Public Health England

Protecting and improving the nation's health

Guidance for investigating non-infectious disease clusters from potential environmental causes

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Contents

Executive summary

Clusters of diseases may be identified and reported to Local Authorities or Public Health England (PHE) by concerned citizens or health care professionals. Potential clusters may be groups of people or cases with apparent similar infections (eg flu, measles) or non-infectious diseases such as cancers, chronic diseases, congenital anomalies or unusual illnesses and other chronic diseases. Many apparent non-infectious disease clusters have no cause. In rare cases, clusters may be related to community based external sources eg common environmental exposures.

PHE routinely responds to reports of disease clusters. For infectious diseases, public health practitioners investigate outbreaks on a regular basis. This investigation follows a well-established process based on regional, national and international guidance. For non-infectious diseases (or infectious diseases without person-to-person transmission), disease specific cluster guidance has been developed for particular situations, eg Legionnaires disease, cancer clusters or congenital anomalies. Generic guidelines for non-infectious environmental hazards (NIEH) and chemical incidents were attempted some years ago through UK wide consensus working with Consultants in Communicable Diseases (CCDCs). There is now a need for up to date PHE guidance to assist practitioners and organisations involved in these investigations. This guidance is therefore proposed to help investigate any clusters of non-infectious diseases including clusters of unusual illnesses not covered by existing guidelines.

Exposures to contaminants in the environment may occur from the atmosphere, water, soil, land, or consumer products and can be physical, chemical or radiological in nature. Such environmental exposures can be the cause of sickness, ill-health and disease. Methods for linking such exposures to potential health effects are outlined. Sources of information and data that may be utilised for cluster investigations are summarised.

Similarly to existing guidelines in the United States (US) and the Netherlands, the present guidance is based on a staged approach with comprehensive steps within each stage. The stages begin with the original report of a putative cluster and continue until the final conclusion has been reached. The stepwise approach starts with Stage 1 – a screening process to make a decision on whether the report of a cluster is warrants further investigation. Stage 2 involves the assessment of both the health outcomes and exposure validation, resulting in communication on risk perceptions. Stage 3, if reached, involves an aetiological investigation with quantitative analysis of the relationship between the environmental exposure and the health outcomes. Excellent communication between all parties involved is essential at all stages.

Investigating potential clusters can be difficult and time-consuming and a systematic, integrated approach is needed for responding to such clusters. Reports of potential clusters require a public health response and often further investigation. In addition to having epidemiological and statistical investigations, it is important to understand the social dimensions of a cluster: the community's perception of risk, potential legal ramifications and the role or influence of the media. Addressing communication activities at each stage of the cluster investigation and developing and maintaining community relationships and trust will help the credibility and understanding of the investigation.

The guidance describes some resources that can be utilised to aid cluster investigations such as computer software packages, GIS and mapping. The importance of regular communication and reporting results throughout the investigation is highlighted and some examples of enquiries show the type of situations where this guidance can be used. The guidance also suggests membership of disease cluster investigation teams, and the various roles and responsibilities of such.

This draft was prepared by members of the Environmental Epidemiology Group, Centre for Radiation, Chemical and Environmental Hazards, along with colleagues in the Environmental Hazards and Emergency Department, Field Services (National Infections Service), National Cancer Registration and Analysis Service, Knowledge and Intelligence Teams (Health Improvement Directorate) of PHE, also with colleagues from the Small Area Health Statistics Unit, Imperial College London. We have consulted many experts in epidemiology, health protection, cancer statistics and cluster investigations in the drafting of this guidance.

We welcome comments and suggestions in improving this first version and the guidance, especially feedback on the practical use of implementing this guidance when exploring clusters in practice. We have developed an online survey to capture comments and feedback. Please access the survey here: https://surveys.phe.org.uk/TakeSurvey.aspx?SurveyID=llKImm420

We are looking to include more examples of real-world case studies of cluster investigations with an environmental exposure, either substantiated or not. Please also let us know of any additional useful references or grey literature that are missing. Please also feedback any comments to tony.fletcher@phe.gov.uk

Acknowledgements

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Background and justification

This guidance is proposed to help investigate all clusters of non-infectious diseases including clusters of unusual illnesses. Unusual illness is defined as an illness in which signs and symptoms do not fit any recognisable clinical picture or the illness has a known cause but is not usually expected to occur in the UK or in the setting where it was observed (PHE, 2014a,b, HPA, 2010).

Clusters of diseases may be identified and reported to Local Authorities (LA) or Public Health England (PHE) by concerned citizens or health care professionals. With regards to non-infectious diseases, potential clusters may be groups of people or cases with apparent similar cancers, chronic diseases, congenital anomalies or of unusual illnesses (MMWR, 1990). Many apparent disease clusters have no cause. In rare cases, clusters may be related to community based infections or external sources, eg common environmental exposures.

Investigating potential clusters can be difficult and time consuming and a systematic, integrated approach is needed for responding to such situations. Reports of potential clusters require a public health response. In addition to having epidemiological and statistical investigations, it is important to understand the social dimensions of a cluster (Wright and Rogers, 2014, MMWR, 1990). Investigations of potential clusters should take into account the community's perception of risk, the potential legal ramifications of reported clusters and the influence of the media. This will help in developing and maintaining critical community relationships and trust, which in turn, will help assist the cluster investigation.

PHE and previously, the Health Protection Agency (HPA), has for years responded to reports of disease clusters and prepared guidelines for public health practitioners investigating outbreaks of infectious diseases and for the investigation of unusual illness (HPA, 2010). PHE updated this guidance and it is now standard procedure for PHE Centres to follow this guidance in responding to infectious disease clusters (PHE, 2014a). Some regions also have more localised guidance that they follow, for example see PHE South East Centre's (2014b) Joint Outbreak/Incident Control Plan.

Specific cluster guidance has been developed for certain diseases, eg PHE Guidance for Legionnaires disease (PHE 2016), cancer clusters (UKIACR, 2017), and congenital anomalies (Eurocat, 2018). Generic guidelines for non-infectious environmental hazards (NIEH) and chemical incidents (Irwin, et.al.1999) were attempted some years ago through UK wide consensus

working with Consultants in Communicable Diseases (CCDCs). However, agreed PHE guidelines for investigating non-infectious disease cluster enquiries were previously unavailable. It was therefore necessary to develop guidance and operating procedures to assist practitioners and organisations involved in these investigations.

This guidance is primarily to be used where there is a suspected chemical exposure, but other exposures may also be relevant, including noise, ionizing and non-ionizing radiation. Concern about possible radiation involvement in a cluster of cancers led to the Black Report (Black, 1984) and the formation of the Committee on Medical Aspects of Radiation in the Environment (COMARE) in 1985. The first report of COMARE (1986) investigated the possible increased incidence of cancer in West Cumbria concerned with releases from Sellafield in the 1950s. The first and subsequent COMARE reports – 10th (Bridges, 2005), 11th (Elliott 2006) and 14th (Elliott 2011), focused mainly on childhood cancers and leukaemias including clusters of these conditions. These reports recommended surveillance and monitoring, and the need to develop appropriate methods for cluster analysis in relation to radiation exposure. Given the potential for very long time periods between exposure and disease occurrence (up to many decades) and that potentiality radiation-induced diseases have many causes, making a link (should one exist) can be difficult. This is also true for some chemical risks with long latency. However, this guidance document can be informative for the process of investigating possible clusters of disease in relation to any environmental exposure.

The guidance is based on a staged approach with detailed steps within each stage. The stages begin with the original contact of a report of a potential cluster and continue until the final public health conclusion has been reached. It is important to note that although the guidance contains stages, the boundaries between these stages are not fixed; stages may be combined or worked on consecutively with others. It is important to use local judgement and discretion in furthering the investigation.

Guidance for cluster investigation

Overview of guidance

Local public health authorities are responsible for leading and coordinating cluster investigations. It is expected that the local Director of Public Health (DPH) will conduct the investigation in consultation with a number of relevant stakeholders and expert collaborators. The establishment of an Incident Management Team (IMT) will need to be considered at the appropriate stage. Membership of the IMT may want to consider the appropriate cluster investigation team roles considered in Appendix A. Both the need to establish an IMT and its membership will vary from cluster to cluster and will be determined by the DPH in consultation with the Consultant in Health Protection (CHP) / CCDC in Public Health England Centres (PHECs). Appendix B contains details of suggested roles and responsibilities of the members of an IMT/cluster investigation team and Appendix C contains a real-life example of an enquiry that can trigger the need for a cluster investigation. Appendix D provides links to sources of data that could be required for a cluster investigation.

