

## OPEN SCIENCE OPEN DATA



### EDITORIAL

Benefits and challenges of  
Open Data

252

### OVERVIEW

Updates to the Canadian  
Notifiable Disease Surveillance  
System

257

### OUTBREAK REPORT

New strain of hepatitis A virus  
in men who have sex with men

262

NEXT ISSUE NOVEMBER 7, 2019



# CCDR

## CANADA COMMUNICABLE DISEASE REPORT

The *Canada Communicable Disease Report* (CCDR) is a bilingual, peer-reviewed, open-access, online scientific journal published by the Public Health Agency of Canada (PHAC). It provides timely, authoritative and practical information on infectious diseases to clinicians, public health professionals, and policy-makers to inform policy, program development and practice.

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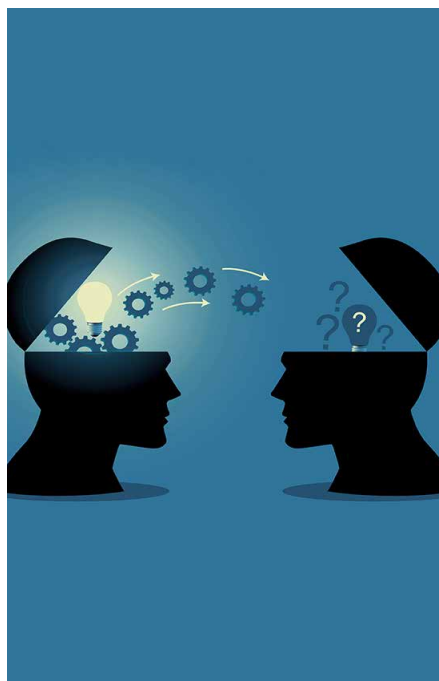
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# OPEN SCIENCE: OPEN DATA

## TABLE OF CONTENTS

### EDITORIAL

- Reaping the benefits of Open Data in public health 252  
*P Huston, VL Edge, E Bernier*

### OVERVIEW

- Updates to the Canadian Notifiable Disease Surveillance System and its interactive website 257  
*S Totten, A Medaglia, S McDermott*

### OUTBREAK REPORT

- Community outbreak of hepatitis A disproportionately affecting men who have sex with men in Toronto, Canada, January 2017–November 2018 262  
*H Sachdeva, M Benusic, S Ota, R Stuart, J Maclachlan, V Dubey, A Andonov*

### ANNOUNCEMENT

- A farewell and a welcome: Passing the baton 269  
*P Huston*

### ID NEWS

- Challenges of Open Science 270  
Making Open Science Work 270



# Reaping the benefits of Open Data in public health

P Huston<sup>1</sup>, VL Edge<sup>1\*</sup>, E Bernier<sup>1</sup>

## Abstract

Open Data is part of a broad global movement that is not only advancing science and scientific communication but also transforming modern society and how decisions are made. What began with a call for Open Science and the rise of online journals has extended to Open Data, based on the premise that if reports on data are open, then the generated or supporting data should be open as well. There have been a number of advances in Open Data over the last decade, spearheaded largely by governments. A real benefit of Open Data is not simply that single databases can be used more widely; it is that these data can also be leveraged, shared and combined with other data. Open Data facilitates scientific collaboration, enriches research and advances analytical capacity to inform decisions. In the human and environmental health realms, for example, the ability to access and combine diverse data can advance early signal detection, improve analysis and evaluation, inform program and policy development, increase capacity for public participation, enable transparency and improve accountability. However, challenges remain. Enormous resources are needed to make the technological shift to open and interoperable databases accessible with common protocols and terminology. Amongst data generators and users, this shift also involves a cultural change: from regarding databases as restricted intellectual property, to considering data as a common good. There is a need to address legal and ethical considerations in making this shift. Finally, along with efforts to modify infrastructure and address the cultural, legal and ethical issues, it is important to share the information equitably and effectively. While there is great potential of the open, timely, equitable and straightforward sharing of data, fully realizing the myriad of benefits of Open Data will depend on how effectively these challenges are addressed.

