

Original qualitative research

Investigating reports of cancer clusters in Canada: a qualitative study of public health communication practices and investigation procedures

Catherine E. Slavik, PhD (1,2); Niko Yiannakoulis, PhD (1)

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Abstract

Introduction: Public health officials provide an important public service responding to community concerns around cancer and often receive requests to investigate patterns of cancer incidence and communicate findings with citizens. In this study, we identified procedures Canadian public health officials followed when investigating reports of cancer clusters, and explored the challenges officials faced conducting risk communication with communities.

Methods: Thirteen interviews were administered by telephone with 15 officials across Canadian jurisdictions and analyzed using thematic analysis. A content analysis of procedural documents received from five provinces was also undertaken.

Results: A third of provinces/territories in this study did not use any consistent guidelines to investigate reports of cancer clusters, a third used their own guidelines and a third used guidelines from other countries. Each Canadian jurisdiction identified a different agency or individual responsible for investigating cluster inquiries. Officials in most interviews considered public education to be the primary objective of risk communication during an investigation. Officials in only 4 of 13 interviews cited an overall positive response from the public after investigating reports of a cancer cluster.

Conclusion: Differences in practices used to investigate suspected cancer clusters by public health officials were revealed in this work. Establishing pan-Canadian cancer cluster guidelines could improve procedural consistency across jurisdictions and offer enhanced opportunities to compare cluster responses for evaluation. A reporting system to track reported clusters may improve information sharing between federal, provincial/territorial and local investigators. During formal investigations, face-to-face participatory communication approaches should be explored to improve citizen engagement and manage community concerns.

Keywords: *space-time clustering, neoplasms, investigative techniques, guideline adherence, health communication, Canada*

Introduction

Public health officials play a vital role investigating and responding to community reports of space-time disease clustering. Although clusters of various health outcomes including birth defects,¹ neurological diseases such as multiple sclerosis,²

and cancers³ have been reported in numerous Canadian communities in recent years, cancer clusters attract an exceptional level of enduring public concern and extensive media interest for a couple of reasons. First, cancer clusters occur when a greater-than-expected number of cases of cancer occur in a group of

Highlights

- This is the first study to explore cluster investigation practices for noncommunicable diseases by public health agencies and officials across Canada.
- Analysis of policy documents revealed inconsistent procedures for investigating clusters in some jurisdictions and a lack of formal protocols and guidelines in others.
- Interviews with health officials revealed a desire for more training for face-to-face risk communication to manage citizen concerns about cancer and improve public trust during full-scale investigations.
- Establishing pan-national cancer cluster guidelines could standardize investigating procedures, enhance comparability between Canadian jurisdictions and lead to the wider-scale adoption of cluster response best practices.

individuals in a specific geographic area during a particular period of time,⁴ and despite the fact that the term “cancer” covers a multitude of diseases with numerous causes, cancer clusters tap into a common anxiety that toxic industrial exposures or environmental pollutants in a geographic location may be to blame.⁵ Second, the long latency of cancer makes it particularly challenging to investigate exposures that may no longer be present and reassure community members that their concerns will be addressed.⁶

Author references:

1. School of Earth, Environment & Society, McMaster University, Hamilton, Ontario, Canada
2. Occupational Cancer Research Centre, Ontario Health, Toronto, Ontario, Canada

Correspondence: Catherine E. Slavik, School of Earth, Environment & Society, General Sciences Building, McMaster University, 1280 Main Street West, Hamilton, ON L8S 4K1; Tel: (905) 525-9140 ext. 28611; Email: ca.slavik@gmail.com

These challenges present difficulties for public health officials communicating and engaging with a fearful and distrustful public,⁷ and are compounded by the statistical challenges officials face when investigating a small number of cases using analyses with low statistical power.⁸ Consequently, in the overwhelming majority of suspected cancer clusters, the role of chance cannot be ruled out when explaining an increase in observed cases of cancer relative to what would be expected, and in very few cases is a link to a specific cause able to be established when they are investigated.⁹

Nonetheless, responding to and investigating reports of cancer clusters remains an important practice for public health officials, who often consider this to be a way of addressing community concerns about cancer incidence¹⁰ without necessitating full-scale, resource-intensive epidemiological studies into disease etiology. Investigating reports of cancer clusters has also been seen as a way to educate citizens on cancer risk factors and known carcinogenic exposures;¹¹ therefore, it continues to be a public service regularly undertaken by public health agencies and officials in Canada and all over the world.¹²

As health officials are not typically able to establish the true presence of a cancer cluster, either because excess cases have not been confirmed or an etiological linkage to an exposure is not possible, very few investigations into a community's reports of a cluster trigger a full-scale epidemiological study. Still, the process of investigating cancer complaints can provide reassurance to citizens and an opportunity to educate the public, if certain best practices are adopted by public health officials in responding to the community's inquiries about cancer. Indeed, Trumbo noted that although very few of the thousands of cancer cluster complaints in the US end up leading to significant investigations, the interactions with community members that take place during the initial response process provide an opportunity for meaningful public education about cancer.¹²