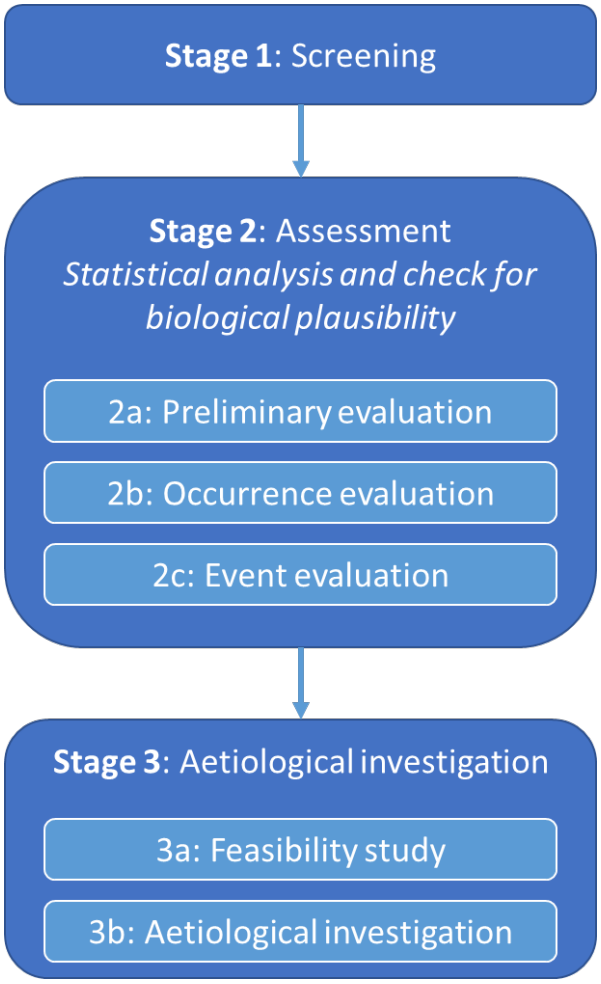
Throughout a cluster investigation it is important to consider 3 tracks. These are, **health**, **exposure** and **communication**, and to progress them in parallel. The relationship between health and exposure must be considered at all stages as well as in the communication aspects of the work (Kreis et al, 2013).

This cluster investigation guidance comprises of 3 distinct stages involving **screening**, **assessment**, and **aetiological investigation**. Screening assesses the need to investigate. Assessment involves both occurrence evaluation and event evaluation involving statistical analysis and checks for biological plausibility. Aetiological investigation can involve a feasibility study of the potential exposure response relationship. The stages are broken down as follows:

For each of the stages, the guidance provides an indication of the purpose and suggested steps and expected outcomes.

At the end of each stage, a decision must be made about whether to proceed further or not, and consideration must be given to the communication of the results of the decision to the public and interested parties.

Figure 1 (page 12) provides an overview of the cluster investigation process proposed in this guidance. In summary, the 3-stage process is as follows:



Definitions

Several definitions of **'cluster'** have been proposed. Three useful definitions are reported below:

1. A cluster is defined as 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 (MMWR, 1990).
2. A disease cluster is defined as an aggregation of relatively uncommon events in space and/or time that are believed or perceived to be greater than that could be expected by chance (PHE 2014a, HPA, 2010).
3. The European Eurocat Working Group on the Management of Clusters and Environmental Exposure Incidents (EUROCAT 2003) defined a cluster of congenital anomaly as 'an aggregation of cases of congenital anomaly in time and/or space which appears to be unusual'. In this definition, 'space' can be the place of residence, or the location used for a common activity, eg workplace.

Steps of a cluster investigation

Overview of the process – flowcharts

The process of a cluster investigation can be described as a series of data gathering and synthesis exercises, going through a stepwise methodological process examining material and reporting on findings at every stage. Figure 1 below shows the process of cluster investigation that is described in this guidance. This shows the whole process from start to the conclusion of the investigation.

Figure 2 shows the Stepwise Cluster Approach, adapted from guidance developed by the Health Council of the Netherlands (2001). This follows a linear fashion that is easy to follow and steps can be addressed in turn, starting with Step 1- establishing the facts. The initial or detailed evaluation is expanded to show that at each step both investigations into relevant exposures and disease clusters are needed. It also shows the investigation tracks of health, exposure and communication occurring in parallel.

Figure 1: Process of cluster investigation

*Communication should occur throughout the process from start to conclusion

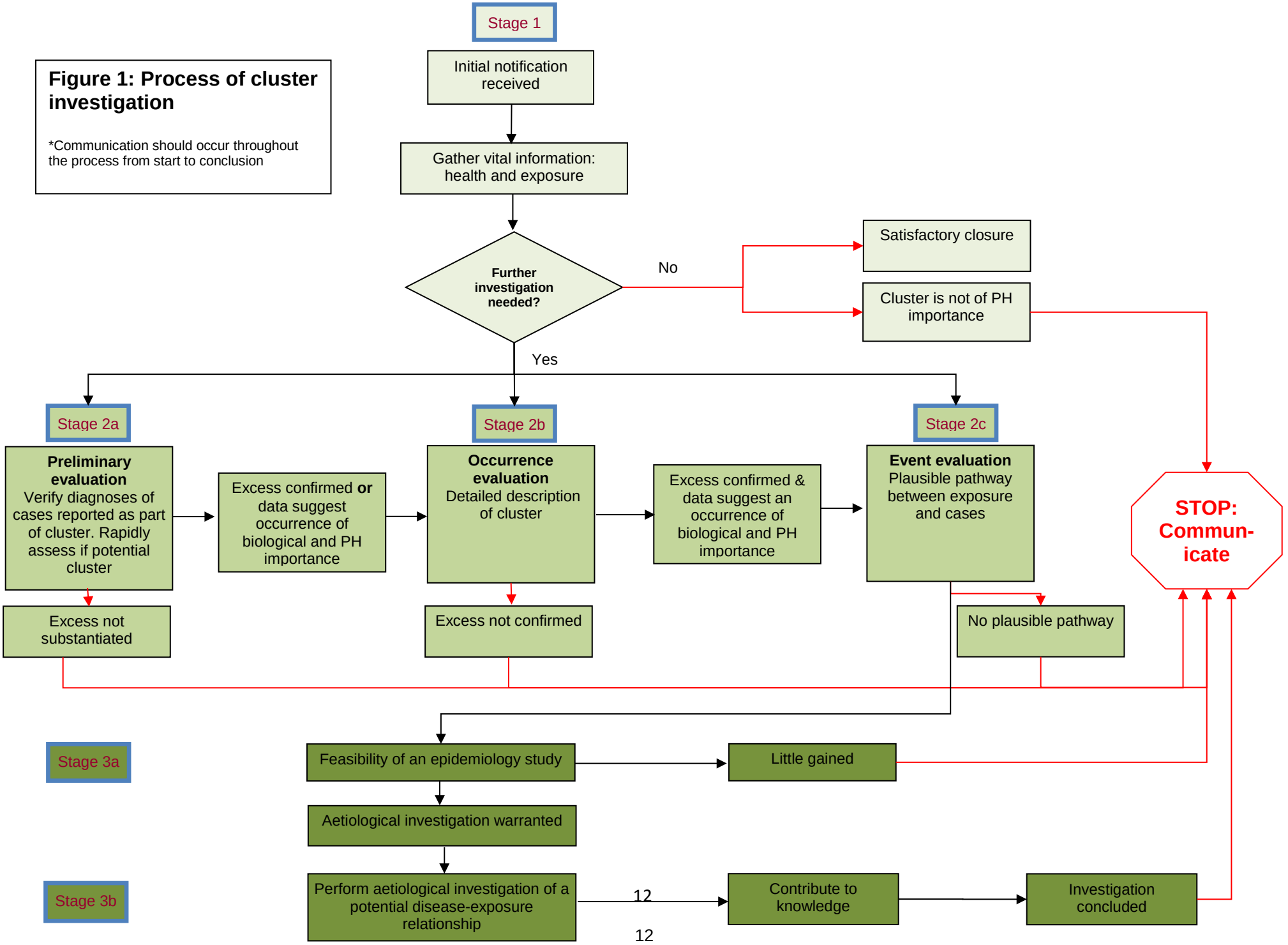
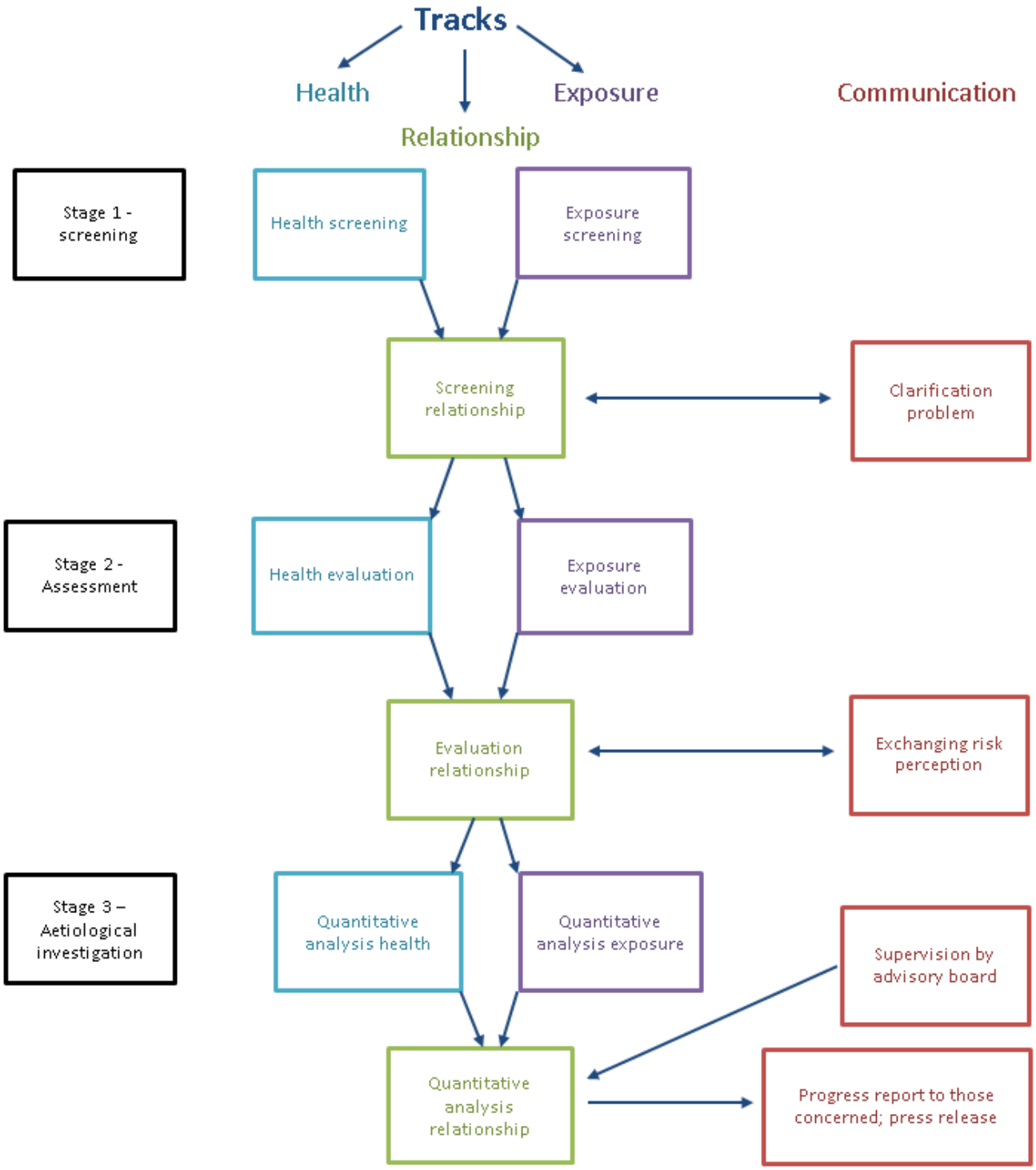
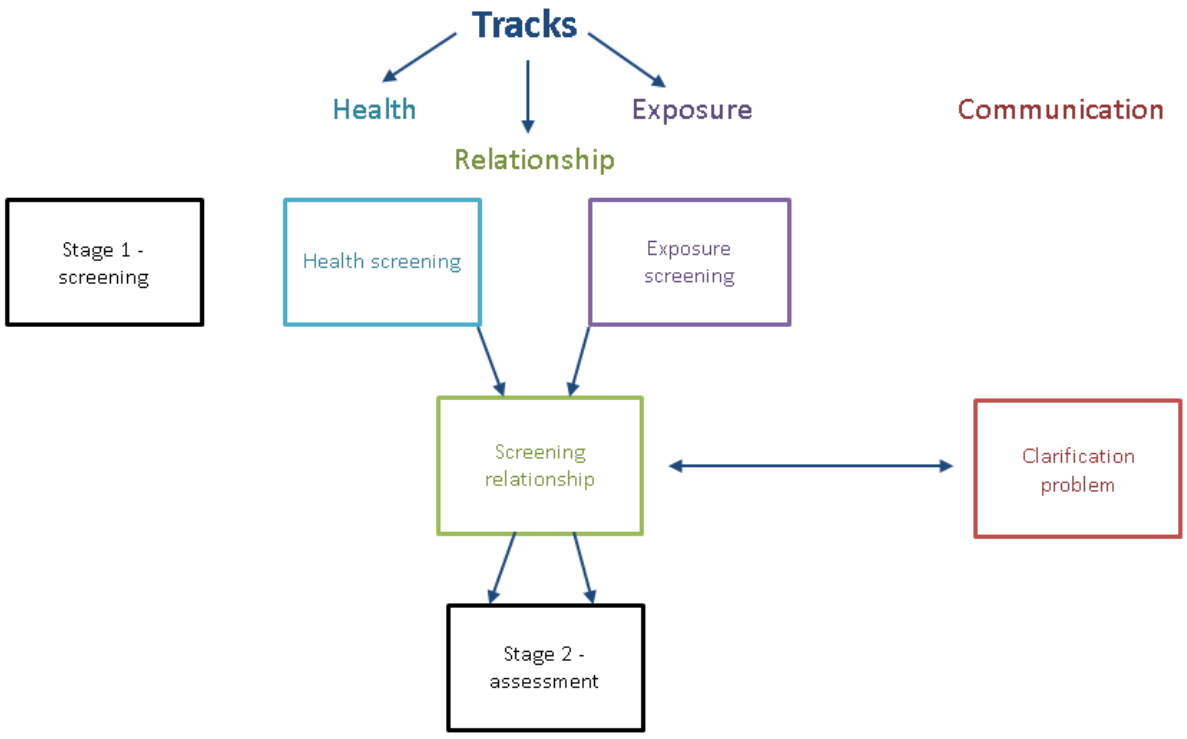