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## Affiliation

<sup>1</sup> Office of the Chief Science Officer, Public Health Agency of Canada, Ottawa ON

## \*Correspondence:

[victoria.edge@canada.ca](mailto:victoria.edge@canada.ca)

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**Keywords:** Open access, Open Science, Open Data, public health science, big data

## Introduction

In June 2013, Canada and the other G8 countries adopted the G8 *Open Data Charter* (1). Open Data is part of a broad global movement that is not only advancing science and scientific communication, but is also transforming modern society and how decisions are made. This global movement is arguably one of the most important advances in evidence-based activities this century. Open Data has been defined as “structured data that is machine-readable, freely shared, used and built on without restrictions.” (2). The two main criteria for Open Data are that they must be freely available online and in a format that allows re-use.

This article provides a brief history of Open Data, explores its potential benefits, challenges and discusses the current state of Open Data in public health in Canada, with a focus on infectious diseases.

## A brief history

Openness and sharing of discovery has been at the heart of science since the scientific method was first described by Aristotle (3). However, historically, neither scientific reports nor the data upon which these reports were based have been easily accessible. Scientific research was published in journals where access required paid subscriptions (or was a benefit of paid membership in an association), and databases were considered as the private and intellectual property of those who developed them. Databases were, and often still are, created and stored in different ways, analyzed by different methods, and thus can be deeply siloed.

In the 1970s, Robert Merton, who is considered the founder of the sociology of science, began advancing the idea that research should be freely accessible to all. He asserted that one “Mertonian norm” in the ethos of modern science was that



each researcher must contribute to the “common pot” and give up intellectual property rights to allow knowledge to move forward (4).

The Open Science movement was enabled by the rise of online journals in the 1990s, reflecting the original intent of science in supporting transparency and collaboration in research and scientific communication (5). The Open Science movement was driven by the observation that research was often paid with public funds, and thus taxpayers should not be restricted access to its outcomes by “paywalls”. This led to broad support and demand for open access to scientific publications and the current trend for authors and journals to adopt the Creative Commons license that enables people to freely read and use scientific publications with appropriate attribution (6). We are still in the midst of this transition, with both open access journals and subscription-based journals.

Supporters of the Open Science ethos went a step further by promoting more general access to generated or collected data. Open Data is based on the idea that not only should the results and reports of research be open, but also the underlying data that inform and support them. Nobel Prize winner, Elinor Ostrom, identified that Open Data was a new kind of “public good”. The thinking was that unlike other types of public good, the use of Open Data does not deplete the common stock, but potentially enriches it (7).

As with Open Science activities more broadly, the capacity to produce and share vast amounts of data soon took on a life of its own through enormous advances in technologies and computing. We are now in an age when the sheer volume of data generated daily is staggering (8). Necessarily, the demand for data storage capacity also keeps growing, with the ongoing evolution of new and more sophisticated data generators. Masses of data are increasingly available through digital platforms, wireless sensors, virtual-reality applications and billions of mobile phones (9). The trend towards Open Data is a global phenomenon, supporting opportunities and innovative trends in data analytics that include “big data”, artificial intelligence and machine learning. Increasingly, there is a call for data to be “open by default” and governments are increasingly including Open Data sets on their websites (10,11). The desire, demand and expectation for Open Data are becoming the new normal.

## The potential of Open Data for public health

It has long been recognized that population health surveillance is one of the pillars of public health, yet the use and development of new technologies to collect, analyze and share surveillance data has been slow to develop, hindering the effectiveness of

informing public health policy and action (12). Open Data is one effective way to address the need to strengthen public health surveillance.

An early example of a strengthened public health surveillance system through the use of open data is the Behavioral Risk Factor Surveillance System (BRFSS). First developed in 15 states in the United States (US) in 1984, it now includes all US states and territories. Public health officials have used BRFSS for monitoring and responding to public health emergencies in real-time, such as developing the public health response to the effects of Hurricane Katrina in 2005 and monitoring the uptake of the H1N1 vaccine during the influenza pandemic in 2009. Currently, BRFSS data are integrated into the emergency response plan for drought-related threats to public health (13). It has been completely open access since 2014 (14).

Canada also has a number of online databases, including several maintained by the Public Health Agency of Canada (PHAC). The Public Health InfoBase (15), for example, offers easy-to-use tools for accessing and viewing public health data pertaining to chronic diseases, mental health, risk and protective factors and associated determinants of health. By using the search function and selecting criteria through drop down menus, users of the Public Health InfoBase can view data from different data sources in various formats.