Cluster response best practices, including incorporating effective risk communication at all stages and supplying concerned citizens with adequate information, are viewed as essential in fostering accurate perceptions of risk.¹³ In addition, transparency

and open communication around cancer cluster investigation procedures have been shown to be important in promoting beliefs around procedural fairness, which in turn increases citizen satisfaction with the results of full-scale investigations and trust in authorities.¹⁴ Furthermore, confusion around the methodologies used to investigate reported clusters and perceived flaws in the investigation procedure can influence beliefs around expert competency and credibility.¹⁵ For these reasons, the United States and other nations have developed guidelines for investigating cancer cluster inquiries to provide public health officials with a systematic methodology for their analysis and to guide their response to citizen concerns.¹⁶⁻¹⁸

Researchers have twice studied the state of cancer cluster investigations in the US, once in the 1990s¹⁹ and most recently a decade ago,⁹ and each time recommended changes to investigation approaches and priorities. In the absence of national guidelines for investigating reports of cancer clusters in Canada, it is not currently known what cancer cluster investigation procedures are used by public health officials across Canadian jurisdictions.

In this study, we aimed to examine the experiences of public health officials who have investigated suspected cancer clusters, particularly with respect to their approaches to responding to inquiries and communicating the results of investigations and the risk of cancer. Although provincial and territorial jurisdictions are responsible for the provision of most services related to health, there exist considerable divergences in the administration and organization of public health policies and practices between the various Canadian provinces and territories due to their local population and geographic characteristics. Some employ a regionalized approach for the delivery of public health programs and services, while others have opted for a top-down, centralized approach.²⁰ Therefore, we hypothesized that the primary agencies and officials responsible for investigating reports of cancer clusters would vary significantly across Canada.

Methods

Ethics approval

Ethics approval for this research was obtained from McMaster University's McMaster Research Ethics Board in the summer of 2019 (MREB#: 1763).

Interviews

The participants selected for interviews for this research project were public health officials from various Canadian jurisdictions who either had had experience investigating reports of a cancer cluster in a community or who would be tasked with investigating should a cancer cluster inquiry arise. Between the fall of 2019 and summer of 2020, a total of 13 telephone interviews were conducted and recorded with 15 public health officials across Canada (two interviews had two participants present). The average interview length was 45 minutes (range: 30–65 min).

Key informants to interview for this project were identified using two approaches to achieve representation from most Canadian provinces and one territory. In jurisdictions where the authors had no prior connections or knowledge of suspected cancer cluster investigations, an email was sent to the province's primary health ministry (or public health agency) through their general inquiry web page to receive the contact information for public health officials responsible for investigating. In other jurisdictions where documented or known suspected cancer clusters had been investigated, the authors contacted the lead public health official in charge of investigating directly according to publicly available reports or news articles.

Interviews were semi-structured and carried out by one researcher (CS). Interviewees received the questions prior to the interview. Questions covered four broad topics: the interviewee's jurisdiction's cancer cluster investigation methodologies, the outcomes of the investigations, the challenges public health officials encountered with risk communication, and communication approaches and goals. This research followed a constructivist framework whereby the data gathered from interviews are recognized as personally and socially constructed knowledge reflective of the participants' individual contexts, while the researchers' interpretation of this data is merely an attempt to elucidate the participants' particular realities.²¹

Analysis

Thematic analysis

Interviews were transcribed using Otter, a speech-to-text transcription software (Otter.ai, Los Altos, CA, USA), with occasional

corrections to words transcribed manually by one researcher (CS) to remedy errors in the automatic transcription process. Transcripts were read several times and a thematic analysis of the interview transcripts was carried out using NVivo 12 (QSR International [Americas] Inc., Burlington, MA, USA). Thematic analyses are a common qualitative analytic method to help identify themes from an extensive set of text-based data.

This study used a semantic approach to analyze participant responses; therefore, responses were analyzed as they were recorded in the interviews.²² One researcher (CS) coded text segments in each interview transcript and categorized codes into common themes that emerged for each question posed to participants to allow for comparisons across interviews. These codes were discussed with the secondary researcher (NY) to assess how well the identified themes related to the research questions of this study and their relation to the dataset. The coding process followed an inductive approach,²³ whereby dominant themes in the data were used to summarize general similarities and differences in investigative practices across Canadian jurisdictions.

Content analysis

In addition to the interview data collected, some officials shared documents summarizing the cancer cluster investigation guidelines or practices used in their jurisdiction. A content analysis of these documents was undertaken using the same coding framework that was used for the interview transcripts to supplement the information that was not already captured in the interviews. The coded themes identified in the thematic analysis of the interview transcripts and the content analysis of the procedural documents were organized and analyzed in an electronic spreadsheet.