Figure 2: Overview of the staged Stepwise Cluster Approach, showing parallel tracks of health, exposure assessment and communication. Adapted from guidance developed by the Health Council of the Netherlands (2001).



Stage 1: Screening

Screening stage flowchart



Purpose

To gather vital information

To develop rapport with the person(s) who reports a possible cluster

To confirm/disprove the suspicion of a cluster

Steps

i. Gather identifying information on the enquirer, unless anonymity is requested: name, address, telephone number, email, and organization affiliation, if any. If anonymity is requested, advise the enquirer that the inability to follow up this will hinder further investigation.

ii. Gather initial data on the potential cluster: suspected health event(s), suspected exposure(s), number of cases, geographic area of concern, time period of concern, and how the caller learned about the cluster.

iii. Obtain identifying information on persons affected (if possible) or enquire about the source from where this information can be obtained: name, sex, age (or birth date, age at diagnosis, age at death), occupation, ethnic origin, diagnosis, date of diagnosis, date of death, address (or approximate geographic location), telephone number, length of time in residence at site of interest, contact person (family, friend), method for contact, and physician contact.

iv. The following need to be considered:

   a. Diseases like cancer are common. However, cancers are of different types and have different risk factors. There is a one in two lifetime probability of developing a cancer in those born after 1960 in the UK[1]. The risk increases with age, and cases among older persons are less likely to be true clusters.

   b. Major birth defects are less common than cancer but still occur in 1%-2% of live births[2].

   c. Length of time in residence is important to determine if a potential exposure may have resulted in the cluster, because of the length of time between exposure and diagnosis.

   d. Cases that occurred among persons now deceased may not be helpful in linking exposure to disease because of the lack of information on exposure and the role of possible confounding factors.

   e. Rare diseases may occasionally 'cluster' in a way that is statistically significant, but such an occurrence may be a statistical phenomenon and not of public health importance. However, it may be part of the natural history of the disease, related to as yet unrecognised or unestablished risk factors, eg leukaemia may show apparent clusters that may be related to viral illness triggers.

   f. Potential relationships can exist between cases:

      - This might be genetic. Cases may be related, in an extended family suggesting a potential for important genetic components
      - Cases might have had infections at the same time (eg mothers might all have had swine flu in pregnancy and children might develop leukaemia a few years later)
      - Or they might have similar exposures in common
      - Occupational exposures are often important.

v. Request further information on cases, obtain more complete data, and plan a follow-up email/telephone contact with the reporter of the cluster, as needed.

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[1] http://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/lifetime-risk#heading-Zero

[2] MacDonald, P.D.M (2012) Methods in Field Epidemiology, Chapter 13, Investigating non-infectious health events in Public Health Practice, p268, Jones Bartlett Learning, Massachusetts.

vi. If required, further clinical information on cases may be acquired from clinicians or appropriate registries.

vii. Follow-up telephone call or contact with the caller should be arranged.

viii. Assure the reporter that he or she will receive a written response (often, the written response (email) simply confirms what has already been communicated by telephone).

ix. Maintain a log of initial contacts, whether they are made in writing, by telephone, or in person. The log should include the date, time, caller identification, information given, health event, exposure, and geographic area. Follow-up contacts should be logged as well, with a brief note as to purpose and result. Local authority complaint/contacts databases or PHE's Health Protection Teams (HPTs) HPZone case management system, PHE CRCE's CIRIS database, or other logging system may be used for this purpose. Each organisation should record all events involving them on their own databases.

x. Make sure to have the reporter's consent before entering personal details in a database. Please ensure that ethical and personal data information rules and regulations are adhered to, such as the Data Protection Act (1998)[3], General Data Protection Regulation (2018)[4], Corporate Information Governance[5] and Caldicott guidelines.

xi. Notify the relevant communications department about the enquiry.

Outcomes

If at step 'vii/viii' results in **satisfactory closure**, i.e. both you and the reporter are satisfied that no further investigation is necessary, **STOP** further investigation, and prepare a summary report for the reporter and communicate your conclusions as appropriate to all parties involved.

