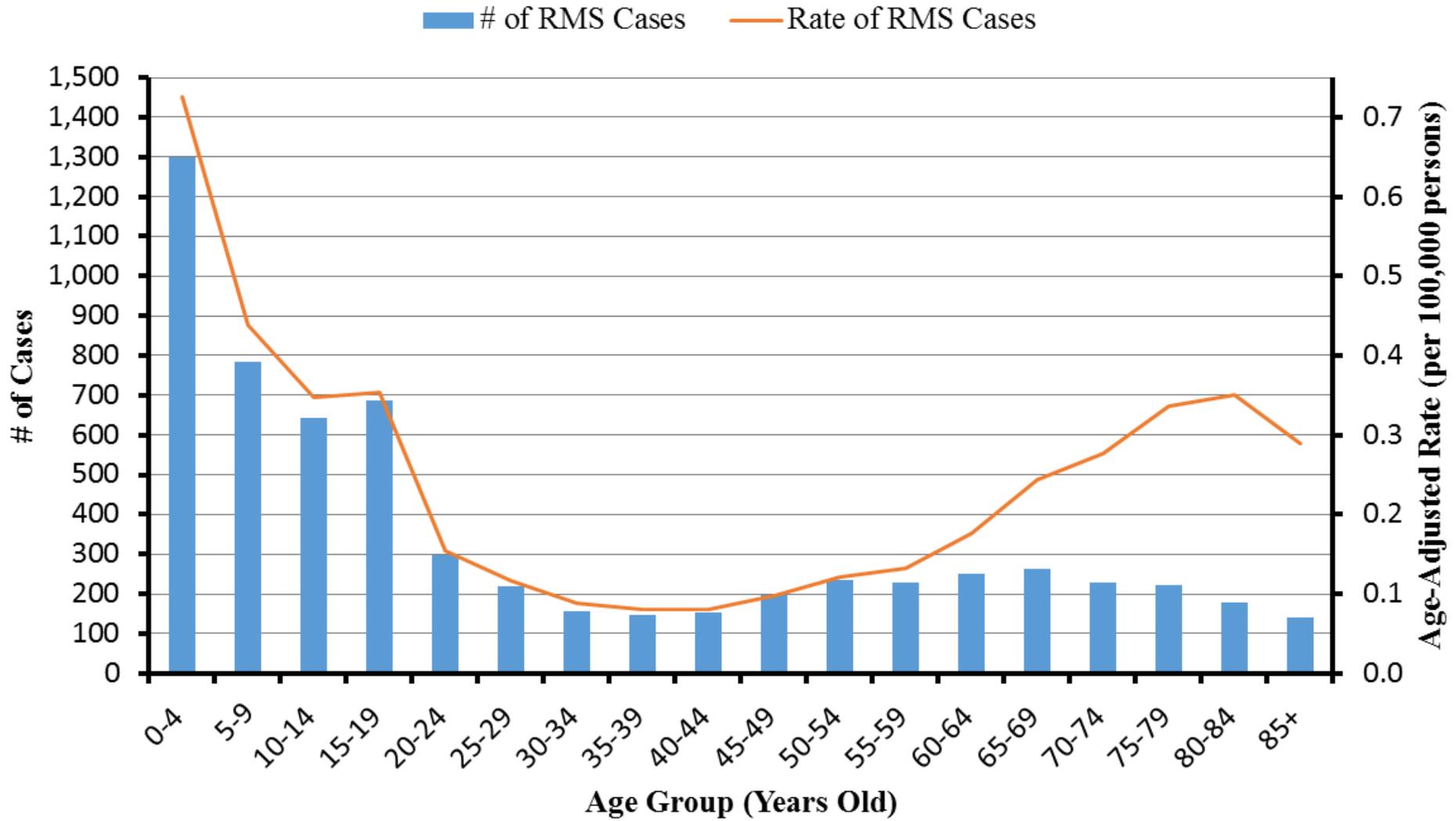
of RMS Cases by Year in the U.S.