Results

Thirteen interviews were conducted with 15 public health officials whose expertise on investigating reports of cancer clusters spanned 7 out of 10 Canadian provinces and one out of three Canadian territories. Additionally, one interview was conducted with a public health official who had investigated a confirmed cancer cluster in a northern Canadian territory while employed under the federal Canadian Public Health Agency's field epidemiology

program, which occasionally deploys epidemiologists to investigate cancer clusters when a provincial or territorial government requests assistance. Four interviews were conducted with participants who had investigated reports of cancer clusters in Ontario, two in Manitoba and one each in Alberta, British Columbia, Saskatchewan, Quebec, New Brunswick, Northwest Territories and in Canada investigated by federal officials.

The job titles of the participants interviewed for this research varied: five were senior epidemiologists at a public health department or agency; five were medical officers of health or chief medical officers at a municipal, regional, provincial or territorial level; four held senior management roles in cancer data analytics departments at a public health agency; and one was a specialist in environmental health at a local public health department. The findings from this study are summarized according to three main themes: investigation procedures, investigation characteristics and communication approaches.

Investigation procedures for responding to reports of cancer clusters

Investigation procedures into suspected cancer clusters by Canadian jurisdiction are summarized in Table 1. Three out of nine jurisdictions (New Brunswick, Northwest Territories and Canada) did not strictly adhere to any one protocol and did not design their own guidelines for investigating reports of cancer clusters. Another three out of nine jurisdictions (British Columbia, Alberta and Manitoba) had each produced their own procedural guidelines to use for investigating reports of cancer clusters. In two jurisdictions, Ontario and Quebec, cluster investigation guidelines from other nations (the US Centers for Disease Control and Prevention [CDC] and France's National Public Health Agency) served as the primary guidance that officials consulted in those provinces to investigate suspected cancer clusters. In Saskatchewan, a procedural document authored by the lead investigating agency was not shared with the researchers and could not be analyzed as part of this study; however, the interviewee there described guidelines that were based largely on those authored by the US CDC.

Of the jurisdictions that shared procedural documents ($n = 5$), three (Ontario, British

Columbia and Quebec) followed a four-step investigation procedure, while the remaining two (Alberta and Manitoba) followed three- and five-step procedures, respectively. All five procedural documents described a primary evaluation stage in which investigators collected information from inquirers about the reported clustering of cancer cases in order to assess the scope of the investigation required. According to the participants we interviewed, most community cancer cluster inquiries do not meet established plausibility criteria based on the information collected about the type(s) and number of cancer cases reported, the geographic boundaries, the timing of diagnoses and any community risk factors; therefore, further assessment (i.e. case evaluation and incidence evaluation using data from a cancer registry) as part of a larger-scale investigation are not typically pursued. Only four jurisdictions followed guidelines that explicitly referenced risk communication in their procedures and of these four, three included risk communication at every step of their investigation.

Interviewees from each jurisdiction described a different lead investigating agency or individual responsible for responding to cancer cluster inquiries. The lead agencies included local, regional and territorial public health departments or agencies (Ontario, Quebec, Northwest Territories) and cancer-specific agencies or departments (British Columbia, Saskatchewan and New Brunswick). In Manitoba, however, the medical officer of health from the regional health authority where the inquiry originated assumes primary responsibility over investigating the complaint, with support from provincial agencies. In Alberta's guidelines, a lead investigating agency or individual is not specified. The procedures there suggest that the initial agency contacted by the citizen may remain involved in either a lead or liaison role while investigating the reported cluster, which is in contrast to the procedures followed in the other eight jurisdictions that have identified one main lead agency or individual in charge.

Investigation characteristics of suspected cancer clusters

Characteristics of the investigations into suspected cancer clusters carried out by the public health officials interviewed for this work are summarized in Table 2. Nearly all officials stated that local

TABLE 1
Characteristics of investigation procedures into suspected cancer clusters and methodologies by Canadian jurisdiction (n = 9)

| Jurisdiction | Lead investigating agency | Other agencies and actors that may be involved in the investigation | Document type consulted | Year produced | Procedural authoring agency | Other guidelines referenced in procedures | Steps defined as part of the procedure | Risk communication included in procedure |
|------------------|--|--|-------------------------|---------------|---|--|---|--|
| Ontario | Local public health department | Provincial public health agency; provincial cancer agency; provincial ministry of environment; provincial ministry of labour | Guideline | 2013 | US CDC | None | 1. Initial contact and response 2. Assessment 3. Determining feasibility of conducting an epidemiological study 4. Conducting an epidemiological investigation | Yes—at every stage |
| British Columbia | Cancer control and research department of provincial cancer agency | Local medical health officer; provincial ministry of health; regional First Nations Health Authority | Guideline | 1998 | British Columbia Cancer Agency | None | 1. Initial contact and response 2. Assessment and case evaluation 3. Determine feasibility of epidemiological study 4. Etiological investigation | No |
| Alberta | Not defined—guidelines state the lead may be whichever initial agency was contacted, the regional Medical Officer of Health, the cancer surveillance department at Alberta Health Services or the surveillance unit of Alberta Health and Wellness | Provincial authority for health service delivery; provincial ministry of health; regional Medical Officer of Health; federal health ministry (for on-reserve investigations) | Guideline | 2011 | Alberta Health and Wellness; Alberta Health Services | US CDC; New Zealand; Europe | 1. Primary evaluation and collection of data from requestor 2. Secondary evaluation and assessment of cases for further action 3. Tertiary evaluation involving ongoing surveillance or etiological investigation | Yes—at every stage |
| Quebec | Regional public health agency | Provincial public health agency; local health or public health professionals; provincial cancer registry; expert advisory committee consisting of medical and public health professionals and toxicologists; provincial ministry of environment; provincial ministry of labour | Guideline | 2005 | Institut de veille sanitaire (France), now part of the Agence nationale de santé publique | Laval University; US CDC; Netherlands; New Zealand | 1. Evaluation of reported cases 2. Validation of cases and environmental exposure 3. In-depth descriptive study 4. Additional epidemiological work | Yes—at every stage |