If the reporter is not satisfied, but the information suggests that the cluster is not of public health importance, STOP further investigation, and prepare a report, communicate your conclusions as appropriate to all parties involved.

If from public health point of view, **further investigation** is required, **PROCEED** to stage 2a.

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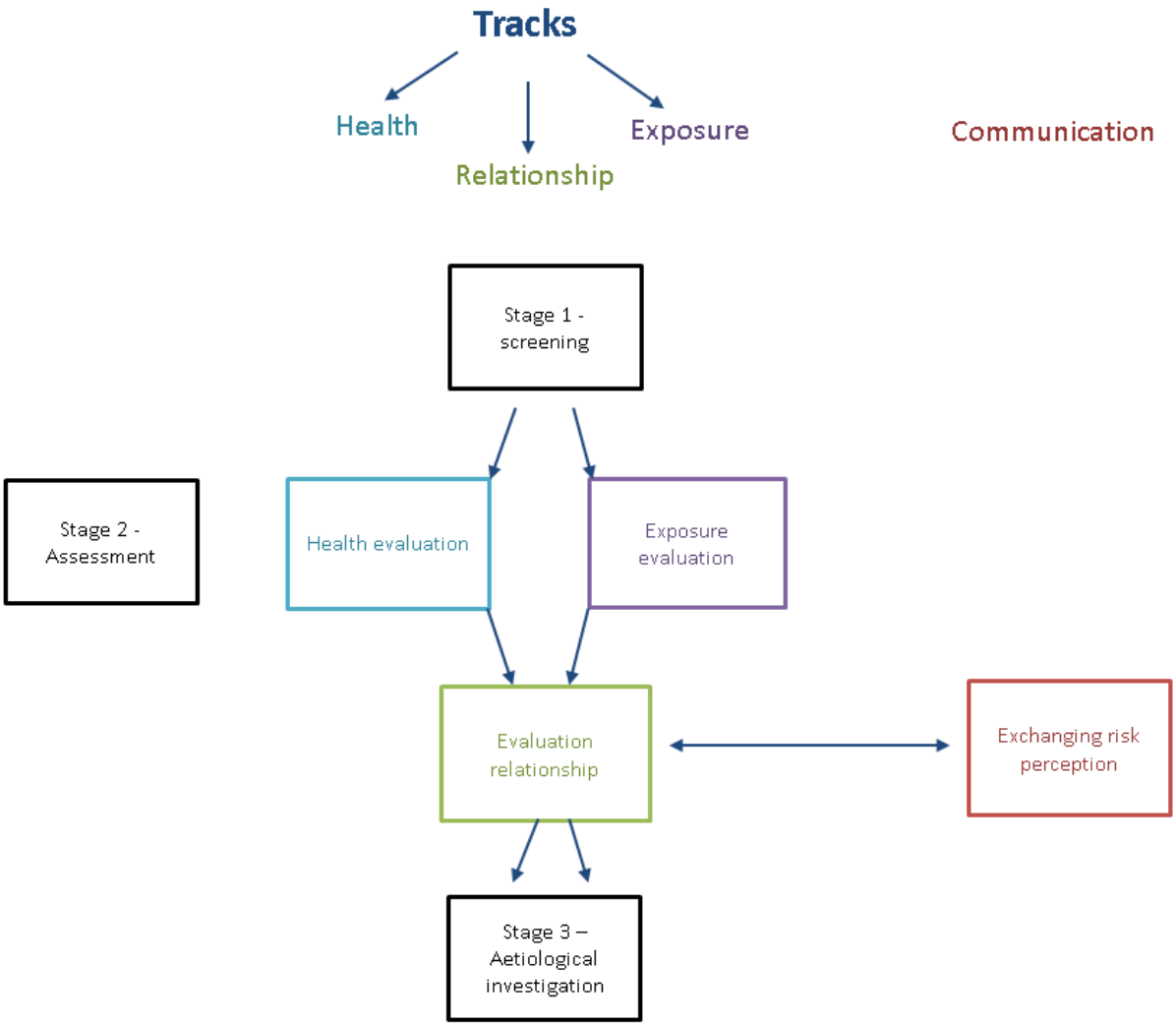
[3] https://www.legislation.gov.uk/ukpga/1998/29/contents

[4] https://www.eugdpr.org/

[5] PHE Information Governance Policy, March 2015. Available on PHEnet.

Stage 2: Assessment (statistical analysis and check for biologic plausibility)

Assessment stage flowchart



Purpose

To initiate and implement a mechanism to evaluate whether an excess has occurred (stages 2a and 2b)

To find out whether the excess can in principle be linked aetiologically to an exposure (stage 2c)

Stages 2a, 2b and 2c are often interrelated and may occur in parallel. Flexibility is required in conducting this part of the investigation and it is important to recognise that a linear approach is may not be possible.

Stage 2a: Preliminary evaluation

Purpose

To verify the diagnosis of cases reported as part of the cluster

To rapidly assess from available data whether an excess number of cases has occurred

Information from the initial contact, possibly with augmentation from other sources, is used to perform a calculation of **observed** versus **expected** occurrence. Cluster identification could be visual (through the production of maps and GIS) or through links to statistical programs such as SaTScan or through the Rapid Inquiry Facility (RIF). The RIF (see Resources section below, page 26) or SaTScan (see below, page 27), or other mapping software can be used to confirm whether there is a statistically significant excess of cases in the selected population.

Steps

i Verify the diagnoses of the cases reported during the initial contact. This may be achieved by contacting the GPs or specialist medical professionals treating patients with the medical condition, or querying disease registers.

ii Determine the appropriate space-time properties (i.e. geographic area and the time period) in which to study the cluster.

iii Prepare a case definition based on available information at hand. Case definitions can be narrow or expanded. A narrow case definition focuses on the most unusual or most coherent group of diseases reported to affect the population of concern. An expanded case definition would likely include a larger number of diseases that were each likely to be related to one another by a common cause. A case definition should include consideration of the time period in question and spatial extent (Time, Place and Person attributes).

iv Determine inclusion criteria for which cases will be included in the analysis. Some cases may need to be excluded from the analysis because they occurred outside the geographic area or the time period decided on for case definition, or because the health event for the case differs from that of other cases. A helpful step may be to tabulate frequencies of health events and examine related descriptive statistics.

v Further Information on expected number of cases may be obtained from expert bodies, such as PHE's Local Knowledge and Intelligence Service (LKIS), NHS Digital or ONS. For cancer registry data (National Cancer Registration and Analysis

Service (NCRAS)6), National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)7 contact PHE's LKIS8.

vi Determine an appropriate reference population and calculate the number of cases expected. The number of cases observed should be compared to the number of cases expected and occurrence rates (or other statistics) calculated for the cluster. This is in order to identify whether or not an excess number of cases has been identified. The reference population could be regional, national or international depending on the geographical extent of the cluster area, on the prevalence of the disease, and on data availability.

vii If the number of cases is sufficient, and if a denominator is available (eg population of a community, number of children in school, or number of employees in a workplace), calculate rates or ratios (eg occurrence rates, standardised morbidity/mortality ratios, or proportional mortality ratios). Compare the calculated statistic with that for the reference population to assess significance. Chi-square tests, z-score test and Poisson regression are commonly used techniques for comparing proportions. DsPH teams may require support from the local PHE Field Services or the PHE LKIS to undertake analysis and interpret findings.

*Although an **advisory group** can be helpful at any point in the process, it may be of particular importance at this point. The occurrence evaluation may vary considerably in size and content; consensus on the appropriate level of effort will facilitate acceptance of the results.*

Outcomes

If cases are verified and if there appears to be evidence of an **excess and the data suggest an occurrence of biological cause and the excess is of public health importance, PROCEED** to Stage 2b, which may already be under way.

If some (or all) of the cases are not verified and an **excess is not substantiated, STOP** further investigation and respond to the reporter, outlining findings and advising that further evaluation is not warranted. Communicate your conclusions as appropriate to all parties involved.

If some of the cases are **not verified** but the data suggest an occurrence of biological and public health importance, **CONSIDER INITIATING** OR **CONTINUING** to Stage 2b. A decision to proceed further at this point should not be based solely on an arbitrary criterion for statistical significance.

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[6] https://www.gov.uk/guidance/national-cancer-registration-and-analysis-service-ncras
[7] https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs
[8] https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/supporting-information/contact-us

Stage 2b: Occurrence evaluation

Purpose

To obtain a more detailed description of the cluster to determine if an excess has occurred through active case finding. To interact with the community, and to conduct descriptive epidemiology

To determine, through active case finding, if an excess has occurred

To interact with the community, and to conduct descriptive epidemiology.

The occurrence evaluation is meant to define the characteristics of the cluster, often requiring a field investigation. This evaluation begins with a **written protocol** that outlines information on data collection, the methods to be used, and the plan of analysis (including a timeline). The main product should be a detailed description of the cluster. Up to and including this stage, the need for resources is expected to be relatively small.

The disease mapping and risk analysis functionalities of the RIF may be used at this stage to help plan appropriate analysis; to provide descriptive statistics of the study area; and to map these, the populations at risk and any potential sources of exposure.