Rate of RMS Cases by Year in the U.S.



RMS Cases by Age Group in the U.S.



RMS in the U.S. from 2005-2013

- 6332 total RMS cases
 - 54% aged 0-19 years
 - 46% aged 20+ years
- Rate of RMS:
 - Aged 0-19 years: 0.46 cases per 100,000 persons
 - Aged 20+ years: 0.14 cases per 100,000 persons

RMS in NH from 2005-2013

- 26 total RMS cases
 - 50% aged 0-19
 - Range 0-5 cases/year
 - 50% aged 20+
 - Range 0-4 cases/year
- Rate of RMS per 100,000 persons:
 - Aged 0-19 years: 0.46 (vs. 0.46 national rate)
 - Aged 20+ years: 0.15 (vs. 0.14 national rate)

Update on the Seacoast Cancer Cluster Investigation

Objectives

- Review cancer cluster criteria
- Review the DHHS protocol for responding to expressed concerns regarding potential cancer clusters
- Update on DHHS progress on RMS/PPB Cluster Investigation

What is a cancer cluster?

- Greater than expected number of observed cases than would typically be observed in a similar setting
- Of cancer cases that involve the same type of cancer or different types that science has proven have the same cause
- That occurs within a carefully defined group of people
- In a defined geographic area
- Over a period of time

What causes cancer clusters?

- Coincidental spatial clustering
- Better access to health care
- Lifestyle behaviors
- Environmental exposures

What role do chemicals play in causing cancer?

- Many people believe chemicals cause most cancers
- Research shows the role they play is small and unclear
- Some common chemicals with known links include (arsenic, asbestos, benzene, DDT, formaldehyde)

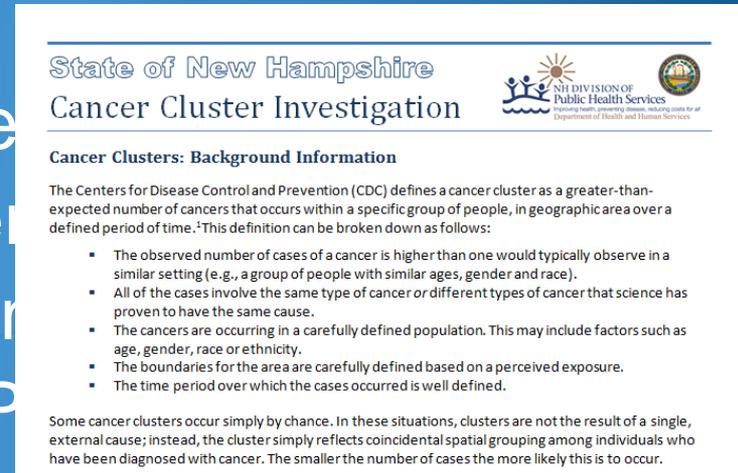
What role do environmental exposures play in causing cancer?

- Getting cancer from environmental exposures depends on:
 - The kind of exposure you come in contact with
 - How much (dose)
 - How long contact lasted (exposure)
 - How often you were exposed
 - How it entered your body (eating, drinking, breathing, touching)
 - Your health at the time of contact
- Proximity to environmental contaminants does not mean it has entered your body or will cause cancer

The protocol was developed...

Based on:

- Knowledge & Understanding
- Past Experience
- CDC Guidelines
- Review of Other Protocols



With input from:

- Division of Public Health Services staff across levels
- Department of Environmental Services staff