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TABLE 1 (continued)
Characteristics of investigation procedures into suspected cancer clusters and methodologies by Canadian jurisdiction (n = 9)

| Jurisdiction | Lead investigating agency | Other agencies and actors that may be involved in the investigation | Document type consulted | Year produced | Procedural authoring agency | Other guidelines referenced in procedures | Steps defined as part of the procedure | Risk communication included in procedure |
|-----------------------|---|--|---|---------------|-----------------------------|---|--|--|
| Manitoba | Medical officer of health from the regional health authority | Provincial cancer agency; provincial cancer registry; provincial ministry of health; provincial ministry of labour | Guideline | 2015 | Regional health authority | US CDC; Alberta guidelines | 1. Primary evaluation and information intake 2. Primary evaluation and assessment of information 3. Secondary evaluation and analysis of data 4. Determine feasibility of epidemiological study 5. Conduct epidemiological study | Yes—at some stages |
| Saskatchewan | Provincial cancer agency | Regional medical health officer; provincial health authority; provincial ministry of health; provincial ministry of labour | Unknown | Early 2000s | Saskatchewan Cancer Agency | US CDC | NA | NA |
| New Brunswick | Cancer department of provincial ministry of health and/or Office of the Chief Medical Officer of Health | Provincial department of environment; communications branch at the provincial department of health; analytics branch at the provincial department of health; regional medical health officer | No formal protocol or guideline strictly followed | NA | NA | US CDC | NA | NA |
| Northwest Territories | Territorial Department of Health and Social Services | Academic researchers and/or expert scientists from other provinces; PHAC field epidemiologist; local clinician | No formal protocol or guideline strictly followed | NA | NA | US CDC; Alberta guidelines | NA | NA |
| Canada | PHAC's Canadian Field Epidemiology Program | Provincial or territorial ministry of health; chief medical health officer from province or territory; provincial, territorial, regional and/or local health authority | No formal protocol or guideline strictly followed | NA | NA | US CDC | NA | NA |

Abbreviations: NA, not available; PHAC, Public Health Agency of Canada; US CDC, United States Centers for Disease Control and Prevention.

TABLE 2
Characteristics of suspected cancer cluster investigations, by interview with Canadian public health officials (n = 13)

| Interview | Jurisdiction | How suspected cancer clusters were reported | Frequency of reports | Environmental or occupational hazards suspected | Involvement of officials trained in risk communication | Perceived public satisfaction with response to report of cluster | Need for ongoing outreach or monitoring after investigation |
|-----------|------------------|--|----------------------|---|--|--|---|
| 1 | Ontario | Citizen reported to local public health department | Less than annual | Yes | Yes | Generally positive | No |
| 2 | Ontario | Citizen reported to local public health department; employer reported to local medical officer of health | Less than annual | Yes | Yes | Positive and negative | No |
| 3 | Ontario | Citizen reported to local public health department; employer reported to local medical officer of health | Less than annual | Yes | Yes—through other government agencies or departments | Positive and negative | No |
| 4 | Ontario | Citizen reported to local public health department | Less than annual | Yes | Yes—through other government agencies or departments | Generally negative | Yes |
| 5 | Manitoba | Health care professional reported to provincial cancer agency; employer reported to provincial cancer agency; First Nations community reported to regional medical officer of health | Annual | Yes | No or not known | Generally positive | No |
| 6 | Manitoba | Citizen reported to regional medical officer of health | Annual | Yes | No or not known | Positive and negative | No |
| 7 | Alberta | Citizen reported to provincial authority for health service delivery; citizen reported to regional medical officer of health; health care professional reported to provincial ministry of health; provincial authority for health service delivery reported to provincial ministry of health; employer reported to provincial ministry of health | Annual | Yes | Yes—through other government agencies or departments | Positive and negative | Yes |
| 8 | British Columbia | Citizen reported through online form to provincial cancer agency; citizen reported to provincial ministry of health; citizen reported to regional medical officer of health | Annual | Yes | No or not known | Positive and negative | No |