Steps

i. Identify and verify all potential cases within the defined geographic and temporal boundaries.

ii. Identify the appropriate databases for both numerator and denominator and their availability.

iii. Identify statistical and epidemiological procedures to be used in describing and analysing the data.

iv. Perform a review of the literature, (eg health literature, chemical fact sheets, toxicological assessments etc.), and consider the epidemiological and biologic plausibility of the purported association (if a suspected source has been put forward).

v. Assess the likelihood that an event-exposure relationship may be established.

vi. Assess community perceptions, reactions, and needs.

vii. Complete the proposed descriptive investigation.

*Although an **advisory group** can be helpful at any point in the process, it will be of particular importance from this point. The occurrence evaluation may vary considerably in size and content; consensus on the appropriate level of effort will facilitate acceptance of the results.*

Outcomes

If an **excess is confirmed and the data suggest an occurrence of biological and public health importance, PROCEED** to Stage 2c.

If an **excess is not confirmed, STOP** the investigation and report the findings to the reporter. Communicate your conclusions as appropriate to all parties involved.

If excess is not confirmed but data suggest an occurrence of biologic and public health importance, consider proceeding to Stage 2c.

Stage 2c: Event evaluation

Purpose

To determine whether there is a plausible pathway between a potential exposure to a known hazard and the cases.

The risk analysis features of the RIF could be used if a potential source of exposure is identified.

Steps

If an exposure to a particular hazard is suspected:

i. Ascertain potential exposure to infectious or chemical or radiological hazards
ii. Carry out a hazard identification for all hazards suspected. The following details should be considered:

    Classification of alleged hazard: toxicity (eg carcinogenic, teratogenic, mutagenic), half-life, status (eg in use or banned).

    Quantification: Potential exposure v. threshold of effect

    Plausibility: Latency period

    Feasibility: Potential pathway and distance from alleged cases in cluster

    Complexity factor: Multiple potential hazards

iii. Establish if the potential hazard identified has previously been linked to the disease.
iv. If no link has been identified, verify potential pathways from known exposure to all cases via detailed literature search and other means, potential pathways from known exposure to all cases
v. Consider the cluster as ‘unexplained’ if none of the above hazards can be plausibly suspected.

If an exposure to a particular hazard is still suspected:

vi. Carry out a literature search to consider potential aetiologies. PHE library services may help conduct this.

vii. Consult and discuss with relevant experts – CRCE, environmental epidemiology, toxicology unit, clinicians, academics, etc.

viii. Research the local environment; find out about the locality/site, discuss with the local authority Environmental Health Practitioners, research the history of the site, etc.

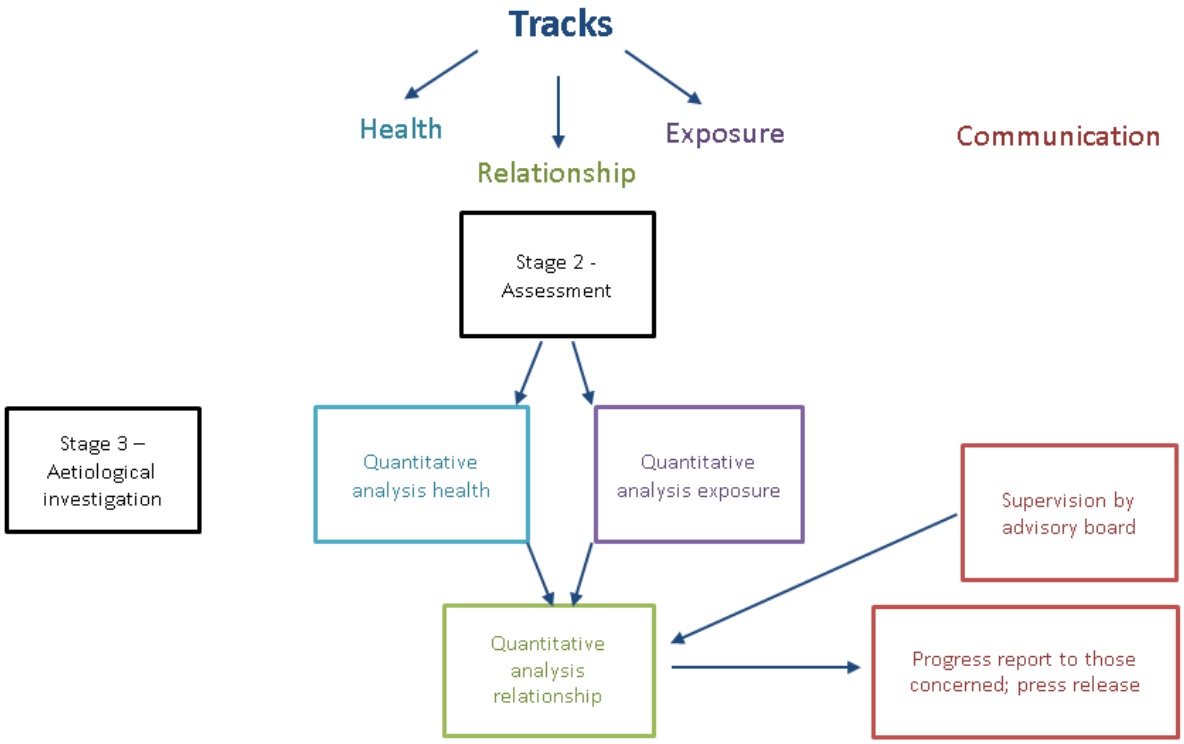
Outcomes

If there is a plausible pathway between exposure and cases, **PROCEED** to stage 3a.

If there is no plausible pathway between exposure and cases, **STOP** the investigation and report findings to the original reporter. Communicate your conclusions as appropriate to all parties involved.

Stage 3: Aetiological investigation

Aetiological investigation stage flowchart:



Stage 3a: Feasibility study

Aim

To determine the feasibility of performing an epidemiological study linking the health event and a putative exposure.

The feasibility study examines the potential for relating the cluster to some exposure(s) of concern. All of the options for geographic and temporal analysis should be considered, including the use of cases that were not part of the original cluster and are of a different geographic locality or time period. In some instances, the feasibility study may provide answers to the basic issue. For example, a national investigation of a particular type of industry could potentially help to identify a health risk and to confirm a suspected disease cluster near a specific plant. In many cases, the evidence from such investigations is often not definitive and debates about health risks may remain for long periods of time. Good communications are therefore essential.

Steps

i. Consider the public health significance of the disease, ability of an epidemiological study to provide definitive results and resources available.

ii. Review the detailed literature search with particular attention to known and putative causes of the outcome(s) of concern.

iii. Determine whether there are sufficient resources to conduct the study. **It may not be feasible for the local authority to conduct an in depth aetiological study. In such circumstances, universities or other research institutes may be an appropriate organisation to carry out the study.**

iv. Consider the appropriate study design, with attendant costs and expected outcomes of alternatives (eg, a consideration of sample size, the appropriateness of using previously identified cases, the geographic area and time period concerned, and the selection of controls).

v. Determine what data should be collected on cases and controls, including physical and laboratory measurements.

vi. Determine the nature, extent, frequency of, and the methods used for, environmental measurements.

vii. Delineate the logistics of data collection and processing.

viii. Determine the appropriate plan of analysis, including hypotheses to be tested and power to detect differences; assess the epidemiological and policy implications of alternative results. Determine the timeline for such analysis and results

ix. Assess the current social and political context, giving consideration to the impact of decisions and outcomes.

Outcomes

If the feasibility study suggests that an **aetiological investigation is warranted**, **PROCEED** to Stage 3b. The investigation may require extensive resources, however, and the decision to proceed will be related to the allocation of resources.

If the feasibility study suggests that **little will be gained from an aetiological investigation**, **STOP** the investigation and summarise the results in a report to the original reporter and all other concerned parties. In some circumstances the public or media may continue to demand further investigation regardless of cost or biological merit. Previous communication at each stage of the investigation with the affected community, relationships, media contacts, and the advisory group/committee interaction and ongoing dialogue as needed will be critical for an appropriate public health outcome.

Stage 3b: Aetiological investigation

Aim

To perform an aetiological investigation of a potential disease- exposure relationship.

In that context, this step is a standard epidemiological study; studies such as a cohort or case control study should be considered.

Cohort study
A cohort study involves identifying a cohort of individuals amongst whom an exposure of interest can be assessed; the cohort can be followed up over time to see which ones develop disease. Individuals in the cohort can be linked via identifiable characteristics to disease and mortality registries. A cohort can be applied retrospectively if good historical exposure records are available, eg occupational radiation exposure data.

Case control study
A case control study could involve obtaining exposure information retrospectively among a group of individuals that are cases and have the disease; the same information should be obtained from a group of carefully chosen individuals that do not have the disease and are controls. The data from the cases is carefully compared to the controls.

Steps

Using the feasibility study as a guide, develop a **protocol**, and implement the study.

Outcome

The results of an aetiological investigation are expected to contribute to epidemiological and public health knowledge. This contribution may take a number of forms, including the demonstration that an association does or does not exist between exposure and disease, or the confirmation of previous findings.