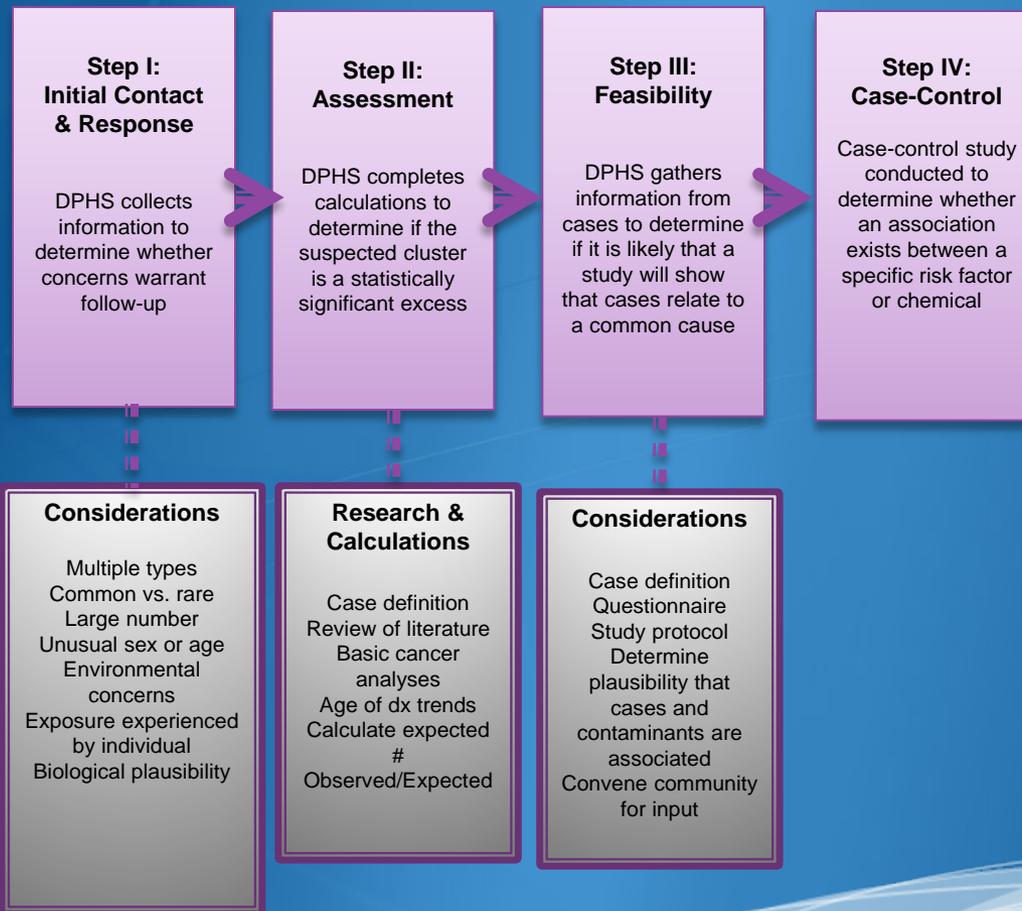




Why have a protocol?

- To protect privacy
- To set expectations about feasibility
- To mitigate fear
- To prevent emotional distress of individuals
- To prevent action to address a perceived health risk prior to taking responsible steps to assess a perceived health outcome
- To assure that concerns are responded to according to best practice

What is the Department's Cancer Cluster Investigation Process?



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RMS Investigation

Step I: Initial Response (3/14-2/15)

- Contacted by Rye residents
- Concerns about RMS cases
- Concerns about environmental exposures

Step II: Assessment (3/15-2/16)

- 5-town area (Ryes, New Castle, Portsmouth, Greenland, North Hampton)
- RMS SIR 6.0 (95% CI 1.9-18.5)
- PPB SIR 20.3 (95% CI 5.1-81)

Step III: Feasibility (2/16-present)

- Finalizing case definition
- Established Community Advisory Group (CAG)
- Developing case questionnaire
 - Review of literature on RMS and PBB
 - Review of animal studies
 - Review of known contaminants in the area
- Developing protocol for case series

RMS Investigation

Step III: Feasibility (2/16-present)

- Finalized case definition
- Established Community Advisory Group (CAG)
- Developed case questionnaire with input from national experts and the CAG
- Developed investigation protocol and reviewed with DHHS legal and reviewing with the CAG
- Requesting exemption from IRB
- Piloting case questionnaire
- Contact families who have contacted us
- Begin provider-based outreach

For More Information

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