In this issue of the *Canada Communicable Disease Report*, Totten et al. describe recent updates to the Canadian Notifiable Disease Surveillance System (CNDSS) and its interactive website (16). Established in 1924, the CNDSS is based on a federal/provincial/territorial collaboration that provides the latest data on key infectious diseases in Canada. Over the years, it has evolved to include an interactive public website that gives anyone the ability to easily create customized figures and tables on multiple diseases and to consider trends by age, sex and year. Currently, this information can be exported into PDF or Excel file formats, but soon it will be possible to download the databases into statistical software programs.

Another example is PulseNet Canada (PNC) run by the PHAC's National Microbiology Laboratory (NML). This system highlights the successful development of high tech, advanced analytical science, providing real-time molecular surveillance and outbreak detection for foodborne disease, such as *Salmonella* and *Listeria* (17). The NML uses whole genome sequencing (wgs) technology for laboratory-based surveillance. PHAC currently is in the process of releasing all PNC-generated wgs data on outbreak strains originating in Canada to the National Centre for Biotechnology Information's GenBank (18) online database. These efforts support Open Data and facilitate real-time data sharing with international, provincial and federal partners as well as industry to improve outbreak investigation, give insights into transmission patterns of emerging infections, and strengthen the One Health approach to surveillance.



An increasingly obvious benefit of Open Data is not simply that a single database can be used more widely; it is that these data can be leveraged, shared and combined with other data sets. This creates novel opportunities for scientific collaboration and partnership. For example, surveillance data on sexually-transmitted infections have been paired with data on the number of hits of public health messaging on social media sites to assess the effectiveness of infectious disease outbreak control (19). Open Data from satellites on weather and environmental indicators has been used to help predict increased risk of floods, fires and extreme weather events to trigger and inform mitigation efforts (20).

Some of the many potential benefits of Open Data in public health are summarized in the textbox below.

**Textbox: Summary of the potential benefits of Open Data in public health**

- Increases opportunities for scientific collaboration and partnerships
- Enriches research and analytical capacity
- Improves early detection of health and environmental threats
- Improves option analysis and monitoring real-time response
- Informs interventions and policy decisions
- Improves evaluation capacity and performance indicators
- Increases capacity for public participation
- Enables transparency and improves accountability

## Challenges of Open Data

While the possibilities of Open Data are vast and promising, there are numerous challenges that need to be addressed to truly reap the benefits. They can be grouped into three key areas: making the technological shift; making the social and cultural shift that includes not only social norms, but also legal and ethical issues; and avoiding the pitfalls.

### Making the technological shift

Open Data requires significant resources to set up databases for public use and combinability. Appropriate technological infrastructure is necessary, including software programs, high capacity computers and cloud-based solutions to store and analyze large amounts of data. Open Data also requires clear standards to ensure transparency regarding the source, how the data are generated, its combinability with other data and its limitations. Finally, there is a need for training to develop different types of expertise in systems and analytics. Some databases, such as the CNDSS, can easily generate quite simple

graphs and trends. However, with the use of more complex databases, the combining of databases or the use of large amounts of data, analytics has become more sophisticated and this requires development of analytical capacity.

### Making the social and cultural shift

Although the call for Open Data began as a popular movement, there is still hesitancy in making some databases freely available. Not everyone wants to, or is able to, share their data. Developing excellent databases take a lot of time, work, resources and skill. If people share their hard-earned databases, will they get appropriate recognition? There has to be some motivation to spend time developing databases without the worry that its use will only enable others to get credit for the analysis and publication of those data. There is also the legitimate concern that open data could be used inappropriately, if the purpose for which the data was collected and the limitations of the data are not well-understood.

The hesitancy to share data is also often linked to legal and ethical issues. Who owns these data? Is there legislative support for data sharing? Especially with healthcare and public health databases, there are concerns about safeguarding privacy and confidentiality. There is a recognition that the call for openness and transparency needs to be tempered by the need to respect privacy and confidentiality. Generally, there are careful protocols for ensuring non-identifiability, but what if this is not done adequately, or the efforts to ensure confidentiality can be circumvented? This hesitancy highlights the need for clear standards and policies.

There is a concern about equity. Without the infrastructure capacity or expertise to access and make use of the data, is it really open to all? This also introduces a number of questions. What type and scope of data are being gathered? Whose interests are being prioritized? These and other aspects regarding equity will be explored during this year's International Open Access Week where the theme is "Open for Whom? Equity in Open Knowledge" (21). Equity is being addressed by international initiatives, such as the Open Government Partnerships that help to support scientists and other governments in less resource-rich environments (22).