Resources to aid cluster investigations

Various computer packages can be utilised at different stages of the cluster investigation for analysing clusters and plotting cases on maps. Common examples are outlined below for guidance; some are only available within PHE teams, eg HPZone mapping function, others are open-source freely downloadable tools. PHE team specialists and local authority public health intelligence teams should be approached for assistance with the application of these tools.

The Imperial College (SAHSU) Rapid Inquiry Facility (RIF)

The Rapid Inquiry Facility (RIF 4.0)[9] is an open source, freely accessible application currently being developed by the Small Area Health Statistics Unit (SAHSU) at Imperial College, London. The RIF is designed to rapidly interrogate environmental, socio-economic, population and geographic data for risk assessment and disease mapping, with links to statistical software, eg for cluster evaluation. The RIF can calculate risks in relation to sources of exposure and generate maps. The RIF integrates advanced methods in statistics, exposure assessment and data visualization. It is integrated with the statistical package 'R' and RIF outputs will be easy to export offering linkage to external software for the assessment of environmental exposures, such as air and noise pollution. Users need to input relevant data; for public health analyses these are datasets such as cancer, congenital anomaly and mortality registrations that are routinely available, provided appropriate ethical and governance permissions are in place.

Once health data are loaded, the RIF 4.0 can be used to investigate potential clusters of disease by exploring spatial patterns of health outcomes and by quickly calculating mortality or morbidity rates and risks for any given condition (eg ICD10 code) for the population within defined areas relative to the population in a local reference region. This can be used to help establish if the **observed** numbers of cases in a suspected cluster are greater than would be **expected** in the population at risk or in comparison to a reference set of disease probabilities. Results can be visualised within the RIF 4.0 or investigated further using integration with R. The results can also be exported for use in other mapping or statistical software such as ArcGIS or SatScan.

The source code of the RIF 4.0 and detailed instructions (eg installations) are available on: Github: (https://github.com/smallAreaHealthStatisticsUnit/rapidInquiryFacility).

Demos and FAQs are available on: SAHSU website: (https://www.sahsu.org/content/rapid-inquiry-facility).

[9] http://www.sahsu.org/content/rapid-inquiry-facility

SaTScan

SaTScan is free software that can be downloaded and locally installed[10]. It is designed to analyse spatial, temporal and space-time data by using spatial, temporal or space-time scan statistics. It is designed to be used to:

- perform geographical surveillance of disease, to detect spatial or space-time disease clusters, and to see if they are statistically significant
- test whether a disease is randomly distributed over space, over time or over space and time
- evaluate the statistical significance of disease cluster alarms
- perform repeated time-periodic disease surveillance for early detection of disease outbreaks

Good tutorials and trial datasets are available. The programme can input commonly used data formats (line lists in MS Excel etc), and outputs can be exported into common formats, eg excel or shapefiles for GIS. Further information about the data types and methods, and examples of practice can be found on the website[12].

DotMapper

DotMapper is a 'R Shiny app' which is downloadable[11]. This means it is an open source tool available to run in 'R' statistical software for creating interactive disease point maps (Smith and Hayward (2016)).
The features of the software allow users to:

- plot locations of cases and (optionally) associated venues of interest
- plot points colour coded according to any categorical variable
- interactively display subsets of data according to multiple variables
- select points by date using slider
- display key details of individual cases or venues by clicking on points
- display summary table of key statistics
- display an epidemic curve by year, quarter, month, week or day

Dotmapper resources are available here: https://github.com/cathsmith57/DotMapper

[10] http://www.satscan.org/
[11] https://github.com/cathsmith57/DotMapper

Geographical Information Systems (GIS)

GIS can be used to plot the location of cases on a map to assess distances between cases and potential sources of exposures. Maps aid the visual interpretation of how clustered or close the cases are and the relative distance to point source locations or potential environmental sources of pollution, eg power station, landfill or power lines, etc. They can also be used to calculate the potential population exposed in an area (numerator and/or denominator).

GIS can also perform analysis of how clustered or spread out cases are, and spatial analysis modules allow statistical testing of clustering. PHE staff can access corporate GIS software (ESRI's ArcGIS) and have access to a range of GIS shapefile datasets, including administration boundaries, population datasets, locations of industries, etc, available from the GIS servers based at Porton Down. Contact gis@phe.gov.uk for help, installation and advice.

Other GIS software can also be utilised, either through licences (eg MapInfo) or freeware (eg QGIS, GRASS, R packages or Google Earth Pro). Online off-the-fly mapping functions can also be utilised through the internet, although patient confidentiality for plotting the location of cases needs to be considered.

HPZone mapping function

Within PHE, HPT's use a case management system called HPZone to record information about cases and public health interventions. HPZone has a mapping function to map the location of cases based on postcodes. However, the postcodes in HPZone are not complete and this can affect the ability to map some locations. Information or surveillance officers in HPTs can provide maps of cases logged on HPZone, which can be used to assess potential clusters. HPZone will be replaced by a custom built Case and Incident Management System (CIMS), which is expected to develop this function further. More information is available on PHEnet[12].

[12] http://phenet.phe.gov.uk/Resources/HPZone/Pages/HPZone.aspx

Reporting results and communicating risk

By following this guidance, a systematic and transparent approach to investigating clusters is suggested. It is important to follow this process so that all organisations and individuals involved, as well as members of the public, can clearly understand why the investigation has been conducted this way, the approach used, and why the investigation was terminated at what stage if appropriate.

It is important for investigators to be aware that all reports and other written communications and documents can become part of legal proceedings if required (Elliott et al, 1992, Wright and Rogers, 2014, and Drijvera and Woudenberg, 1999). Therefore it is important to keep good quality, legible records and document key discussions, decisions and key findings.

Regular risk communication and an exchange of information is important amongst all parties involved. It should be carried out early on, to establish the estimated risk (Kreis, et al, 2013) and for exchange of facts. This communication should also continue throughout all stages of the investigation. Once the investigation is at a stage where the investigator has a clear idea of the estimated risks, this should be communicated to the community in question in an appropriate manner. This must be carefully considered and conducted in a sensitive and appropriate way (Elliott, et al 1992, Wright and Rogers, 2014).

If formal meetings occur or a steering group/IMT is set up, documentation of membership of the groups, minutes of meetings and actions need to be kept and be made available and possibly published on an appropriate website.

A review of academic studies, guidelines and international government reports (Wright and Rogers in 2014) identified 4 factors which are key for effective risk communication in non-infectious disease cluster investigations:

- clear and coherent messages
- understanding of public perception of risk
- early and direct engagement with the concerns of the public
- transparent investigative procedures

The challenging task of effective risk communication of disease cluster investigations can be significantly reduced by the use of this guidance and particular **protocols** which take these points into account.

The use of technical ‘jargon’, whilst it helps to maintain accuracy and clarity among experts, should be avoided in risk communication messages to the public, as the terminology can be difficult to understand (New Zealand Ministry of Health, 1997). Risk communication should also take into account the social context in which an investigation is taking place; ensuring that the messages are clear and well suited to the affected community (Drijvera and Woudenberg, 1999). The high level of uncertainty associated with cluster investigations should be communicated early in the risk communication process, to reduce public expectations to a more realistic level (Sandman, 1991). Taking these factors into account should help clear and coherent risk communication messages. Failure to do so could see the investigation falling out of favour with the community (Wright and Rogers, 2014).

Members of the public have a different perception of risk to that of experts (Wright and Rogers, 2014). The public tend to be more influenced by qualitative assessments, based on whether or not the risk may impact their quality of life and long-term health, rather than the experts’ quantitative technical assessments of specific risks (Wright and Rogers, 2014). An understanding of the differences in perception when communicating messages would ensure that the level of real risk is communicated effectively to the affected communities.

Involving the public in the cluster investigation from an early stage is an important step to gain trust and establish a healthy relationship (Aldrich and Griffith, 1992). Trust can explain up to 50% of co-operation (Wright and Rogers, 2014) and is a vital part of effective risk communication (Rogers et al, 2007). The review also found that being transparent and open throughout the investigation is advised in the literature in order to build trust (Chess et al, 1988). Telephone hotlines, public forums, and personal meetings with the community are ways used in North Carolina’s cluster investigation protocol (Graber and Aldrich cited in Wright and Rogers, 2014), to maintain openness throughout the investigation process. Acknowledgement of emails, correspondence and information shared via websites or other online forums can help to assure that information is acknowledged, shared and freely available.

Wright and Rogers’ review (2014) recommends a proactive approach for the investigation and communication of clusters. Pearce et al. (in Wright and Rogers, 2014), suggest that due to the similarities in messages and elements of disease cluster communications, standard statements can be developed and tested with non-experts before an incident occurs. Although these messages will need to be modified for different scenarios, testing communications may identify information needs from the public and make for accurate and prompt risk communications during incidents, consequently building trust with affected communities.

The Draft WHO (2018)[13] 'Manual for investigating outbreaks of illnesses of possible chemical aetiology: Guidance for investigation and control' contains some useful templates for collecting records of enquiries regarding potential clusters, guidelines on the contents of media messages, press releases and worksheets for identifying stakeholders. This manual will be publicly available shortly.