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TABLE 2 (continued)
Characteristics of suspected cancer cluster investigations, by interview with Canadian public health officials (n = 13)

| Interview | Jurisdiction | How suspected cancer clusters were reported | Frequency of reports | Environmental or occupational hazards suspected | Involvement of officials trained in risk communication | Perceived public satisfaction with response to report of cluster | Need for ongoing outreach or monitoring after investigation |
|-----------|----------------------------|--|---|---|--|--|---|
| 9 | Saskatchewan | Citizen reported to regional medical officer of health; citizen reported to health care professional | Annual | Yes | Yes—through other government agencies or departments | Generally positive | No |
| 10 | Quebec | Health care professional reported to regional public health agency; employer reported to regional public health agency | Less than annual | Yes | Yes | Generally negative | Yes |
| 11 | New Brunswick ^a | Citizen requested information; health care professionals requested information; news media requested information | Never; respond to general requests for information on cancer on an annual basis | No | No or not known | N/A | N/A |
| 12 | Northwest Territories | Citizen reported to local health authorities; local clinician reported to territorial ministry of health; cluster discovered during routine surveillance of cancer data by territorial health ministry | Less than annual | Yes | Yes—through nongovernmental organizations | Positive and negative | Yes |
| 13 | Canada | Provincial or territorial or regional lead of investigating agency reported to PHAC | Less than annual | Yes | No or not known | Generally positive | Yes |

Abbreviations: N/A, not applicable; PHAC, Public Health Agency of Canada.

^a Investigators noted they had never launched an investigation and had never taken action beyond responding to a citizen's concerns about cancer with public education.

citizens brought forward the majority of inquiries surrounding cancer clusters due to concerns about local cancer cases. However, an official interviewed in one province, Quebec, identified clinicians and employers as the most frequent initiators of cancer cluster reports. All officials had been involved in the large-scale investigation of at least one suspected cancer cluster in their province or territory over the course of their career. In five interviews, officials stated they received requests to investigate reports of cancer clusters on an annual basis, whereas in seven interviews, officials reported that they received requests less frequently. Officials interviewed in one province, New Brunswick, had never received a report of a cancer cluster but had frequently responded to more general inquiries about cancer rates from the public and other stakeholders that were not necessarily tied to a specific geographic location or timeline.

All officials interviewed confirmed that environmental or occupational exposures were suspected and assessed in at least one of the reported cancer clusters they had investigated. In five interviews, officials stated they either did not have staff trained in risk communication or were not aware of any such training. In three interviews, officials stated they had direct access to staff with risk communication training, while in five interviews, officials stated they had occasional access to this expertise through other governmental or nongovernmental agencies. Officials in four interviews perceived an overall positive response from the public after responding to reports of a cancer cluster, while in eight others, officials perceived either a mostly negative response or a mix of positive and negative responses from the public. In five interviews, officials cited the need for ongoing community outreach after they finished investigating a suspected cancer cluster because either the community had requested further monitoring of cancer incidence rates or public health officials were gathering more data to observe trends.

Communication approaches

The primary themes that emerged from our interviews with Canadian public health officials regarding communication approaches and challenges encountered while investigating reports of cancer clusters are summarized in Table 3. Officials

in eight interviews stated that the main messages communicated during and after investigating a suspected cancer cluster consisted of explanations of the difference between observed versus expected cancer incidence rates and explaining various risk factors that are associated with increased rates of cancer (e.g. sun exposure, smoking, etc.). Officials in three interviews also discussed communicating with citizens why their agency was or was not pursuing further action investigating the report of a cancer cluster as a primary theme.

All officials interviewed identified the local community members and other government agencies as key stakeholders to communicate with about the progress of an investigation; however, there was less agreement about the importance of communicating with other stakeholders. In just over half of the interviews, officials identified local elected officials (e.g. city councillors, members of parliament, etc.) as key communication stakeholders, whereas the news media, employers and nongovernmental organizations were identified less frequently (in 23%, 23% and 8% of interviews, respectively).

In most interviews, officials perceived the biggest challenges with communicating risk to citizens to be as a result of the complexity of information related to statistics and cancer rates (77%), due to issues addressing public perceptions of cancer risk (77%) and due to difficulties with crafting effective messages on risk (70%). Another challenge to communicating risk effectively identified in three interviews included language barriers and special cultural considerations when communicating with citizens whose mother tongue was not one of Canada's two official languages (i.e. English and French) or with recent immigrants to Canada. In most interviews, officials saw the main purpose of conducting risk communication while investigating a suspected cancer cluster as a way to educate the public on cancer (85%). Other goals of risk communication identified less frequently in the interviews included promoting changes to health behaviours (38%), addressing public concerns (38%) and improving public perceptions of government transparency (23%).