### Avoiding the pitfalls

There are two obvious pitfalls with the Open Data movement that need to be managed. The first is the need for common language, definitions, principles and tools—a common understanding of data management and best practices for data sharing agreements. This common approach is particularly important in situations where multiple disciplines are involved, where there are often different assumptions, different methodologies and practices, and when the same or similar terms can have different meanings.



Secondly, with so much focus on infrastructure, management and analytical capacity, there is a need to ensure that efforts are made to communicate the results of data-driven research effectively. With data creation growing at unprecedented rates, we are gathering more data than we can digest and deliver in an understandable way. For the analysis of open data to have optimal uptake, there is a need to advance ways of presenting data that will ensure that it is both succinct and understandable. With more and more data available, data are often combined from different disciplines, which means greater creativity in summarizing data—not only with tables and figures, but also visual abstracts, infographics, dashboards and more.

## Discussion

Open Data represents a fundamental and massive shift in how we conduct research, make decisions, develop policy and evaluate our interventions. There is increasing pressure and expectation by the public for researchers and governments to show and share the data and information that public funds have generated. The potential benefits of making data open and accessible are very exciting; however, the challenges in making this happen are substantial and should not to be underestimated.

So where are we in terms of addressing the challenges and reaping the benefits of Open Data in public health? With respect to the technological shift, there has been a lot of progress, but appropriate technology and infrastructure is still being developed at all levels of government. Some areas of public health science, such as bioinformatics, are well ahead in current activities and in future planning for technologies and infrastructures. Other areas are less well developed. In addition, a socio-cultural shift is still underway and there remain those who are still hesitant to share their data.

Addressing concerns around legal and contractual obligations will require careful and considered legislative change in some domains. For example, a recent federal plan to advance Open Data identified the need to update the *Statistics Act* (23). For public health, specifically, work is underway to balance Open Data with regulatory limitations, and address privacy and confidentiality concerns. In avoiding the numerous potential pitfalls, developing a common language and applying best practices in data sharing, we are in the early days. In Canada, the *Multilateral Information Sharing Agreement* (MLISA) is likely to be a landmark document that identifies best practices for the sharing of public health surveillance information amongst the federal, provincial and territorial governments; however, the details of this agreement are still being advanced (24). For example, MLISA includes appropriate attribution, which is a hallmark of the Creative Commons license, but which has not been a widespread feature of Open Data. The MLISA also includes safeguards to promote and ensure appropriate use

of data. These features have gone a long way to address the concerns of those who created the databases that their work will be acknowledged and used appropriately.

In terms of effectively communicating the results, a lot of progress has been made since the early days when data sets were simply placed on the web with little explanation. Although there has been a perennial need to make scientific communications accessible, this need becomes even more acute with the data revolution that is currently underway. We need to find more ways to summarize data and make the key messages evermore succinct and memorable.

With Open Data still very much in development in public health, what are the next steps? When considering the increased use of Open Data demands balanced against limited resources, there is a need to better understand the type, degree of uptake and use of Open Data. Good, reliable and freely accessible public health data could be useful to students and researchers (undergraduate to postdoctoral), federal, provincial and territorial governments, non-profit organizations, healthcare and public health professionals, as well as journalists. The idea of the “public good” derived from Open Data is attractive in principle, but is it actually being used and to what extent? It would also be interesting to assess if more access to health data increases engagement in personal and public health. Further to this, innovative projects that ask for public support and involvement in open data generation or analysis, through activities such as crowd-sourcing (25) or hack-a-thons (26), could extend the reach and resources of public health.

## Conclusion

Technologies and science will continue to contribute to the explosive generation of data. The possibilities that these data create have captured the scientific imagination. The global trend to embrace Open Science and Open Data reflects the inherent desire by many to work collaboratively to address complex issues, recognizing the benefit of multiple perspectives, the leveraging of resources, the advancement of research methodologies and the benefits of timely, robust data to inform decisions made in many domains. Public health has started to reap the many anticipated benefits that openness and transparency of data present; and work continues to address the significant challenges involved in making a successful transition towards this “new normal”. Stay tuned.

## Authors' statement

All authors conceptually developed the manuscript together. PH wrote the first draft, VLE and EB contributed to subsequent drafts and all signed off on the final version. P Huston was the Editor-in-Chief of the *Canada Communicable Disease Report* at the time this was written, but recused herself from all



editorial decisions on the manuscript. M Deilgat, the incoming Editor-in-Chief took the editorial decisions on the manuscript.