[13] This draft is in production and not yet publicly available (Summer 2018)

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Appendices

Appendix A: Cluster investigation protocol – suggested membership of investigation teams

Each cluster investigation may have slightly different roles for the investigation teams, depending on the situation. The following members of the cluster investigation team are suggested for cluster investigations led by PHE, which have reached stage 2:

Cluster investigation team

- Project Manager: Local Authority DPH or their nominated deputy, eg Consultant in Public Health/Health Protection or CCDC
- Consultant Epidemiologist, preferably but not necessarily with experience in environmental epidemiology. PHE employs Consultant Epidemiologists in the Field Services of the National Infection Service, PHE Centres and CRCE
- Project Co-ordinator: Epidemiology Scientist, supported by Field Epidemiology Training Programme (FETP) Fellow if available
- Project administrative secretary to provide admin support.

The following may be invited and are often required:

- Exposure Assessment Department (EAD) officer, (CRCE, PHE): contribution to population exposure assessment and risk assessment if required
- Toxicologist: contribution of toxicological advice on interpretation of health impacts
- Environmental Hazards and Emergency Division (EHED) officer: contribution to risk assessment, and contribution to risk management (communication with PHEC and Local Departments of Public Health, Local Authorities etc.)
- Field Epidemiology/Health Improvement Directorate officer: (i) contribution to epidemiological and statistical analyses; (ii) contribution to risk management (communication to Regional Directors of Public Health)
- Communications officer: on all aspects concerning communications

Cluster Project Scientific Advisory Group

A Cluster Project Scientific Advisory Group could comprise of the following:

- Chair of Scientific Advisory Group: a Consultant Epidemiologist (nominated by the PHE Field Service) Secretary to Scientific Advisory Group: Head of Environmental Epidemiology Group, CRCE
- PHE CRCE officer: Scientific Officer from CRCE Environmental Epidemiology Group, supported by FETP Fellow, based at CRCE or other site
- PHE Statistics Unit (Colindale) statistician
- PHE Health Improvement Directorate officer
- Academic member 'exposure': eg Institute of Occupational Medicine or other
- Academic member 'health': eg Small Area Health Statistics Unit (SAHSU) or other

Cluster Project Stakeholder Group

A Cluster Project Stakeholder Group could comprise of the following:

- Convenor of Stakeholder group: selected from officers who are members of the 'cluster investigation team' and are part of either EAD, EHED, TOX or EPI
- Secretary to Stakeholder group: selected from officers who are members of the 'cluster investigation team' and are part of either EAD, EHED, TOX or EPI
- Member representing local PHE Centres
- Member representing Department of Health and Social Care
- Member representing other relevant Government Department
- Member representing Association of the Directors of Public Health
- Member representing Chartered Institute of Environmental Health (CIEH)
- Member representing Local Government Association (LGA)
- Member(s) representing local residents or patient associations, etc.

Other agencies

Depending on the scenario, other relevant agencies might also be involved, such as:

- Environment Agency
- National Cancer Registration and Analysis Service
- Other academic expertise
- Water companies
- Local authority departments, eg Environmental Health
- Committee on Medical Aspects of Radiation in the Environment (COMARE)
- DEFRA
- Department of Health and Social Care
- Foods Standards Agency
- Local community or patient focus groups, e.g local HealthWatch group
- Expert international bodies

Appendix B: Tool kit: Roles and responsibilities for cluster investigation team members at each stage of the investigation process

Enquiries on potential clusters could come from a wide variety of sources.

The roles and responsibilities for investigation of clusters of non-infectious disease are numerous and insufficiently well-defined in the context of the public health landscape. Therefore, it seems necessary for any guidance produced to be developed in consultation with a wide range of stakeholders both within and outside of PHE. The scope of the project may be supplemented by an additional effort to clarify proposed roles and responsibilities of each stakeholder. It may not be too onerous but would require a meeting of stakeholders to agree a process for handling of cluster investigation tasks.

The responsibility for activities such as cluster investigation lies with the Public Health Teams of Local Authorities and this makes the Director of Public Health (DPH) of the responsible LA the key decision maker in all such situations. In addition, the costs of such investigations will have to be borne by the local authority in question. It is also expected that the local DPH will conduct the investigation in consultation with a number of relevant stakeholders and expert collaborators. This appendix suggests the collaborators involved in the different stages of investigation.

PHE/Corporate Communications teams should be involved at least from stage 2 onwards, and potentially should be informed even at stage 1.

Stage 1: Screening

Individuals receiving the initial enquiry could be varied, for example received via the Public Health Teams or Director of Public Health in the Local Authority, HPT, local Public Health England Centre (PHEC), or PHE-CRCE Emergencies and Environmental Hazards Department (EHED), or via PHE Health Improvement (HI) Directorate (Knowledge and Intelligence). The screening process should be discussed with these stakeholders to help inform the decision and outcome of the screening.

Stage 2: Assessment (Statistical analysis and check for biologic plausibility)

Stage 2a: Preliminary evaluation
Determining the appropriate geographic area and time period in which to study the cluster could be decided by a local Director of Public Health or CHP, but such decision should be reached in consultation with local partners and after involvement of an environmental epidemiologist and/or other PHE staff specialising in environmental hazards and/or statistics such as the PHE Colindale Statistics and Modelling Unit. LAs should liaise with their regional PHEC in order to access these specialists.

Stage 2b: Occurrence evaluation
PHE National Cancer Registration and Analysis Service (Health Improvement) staff have considerable experience of dealing with putative cancer clusters and in many cases their involvement would be required.

Further information on the number of cases may be obtained from expert bodies, eg Small Area Health Statistics Unit (SAHSU), NCARDRS or ONS or NHS Digital. Other PHE staff such as epidemiologists and/or surveillance staff based at CRCE or NIS, Field Services, or other epidemiologists working for other agencies (eg the International Agency for Research on Cancer (IARC)), may also be involved.

The local DPH Team may choose to delegate the investigation to relevant experts. For example data on cases and local health outcomes rates could be obtained from PHE Knowledge and Intelligence teams, or local authority public health departments, and data on environmental exposures from CRCE.

Stage 2c: Event evaluation
The overall task when confronted with a statistically significant occurrence of a cluster needs expert advice from several disciplines. PHE staff may be consulted to explore, document and/or establish if there is a potential pathway from a putative hazard to the reported disease. This step is desk-based and does not require conducting a new field survey to test any hypothesis. If occurrence is not excluded, and a putative source for the cluster is identified, then the next stage in the process would require consultation and/or involvement of the following:

- exposure expert (in PHE or external, as appropriate)
- hazard expert (in PHE or external, as appropriate)
- reaching a conclusion at Stage 2c may require multi-agency liaison, eg environmental health, Environment Agency, DEFRA, NCARDRS, SAHSU, etc.

Stage 3a: Feasibility study

It is expected that a very small proportion of all cluster investigations will ever reach stage 3, as most tend to be addressed within stage 2. If Stage 2c has reached a conclusion that does not exclude a source or potential environmental cause for the cluster, the next stage is for PHE staff to plan and test the possibility that a new investigation would be required to confirm or exclude the association of a putative cause with the health endpoints reported as a cluster.

It is not necessary that PHE would conduct the investigation at this stage, as the task may be delegated to an external agency. Also, it is not necessary to conduct the investigation using routine data in areas different from the cluster (for example using small area data). Other study designs may be appropriate at this stage, or a combination of small area and field work. It would be desirable that, whoever is leading the investigation, an environmental epidemiologist and/or other relevant specialist personnel and organisations would be consulted. The specific specialist to be consulted would depend on the nature of the putative exposure.

Stage 3b: Aetiological investigation

If a scoping study investigation concluded that a new study was necessary and feasible in order to address the epidemiological question at hand, then PHE management support for this investigation is expected to be required. Once obtained, an aetiological investigation should be established, and led by a suitably qualified and experienced environmental epidemiologist, in collaboration with all relevant specialist personnel and organisations. The aetiological investigation may or may not include the geographical area where the cluster was first reported.

Appendix C: Examples of cluster investigations carried out

Response to an MP's enquiry about a possible cluster due to environmental pollution

The following is a description of a local authority's actions and responses to a real incident

Chain of events

1. A Member of Parliament (MP) emailed the health development department at the local authority (LA) about a high percentage of 'unusual' cancers in the locality. The LA checked with the Primary Care Trust (PCT) who said there was no raised rate of cancer in the village.

2. The Health Development department passed the enquiry to the LA environmental health department.

3. Environmental Health:

- superficially investigated via the internet about chemicals used in the processes alleged
- superficially found out causes of the disease
- wanted to ask HPU[14] for advice before undertaking any actions (such as interviewing MP, taking samples of water and land)
- the HPU asked PHE CRCE for help

MP emails to local authority

> Dear Sirs
>
> I wish to make enquiries into a possible health risk to people living in and around the village of <village>.
>
> It has come to my attention that there has been a high percentage of 'unusual' cancers within the population of [name of village] with a particular emphasis on leukaemia spanning 50 years (or more).
>
> Whilst I don't hold any environmental or medical qualifications, I do know about statistics and averages. From what I understand there is a very high percentage of rare cancers being reported in and around [village].
>
> My personal knowledge extends to my father-in-law who has lived his entire life in [village] and is currently fighting for his life with Leukaemia. The doctors tell me this form of cancer is not an inherited disease. However, my father-in-law lost his brother and mother to the same cancer and they both lived their entire life in [village].