When discussing specific approaches to disseminating information and communicating results with stakeholders after a

suspected cancer cluster had been investigated, officials discussed the use of printed text documents (e.g. reports, brochures) and face-to-face interactions with community members (e.g. town halls, one-on-one meetings) as the most common formats of information sharing (85% and 77%, respectively). In cases where the suspected cancer cluster was addressed with a response at an early stage of the process without necessarily requiring the launch of a large-scale investigation, officials in most interviews stated that telephone or email correspondence with the individual(s) raising the concern was carried out (70%). In six interviews, officials also discussed presenting results from the investigation of a reported cancer cluster using visual tools (e.g. PowerPoint) to stakeholders.

The officials interviewed had mixed experiences when it came to leveraging the news media as information disseminators while investigating reports of a cancer cluster. The media's role in assisting with information sharing during the investigation was perceived as positive by officials in six interviews, some of whom discussed collaborating with local news media to report on the results of their investigations. However, in seven interviews, officials said the media played either a negative or neutral role in sharing information about investigating suspected cancer clusters.

Discussion

Despite past concerns raised about their overall value in other jurisdictions,⁶ we found that cancer cluster investigations are regularly undertaken by Canadian public health officials for the purposes of educating the public about cancer and exploring whether observed incidences of cancer in a community occur at levels that are higher than expected. While these goals were found to be consistent across Canada, the investigation procedures varied considerably across the provinces and territory included in this study. In the absence of national cancer cluster guidelines, each Canadian jurisdiction has taken a different approach to investigating clusters, whereby some have produced their own guidelines and others have opted mostly to follow the US CDC's procedures.

This patchwork of approaches has resulted in little procedural consistency for carrying

TABLE 3
Primary themes from interviews with Canadian public health officials about communication approaches and challenges during cancer cluster investigations (n = 13)

| Topic | Themes | Number of interviews with theme present (%) |
|--|---|---|
| Main messages communicated to community during/after investigation | Observed vs. expected incidence rates | 8 (62%) |
| | Cancer risk factors | 8 (62%) |
| | Why pursuing investigation or why not | 3 (23%) |
| Key stakeholders for communication | Citizens/community | 13 (100%) |
| | Other government agencies or ministries | 13 (100%) |
| | Local elected officials | 7 (54%) |
| | Employers | 3 (23%) |
| | News media | 3 (23%) |
| | Nongovernmental organizations | 1 (8%) |
| Challenges communicating risk | Complexity of information | 10 (77%) |
| | Addressing public perceptions of risk | 10 (77%) |
| | Crafting messages on risk | 9 (70%) |
| | Language and/or cultural considerations | 3 (23%) |
| Purpose of risk communication | Public education | 11 (85%) |
| | Health behaviour change | 5 (38%) |
| | Address public concerns | 5 (38%) |
| | Improve transparency | 3 (23%) |
| Communication formats used to share results or investigation conclusions | Printed texts (e.g. reports, brochures) | 11 (85%) |
| | Face-to-face | 10 (77%) |
| | Telephone or email | 9 (70%) |
| | Presentations | 6 (46%) |
| Role of the media in information sharing | Positive role | 6 (46%) |
| | Negative role | 5 (38%) |
| | Neutral | 2 (15%) |

out investigations into reports of cancer clusters in Canadian communities, which can generate confusion among investigators regarding which guidelines to follow and how to effectively respond. Indeed, one participant we spoke to described having to pose questions through an email listserv to find out what guidelines were commonly used in their own jurisdiction and to informally gather advice from other epidemiologists regarding cluster investigation best practices.

The establishment of pan-Canadian guidelines in cooperation with all Canadian provinces and territories could therefore make the process of responding to reports of cancer clusters more consistent across and within Canadian jurisdictions, and would especially benefit jurisdictions without clear procedures or guidelines in

place. Pan-Canadian guidelines could also delineate the specific duties of investigators and what skills and expertise they are likely to require, which would benefit jurisdictions where lead investigators have not been identified by eliminating some of the current guesswork around which agencies and individuals should be tasked with investigating suspected cancer clusters in each Canadian jurisdiction.

In addition, the approaches used by Canadian officials to investigate suspected cancer clusters (wherever guidelines were used) did not always appear to make use of evidence-based procedural best practices. For example, although it is widely known that the public's interest in cancer clusters is highly influenced by perceived environmental hazards and harmful exposures,⁹ only one jurisdiction included

environmental exposure validation as a defined action in their investigation protocol. Further, only three jurisdictions explicitly specified a step for examining the feasibility of an epidemiological study of the reported cancer cluster as a part of their procedural guidelines. This is surprising, given the increasing reluctance of officials to pursue large-scale epidemiological studies of most suspected cancer clusters—except for those that meet specific criteria to warrant an investigation—due to limited time and resources.²⁴

Interestingly, despite most officials having identified information on cancer risk factors as a primary message communicated during the course of investigations, only a third of the Canadian jurisdictions we studied included risk communication at every step of their investigation protocols.