## Conflict of interest

None.

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# Updates to the Canadian Notifiable Disease Surveillance System and its interactive website

S Totten<sup>1\*</sup>, A Medaglia<sup>1</sup>, S McDermott<sup>1</sup>

## Abstract

The Canadian Notifiable Disease Surveillance System (CNDSS) provides data on diseases that have been identified as priorities for public health monitoring and control. Several advances that have been made on Notifiable Diseases Online, the CNDSS interactive website, are consistent with the Government of Canada's commitment to Open Data. This article provides an update on changes in case definitions that have been made since the case definitions were last published in 2009, and describes updates that have been made to the interactive website since 2013.

Changes were made to the case definitions of five diseases. For hepatitis C, the new case definition now distinguishes between acute and chronic infection. For cyclosporiasis, the probable case definition requires an epidemiologic link, with the clarification that this would likely be due to exposure to a common food source. For rabies, the probable case definition now refers to detection of rabies-neutralizing antibody instead of specific antibody titres. For Lyme disease the revised confirmed and probable case definitions now identify five options for Lyme disease risk areas instead of endemic areas. For tuberculosis the revised case definition now includes nucleic acid amplification testing in addition to culture for diagnosis.

The Notifiable Diseases Online website is an interactive tool that enables users to create customized figures and tables. Since a major redesign in 2013, numerous changes have been made to the look and feel of the site. Figures and tables can now be extracted as Excel or PDF files and large datasets are exportable into Excel files for further analysis. Case definitions in the national surveillance system will be updated as needed and its interactive website will continue to be improved and updated in response to user comments.

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## Affiliation

<sup>1</sup> Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada, Ottawa ON

## \*Correspondence:

[stephanie.totten@canada.ca](mailto:stephanie.totten@canada.ca)

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**Keywords:** surveillance, notifiable diseases, case definition, Canada, update

## Introduction

Surveillance of health-related events is an essential function of public health and supports Canada's efforts to advance public health nationally and internationally. The Canadian Notifiable Disease Surveillance System (CNDSS) is operated by the Public Health Agency of Canada (PHAC). This national surveillance system monitors infectious diseases that have been identified collectively by the federal, provincial and territorial governments. It provides timely and accurate data to inform public health programs and policies (1). This is now part of the Government of Canada's Open Data initiative that aims to provide Canadians with access to data that are produced, collected and used across the federal government (2). Surveillance is one of the main sources of Open Data in public health.

## Background

The national collection of data on communicable diseases was first undertaken in 1924 by the Dominion Bureau of Statistics (now Statistics Canada). This responsibility was transferred to Health Canada's Laboratory Centre for Disease Control in 1988, and then to PHAC (upon the Agency's creation) in 2004. These data are received and used under the legislative authority of the *Statistics Act and the Department of Health Act*.

Provincial and territorial laws mandate that healthcare providers, hospitals and laboratories report cases of certain conditions to public health authorities. These are generally called reportable diseases. Many reportable diseases are also national notifiable diseases (NNDs), but this is not uniformly true. Provincial/territorial public health authorities report voluntarily on NNDs to the federal government, for national aggregation and reporting.



For NNDs, the list of designated diseases is maintained through a collaborative federal/provincial/territorial process (3–5). Currently, there are 56 NNDs, and for the majority of diseases, cases are reported annually from provincial/territorial authorities to the CNDSS, along with basic demographic information on age and sex. A few diseases (i.e. HIV/AIDS, tuberculosis, West Nile virus, Creutzfeldt-Jakob disease, influenza and acute flaccid paralysis) are reported directly to PHAC disease-specific programs, due to the complexity of the disease or its surveillance system.

Case definitions in the CNDSS are intended to support public health activities rather than clinical diagnosis. Standardized case definitions for NND were first developed through a federal/provincial/territorial process in 1991, with subsequent editions in 2000 (6) and 2009 (7). Following the 2009 revision, the decision was taken to make future updates on a case-by-case basis.

A rudimentary interactive website was launched for the CNDSS in 2001 to replace the printed annual reports. In 2013, a redesigned [Notifiable Diseases Online](#) (NDO) was launched in response to user feedback and new accessibility requirements. It included all CNDSS data (going back to 1924, where available). Since 2013, further enhancements have been made, including greater interactivity and more options in the chart function (1). Currently, approximately 600 unique users visit the site each month.