[14] Health Protection Unit – at the time, now HPT

Furthermore, given the proximity to their house in [village], there has been other fatal cases of adult and childhood leukaemia and other very rare forms of cancer which some have survived and some not.

I have started some enquiries myself with residents of [village] and hope to have more information in a month or two. If the number of cancers in [village] do flag up has disproportionately high for the population and given the cancers are leukaemia and other rare forms then I have 5 possible causes so far.

1. My father in law suggests it might have something to do with the pylons.
2. Up a road (where I lived for 10 years) there is what we locals call 'The Pickle Yard'. It is where [village] estate soaked all the timber with wood preserver for many many years. I wonder if this chemical somehow got into the soil and even water supply? Since it is based on the hillside the fluid would soak down into the village. The yard was closed down a few years ago for health and safety reasons. [MP's emphasis].
3. XXXXX yard on the same hill stores scrap metal and other substances. Been there for years and years and who knows what chemicals etc have soaked into the ground. Again any pollution would work its way down the hill into the village.
4. The fields on the hill have been farmed for years and chemicals have been used etc. These chemicals could get into the water supply.
5. The army etc used [village] during the war for storage, did they leave harmful chemicals behind?

I don't wish to sound like a scare monger but 3 members of the same family to develop leukaemia who lived in the same village all their life is very rare and unusual.

Response sent by CRCE to the local HPU for dissemination

Causes and rates of cancer

There is little information provided in the MP's emails regarding the suggested cluster of cancers, although it appears that although there are at least 3 cases of leukaemia, MP is concerned about a range of different cancers, which have occurred over 50 years. Unfortunately, DH figures show that more than 250,000 people are diagnosed with cancer in England every year, and there are nearly 2 million people living with or surviving cancer today. There are many different types of cancer and each may have many different causes, whether these are due to genetic, lifestyle (such as smoking or diet) or environmental reasons (such as UV radiation). It is therefore not unusual to perceive that the rates of cancer are high and it would be very unlikely for there to be a common aetiology for a range of different cancers.

In the email trail, Health department at LA says that "My contact in public health who has been investigating unusual incidents of cancer for MP has found no evidence to suggest that the rates of cancer in [village] are unusual." If the PCT (now CCG/LA) has checked that the rates of cancer are as expected, then this can be used to reassure MP there is no cause for concern. However, I have provided some more information below with regards environmental exposure to chemicals.

Environmental exposure to chemicals

The UK has a wide and varied industrial heritage, with scrapyards and chemical works, as well as electricity pylons and agricultural land spread widely across the country. Some areas have high concentrations of industry; however it is unlikely that [village] has a significant industrial heritage. MP lists a few potential local sources of chemicals that he suggests may be the cause of the cancers, including nearby farms, a wood yard and metal scrap yard. Although these activities may use chemicals, the presence of chemicals in the environment does not always lead to exposure. Generally speaking, in order for adverse health effects to occur, a person must come into contact by breathing, eating, or drinking the substance or by skin contact. Following exposure to any chemical, the adverse health effects you may encounter depend on several factors, including the amount to which you are exposed (dose), the way you are exposed, the duration of exposure, the form of the chemical and if you were exposed to any other chemicals. It is unlikely that the

activities listed by MP, even if they had contaminated the environment, would lead to significant exposures to the residents of <village> as no exposure pathway has been established.

In consideration of the points above, it would not seem appropriate to carry out extensive environmental investigation into this issue at this stage, especially where public health investigations have indicated a lack of evidence of excess cancer rates.

Use of the Imperial College (SAHSU) Rapid Inquiry Facility

The SAHSU Rapid Inquiry Facility (RIF) was used to investigate local concerns about an apparent excess of leukaemia in the vicinity of contaminated groundwater plumes from oil refineries in 2 counties in the state of Utah, USA.

Cancer data from the Utah Cancer Registry was used in the RIF to calculate the relative risk for the potentially exposed population for lung cancer, kidney cancer, and non-Hodgkin lymphoma, during 6 consecutive 5-year time intervals (1975-2004). The RIF was also used to map the area level cancer rate in comparison to the total study area rate and the 6 consecutive 5-year analytical periods. Clusters were identified using visual inspection of the RIF maps; with further statistical testing for clusters being conducted using SaTScan. This study identified kidney and lung cancer to be statistically elevated for the potentially exposed population for one and two time periods. The menu-driven RIF was found to be simpler to use than other tools that often require programming and the authors felt that the use of the RIF disease-mapping feature enhanced the interpretation of SaTScan results.

A fuller report of the above investigation is contained in:
Ball, W et al, Comparison of Different Methods for Spatial Analysis of Cancer Data in Utah, Environ Health Perspect. *Aug 2008; 116(8): 1120–1124.*

Appendix D: Data sources

Examples of sources of data that can be used for cluster investigations.

Data	Examples	Where data is held or contacts
Cancer data	How many cases of breast cancer have there been in an area?	National Cancer Registration and Analysis Service. https://www.gov.uk/guidance/national-cancer-registration-and-analysis-service-ncras Health Improvement Directorate, PHE
Congenital abnormality data	Number of cases of gastroschisis in a ward	National Congenital Anomaly and Rare Diseases Registration Service https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs Health Improvement Directorate, PHE
PHE enquiry data on environmental incidents	Incidents related to a certain landfill or industry requiring public health advice	Chemical Incidents Reporting - CIRIS, Environmental Hazards and Emergencies Department, CRCE Duty desk: CRCE-EHE@phe.gov.uk
Population data	LSOAs, age, ethnicity	GIS team, Porton Down, PHE: gis@phe.gov.uk Census data: https://www.ons.gov.uk/census/2011census Office of National Statistics: https://www.ons.gov.uk/
Geographical boundaries	Postcodes, LSOAs	GIS team Porton Down, PHE: gis@phe.gov.uk Office of National Statistics: https://www.ons.gov.uk/methodology/geography/geographicalproducts/digitalboundaries
Environmental data – data on industrial processes	What pollutants are coming from an industry? Landfill emissions, incinerator emission data, water pollution	Environment Agency http://apps.environment-agency.gov.uk/wiyby/default.aspx
Meteorological data	Wind direction, wind speed, atmospheric dispersion effects	Meteorological Office https://www.metoffice.gov.uk/services/data-provision
Water data	Levels of chemicals in drinking water	Drinking Water Inspectorate: http://www.dwi.gov.uk/ Local authority- environmental health

Air pollution data	Levels of outdoor air pollution in an area	UK Air Quality Information Resource: https://uk-air.defra.gov.uk/
Radiation levels	Radiation levels in an area	PHE UK maps of Radon: http://www.ukradon.org/information/ukmaps Monitoring radioactivity: https://www.gov.uk/guidance/monitoring-radioactivity
Housing data	Age of houses, location of houses to landfill sites	Local authority – housing department GIS maps Housing stock age details from Valuation Office Agency: https://data.london.gov.uk/dataset/property-build-period-lsoa
Health data	Hospital Episode Statistics (HES)/ A&E records	NHS Digital: https://digital.nhs.uk/ SAHSU- http://www.sahsu.org/
	Case data- incidence and prevalence of diseases and risk factors	PHE data and analysis tools: https://www.gov.uk/guidance/phe-data-and-analysis-tools
	ONS Births and Deaths	PHE Data Lake, K&I, Health Improvement Directorate Office of National Statistics: https://www.ons.gov.uk/
	GP consultations/Real Time Syndromic Surveillance (ReSST)	ReSST team, NIS, West Midlands, syndromic.surveillance@phe.gov.uk

Glossary

CCDCs/CHP	Consultants in Communicable Disease Control/Consultants in Heath Protection
CIRIS	Chemical Incident Response and Information System, used by EHED, CRCE, PHE
CRCE	Centre for Radiation, Chemical and Environmental Hazards, PHE
DsPH/DPH	Local Authority Director(s) of Public Health
EHED	Environmental Hazards and Emergencies Department, part of CRCE, PHE
EPHT	Environmental Public Health Tracking
GIS	Geographical Information System
HI	Health Improvement Directorate, PHE
HPTs	Health Protection Teams, part of PHECs
HPZone	HPZone is the case management system used in HPTs in PHE to record details of cases, incidents and enquiries received
IMT	Incident Management Team
K&I/LKIS	PHE's Knowledge and Intelligence Service, part of HI Directorate
LA	Local Authority
NCARDRS	National Congenital Anomaly and Rare Disease Registration Service
NCRAS	National Cancer Registration and Analysis Service
NIEH	Non-infectious environmental hazards
ONS	Office for National Statistics
PH	Public health
PHE	Public Health England
PHEC	Public Health England Centre
RIF	Rapid Inquiry Facility, developed by SAHSU, Imperial College London
SaTScan	Software for the spatial, temporal, and space-time scan statistics
SAHSU	Small Area Health Statistics Unit, Imperial College, London.
UKIACR	United Kingdom and Ireland Association of Cancer Registries