Therefore, establishing pan-Canadian cancer cluster guidelines could benefit public health officials, as well as members of the community where the concern originated, by encouraging a more widespread adoption of procedural best practices surrounding risk communication and other initiatives that may improve the public's understanding of cancer.

However, the case for pan-Canadian cancer cluster guidelines goes beyond achieving procedural uniformity and aiding officials in jurisdictions where guidelines are either lacking or do not currently exist; they would also allow investigators to count and compare reported cancer clusters across all Canadian jurisdictions, a practice which is currently hampered by large discrepancies in how cluster concerns are documented and which inquiries are escalated. For example, one participant we spoke to noted that they did not investigate reports of cancer clusters until each individual case (within the suspected cluster) made contact with the investigator to confirm their diagnosis so that the investigator could determine whether the consistent case definition criterion had been met. In other jurisdictions, complaints of clusters were validated through a crude assessment of observed versus expected rates in the area of interest. Establishing pan-Canadian guidelines that outline a consistent approach for validating reports of cancer clusters would help illuminate whether differences in the number of clusters that get investigated in Canadian jurisdictions were due to a true difference in the number of reported clusters requiring investigation, or due to differences in the way officials were responding to the reported clusters.

Finally, there are two significant scenarios in which pan-Canadian guidelines for cancer clusters would be beneficial due to federal jurisdiction over health matters. The first involves clusters arising in Indigenous communities, where provincial and federal jurisdictional ambiguities remain and the need for national policy frameworks on health matters has previously been raised beyond cancer clusters.²⁵ The second involves clusters for which a cross-boundary environmental exposure is suspected either across two provinces or across the Canada-US border,²⁶ whereby the federal government would also have jurisdiction over such matters.

Our study also brought to light some experiences of cancer cluster investigators that were shared across Canadian jurisdictions. There was considerable agreement among the public health officials interviewed regarding the challenges they faced in communicating risk to stakeholders, which included communicating complex statistical information and addressing the public's perceptions of high risks to health from environmental hazards. These challenges suggest that public health officials would benefit greatly from more support from specialized communications staff with this type of training. Indeed, these findings are consistent with those from a survey of US state health departments conducting cancer cluster investigations, in which 75% of states indicated they would benefit from more resources in risk communication.²⁷ However, most of the officials we interviewed said they had no direct access to staff trained in risk communication in their department. Fortunately, best practices for risk communication have been widely published,²⁸⁻³⁰ however, in the absence of a cross-Canadian, cluster-reporting database with investigation resources that are easily accessible to public health officials alongside procedural guidelines, investigators may be missing out on a useful tool for conducting risk communication more effectively and cohesively.

A type of national cancer cluster-reporting database called the Cancer Cluster Public Inquiry Triage System, as well as an electronic listserver, were established by the US CDC's National Center for Environmental Health (NCEH) in 2002. The database was developed to track the public's cancer cluster concerns and improve information sharing between federal, state and local public health agencies by providing a mechanism to share expertise and scientific methods.³¹ A similar Canadian cluster-reporting database could be used to establish a platform for federal, provincial and local investigators to share knowledge and best practices about responding to initial reports of clusters. The database could be especially beneficial to more junior investigators by providing them with a network of senior experts to consult on cancer cluster investigative methodologies, should a full-scale cluster investigation be warranted once initial concerns are validated and other criteria established by the investigators are met.

Additionally, this kind of database would offer Canadian public health officials an opportunity to study patterns of citizen expressions of concerns about cancer and particular hazards. Analyzing these complaints could help officials identify which communities would benefit the most from education campaigns about cancer and cancer risk factors and could supply citizens with valuable information on specific cancers or local hazards. For example, the US NCEH used their database to study which types of cancers were most frequently cited by cluster inquirers, to inform their development of additional educational tools.³¹ In a recent survey, approximately half of US states were found to regularly report cancer inquiries as a part of the tracking program.³² In other jurisdictions, regulators have leveraged databases containing data on complaints about hazardous exposures to direct efforts towards targeted exposure assessment studies and improve the management of exposure risks.³³

Another interesting finding from this work was the agreement found among public health officials interviewed regarding the primary purpose of risk communication as a means to conduct public education on cancer risk. While this is an important objective of any public health agency during routine activities, this goal may fall short in addressing the expectations of a citizen reporting a cancer cluster, whose primary objective is to seek answers for an unexplained pattern of cancer diagnoses. Other research has found that when a cluster investigation does not confirm the presence of a statistically significant excess in cancer, concerned citizens often persist in believing that the cluster of cancer cases cannot be random, largely due to a lack of trust in public health experts.³⁴

Therefore, addressing public concerns about the perceived threat and maintaining trust and credibility ought to be a primary goal of risk communication during an investigation and may require a different communications approach compared to one that centres on education alone. In fact, one official interviewed observed that being transparent with citizens about what steps were taken to come to the decision on whether to investigate their concerns or not contributed to the overall positive response they received from local community members, despite the investigation not progressing to a full epidemiological study to identify the causes of cancer.