## Objectives

The objectives of this article are to describe the process by which NND case definitions are updated, summarize revisions to five NND case definitions made since the 2009 CNDSS edition and summarize the recent enhancements to the NDO interactive online query tool.

## How National Notifiable Diseases case definitions are updated

Case definition updates are coordinated through the Pan-Canadian Public Health Network (PHN). Case definition reviews may be initiated at any time of year if the need is identified by epidemiologic or laboratory programs at the federal or provincial/territorial level. Between 2009 and 2013, updated definitions were developed through informal federal/provincial/territorial collaborations and reviewed by the PHN's Communicable and Infectious Disease Steering Committee (CIDSC) prior to implementation in national surveillance. In 2013, a more formal process was approved by the Public Health Network Council. This process includes an annual invitation for an expression of interest. When the decision is made to proceed, a technical task group is formed, conducts a review and makes

recommendations to the CIDSC. Task groups include laboratory, epidemiology and clinical experts, as well as others nominated by provincial/territorial CIDSC members. Once approved by CIDSC, the new case definition is implemented for routine surveillance. Typically, most provinces and territories adopt the national case definitions for their own use; however, for some diseases, there are slight variations between the national case definitions and those used in provincial/territorial public health surveillance.

## Updates on five case definitions

Since the publication of the 2009 edition of the CNDSS case definitions, five reviews have been conducted to revise case definitions (8). Three of the case definition reviews (hepatitis C, cyclosporiasis and rabies) were conducted prior to 2013 and two reviews (Lyme disease and tuberculosis) were conducted after the establishment of the Pan-Canadian Public Health Network protocol in 2013.

### Hepatitis C

The 2009 national case definition for hepatitis C (7) did not distinguish between acute and chronic infection. The updated definition includes a definition of acute (recently acquired) hepatitis C virus infection, using symptoms, serology and other clinical tests, or documented seroconversion within a 12-month period. All other hepatitis C cases are to be reported under an unspecified category that includes chronic and resolved infections. This change in case definition is not expected to impact the total number of cases of hepatitis C reported annually. However, it will allow for analysis of trends of recently-acquired infection as a proxy for incidence. This case definition was approved by CIDSC in 2011.

### Cyclosporiasis

The 2009 case definition for probable cyclosporiasis (7) was revised to align better with other enteric disease probable case definitions in Canada and the United States. Specifically, the revised definition requires probable cases to be epidemiologically-linked to a laboratory-confirmed case. An additional statement was added to the comments section to identify that direct person-to-person transmission is unlikely to occur and that an epidemiologic link is likely to be through exposure to a common food source. This change in case definition is not expected to impact the total number of cases of cyclosporiasis reported nationally, as the CNDSS reports only on confirmed cases. The change has no implications at the laboratory level, as the probable case definition is not based on laboratory criteria. This case definition was approved by CIDSC in 2012.



## Rabies

The 2009 case definition of probable rabies was changed, as the laboratory criteria were confusing. The 2009 case definition referred to specific antibody titres when, in fact, antibody thresholds are not necessary for the diagnosis of rabies. The reference to the titre of greater or equal to five in the probable case definition was removed and replaced with the phrase “detection of rabies-neutralizing antibody”. In addition, the reference to the detection threshold of 0.5 IU/ml was removed from the Laboratory Comments section. The wording of the Laboratory Comments section was also changed to emphasize that serology should be used only in conjunction with additional testing for the diagnosis of rabies. These changes are not expected to affect the reporting of cases of this rare disease. As the Canadian Public Health Laboratory Network had already been consulted and was in agreement with all changes to this updated case definition, it was presented to CIDSC for information only in 2012.

## Lyme disease

The 2009 case definition for Lyme disease (7) included very specific guidelines for the identification of an endemic area, which required extensive, resource-intensive surveillance by reporting jurisdictions. Evidence of exposure to environmental risk is recommended when using serologic methods to diagnose Lyme disease (9), so the revised case definition identifies five options for Lyme disease risk areas, including two methods of active field surveillance; passive tick surveillance; signals from human case surveillance; and validated predictive models. Additional details on appropriate clinical specimens for laboratory diagnosis were added. These changes are expected to improve the identification of Lyme disease risk and reporting of Lyme disease cases by provincial and territorial public health authorities. The changes to the national case definition are expected to increase the number of probable and confirmed cases, based on the five options to identify risk areas. This case definition was approved by CIDSC in 2016 and has been implemented in all jurisdictions except Saskatchewan.