Thus, rather than trying to identify a cancer cluster based on a small number of cases that are typically too limited for an informative statistical analysis, public health experts would do better to divert resources towards addressing public concerns about cancer. Indeed, Rothman commented that “responding to reports of perceived clusters is to assuage community anxiety about environmental problems. The investigation of cluster reports can thus serve both social and scientific ends, and might be seen more constructively as a social service than as a scientific activity.”^{35,p.14}

Using face-to-face, two-way communication approaches to deliver the findings of an investigation into a suspected cancer cluster has also been found to be an effective way to reduce tensions and address concerns,³⁶ a view that was echoed by most of the officials interviewed in this work. Therefore, this method for communicating with public stakeholders should be considered over other communication formats, though it may require some extra training or resources targeted towards community engagement.

Investigators should assess the desire for face-to-face communication among the inquirer(s) and the feasibility of incorporating these approaches.³⁷ Feasibility will depend on the time required to tailor messaging to a community’s needs and the costs of facilitating discussions that may occur in person (e.g. townhall) or those that occur increasingly on virtual platforms (e.g. Zoom meetings). Interestingly, one interviewee discussed seeing noticeable improvements in public trust after hiring an external, nongovernmental organization to coordinate in-person meetings to share information and lead discussions with community members during a suspected cancer cluster investigation, such that public health officials were participants in the discussion with local community members rather than leading the conversation. This kind of approach is rooted in participatory communication theory surrounding horizontal models of communication³⁸ and should continue to be explored by public health officials conducting work with community stakeholders as a way to foster trust with local community members.

Strengths and limitations

This is the first study to explore cluster investigation practices for noncommunicable

diseases by public health agencies and officials across Canada. The broad regional coverage of procedural practices that was captured using both a thematic analysis of expert interviews and a content analysis of text documents should be viewed as a major strength of a study of this kind.

Still, this study has some important limitations. Firstly, although we attempted to obtain a diverse sample of participants with various experiences conducting cancer cluster investigations across Canada, we did not interview an exhaustive list of public health officials who have investigated every cluster. Our participant recruitment approach instead centred on collecting detailed perspectives from a smaller sample of key experts. Another limitation of this study includes the challenges associated with comparing jurisdictions within and outside of Canada where public health agencies and departments vary widely with respect to their organization, administration of duties and resources. Future research examining the strengths and weaknesses of investigation approaches in various jurisdictions globally could provide more context for comparisons. In addition, it is possible that responses from other investigators in each province/territory could have differed depending on the scope of knowledge and experience of the public health official interviewed. However, the experiences of officials interviewed in this study still provide a snapshot of the common challenges likely encountered by officials investigating cancer clusters in many other jurisdictions.

Conclusion

In summary, although this work has demonstrated the usability and accessibility of the CDC’s cancer cluster guidelines as a great resource internationally, it has also highlighted some benefits of establishing pan-Canadian guidelines for investigating reports of cancer clusters. Pan-Canadian guidelines would not only improve procedural consistency across local and provincial/territorial agencies and address important discrepancies in public health practices when responding to inquiries around suspected cancer clusters in Canada, but they are also warranted in situations in which the federal government already has jurisdiction over environmental health matters. Furthermore, achieving greater consistency in approaches across Canadian jurisdictions through the establishment of pan-Canadian guidelines

would allow investigators to draw comparisons across cancer cluster responses from different provinces and territories and facilitate evaluations of the procedures adopted.

This study also identified the benefits of developing a Canadian database for clusters to serve as a reporting system to track citizen concerns and as a resource sharing platform for health officials responding to reports of clusters. Such a database would also help local, provincial and federal agencies carry out public health education to supply valuable information in response to citizen inquiries about cancer clusters, and might also address some citizen concerns around cancer without necessitating the launch of cluster investigations that are unlikely to reveal any definitive answers around the suspected causes of cancers. However, public education is carried out most effectively when health officials responding to community concerns have the necessary skills and training in risk communication, which appears to be a key challenge area among the officials we interviewed.

Furthermore, for the rare instances in which cluster investigators proceed beyond the initial stages of a cluster response and towards a more formal investigation, we have proposed, based on the views expressed by the public health officials we spoke to, that investigators consider face-to-face, participatory communication approaches when feasible. Leveraging participatory communication practices during this investigative phase may improve engagement with the public when delivering findings from the investigation and, importantly, may help officials manage the community’s expectations around the results of investigations with an open and transparent dialogue. Since many citizens report suspected cancer clusters in the hope of uncovering answers about the cause of their diagnosis or that of a loved one, the inability of most cluster investigations to meet these expectations ought to be a key fact communicated honestly with concerned citizens from the moment that investigators respond to a cluster inquiry.

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Conflicts of interest

The authors declare no conflicts of interest.

Authors' contributions and statement

All authors contributed to the study's conception and design. CS led the data collection, analysis and manuscript preparation for this work. NY provided analytical assistance and comments on all drafts of the manuscript. Both authors approved of the final manuscript for submission.

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