## Tuberculosis

The 2009 case definition (7) for tuberculosis included culture detection only for laboratory-confirmed cases. The revised case definition includes nucleic acid amplification testing, as it is increasingly used for laboratory confirmation of *Mycobacterium tuberculosis* infection. In addition, cases previously classified as “clinically-confirmed” are now referred to as “clinically-diagnosed” and the criteria for these cases were updated to reflect those being used in practice in the reporting jurisdictions. These changes are not expected to impact national trends in tuberculosis surveillance data. This case definition was approved by CIDSC in early 2019, and will be implemented as of January 2020 for the reporting of 2019 annual tuberculosis data.

The updates to these case definitions are summarized in **Table 1**.

**Table 1: Summary of revisions to case definitions of Nationally Notifiable Diseases: 2009-early 2019**

Nationally Notifiable Disease (year changed)	Summary of change	Rationale	Expected impact on national trends
Hepatitis C (2011)	Case definition now distinguishes between acute and chronic infection	Previous definition lacked detail that was available in some jurisdictions	No change to total number of cases
Cyclosporiasis (2012)	The probable case definition now requires cases to be epidemiologically linked to a laboratory-confirmed case (likely through a common food source)	To align better with other enteric disease probable case definitions in Canada and the United States	No change
Rabies, human (2012)	The probable case definition now includes a “detection of rabies-neutralizing antibody” instead of specific antibody titres	Specific antibody titres are not necessary for the diagnosis of rabies	No change
Lyme disease (2016)	The revised case definition identifies five options for determining Lyme disease risk areas rather than requiring evidence of an endemic area	Identifying an endemic area requires extensive, resource-intensive surveillance	An increase in the identification of confirmed and probable cases
Tuberculosis (2019; effective January 2020)	The confirmed case definition now includes nucleic acid amplification testing and refinements to the clinical case definition	Adding NAAT and refinements of terms reflect current best practices	No change

Abbreviation: NAAT, nucleic acid amplification test

## Updates to Notifiable Diseases Online

Since its relaunch in 2013, annual updates have included improvements to the look and feel of the NDO interactive site. In 2017, a function was added for users to download their query and the resulting online data into a PDF or in a Microsoft Excel spreadsheet. In 2018, a new custom charts function was introduced that includes a variety of options for data outputs. For example, to obtain a simple chart of national



trends for campylobacter and salmonella infections between 1991 and 2016, a user can simply identify these two diseases and the time period of interest, and a graph showing trends over time will automatically be created (**Appendix 1a**). Custom charts can also be created according to specifications (i.e. axis definitions and variable groupings), and filters can be applied as needed (i.e. by age group, sex and year). The benefits of customization include the ability to visualize data for multiple diseases, age groups and sex categories, according to user needs (**Appendix 1b**). Both simple and custom charts can then be exported into a PDF or Excel format.

It is now possible to extract a large aggregate dataset that includes any or all available NND data, for all available years since 1924. This function creates an Excel workbook containing all the data, with the data limitations and disease descriptions in the "Notes" tab and the data table in the "Data" tab. Data extracts can be broken down by age and sex from the year 1991 onwards. Updates planned for late 2019, include the exportation of comma-separated values file formats in the large data extract function, for easier importation into statistical analysis packages, as well as enhanced visualization of data reporting variations, which enable the user to understand with a quick look how nationally representative the data are for a given disease.

## Conclusion

The CNDSS and the NDO provide open data on all 56 notifiable diseases in Canada and the interactive website has been improved to meet user needs. The revised case definitions and increased functionality of the website have enhanced the capacity for people who are interested in these data to access it and create useful tables and figures that are tailored to their information needs. These data can increase awareness of infectious disease trends and inform the development and evaluation of public health programs and policies at the national level. This accessible database is also consistent with the Government of Canada's commitment to Open Data and Open Science, with the overall goal of increasing our national capacity to prevent, mitigate and control communicable and infectious diseases in Canada. Improvements to the functionality of the website will continue to be made; users of the CNDSS and NDO are encouraged to suggest additional updates via email to [phac.nd-mado.aspc@canada.ca](mailto:phac.nd-mado.aspc@canada.ca).

## Authors' statement

ST — Writing original draft, review and editing  
AM — Review and editing  
SM — Review and editing

## Conflict of interest

None.

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## Funding

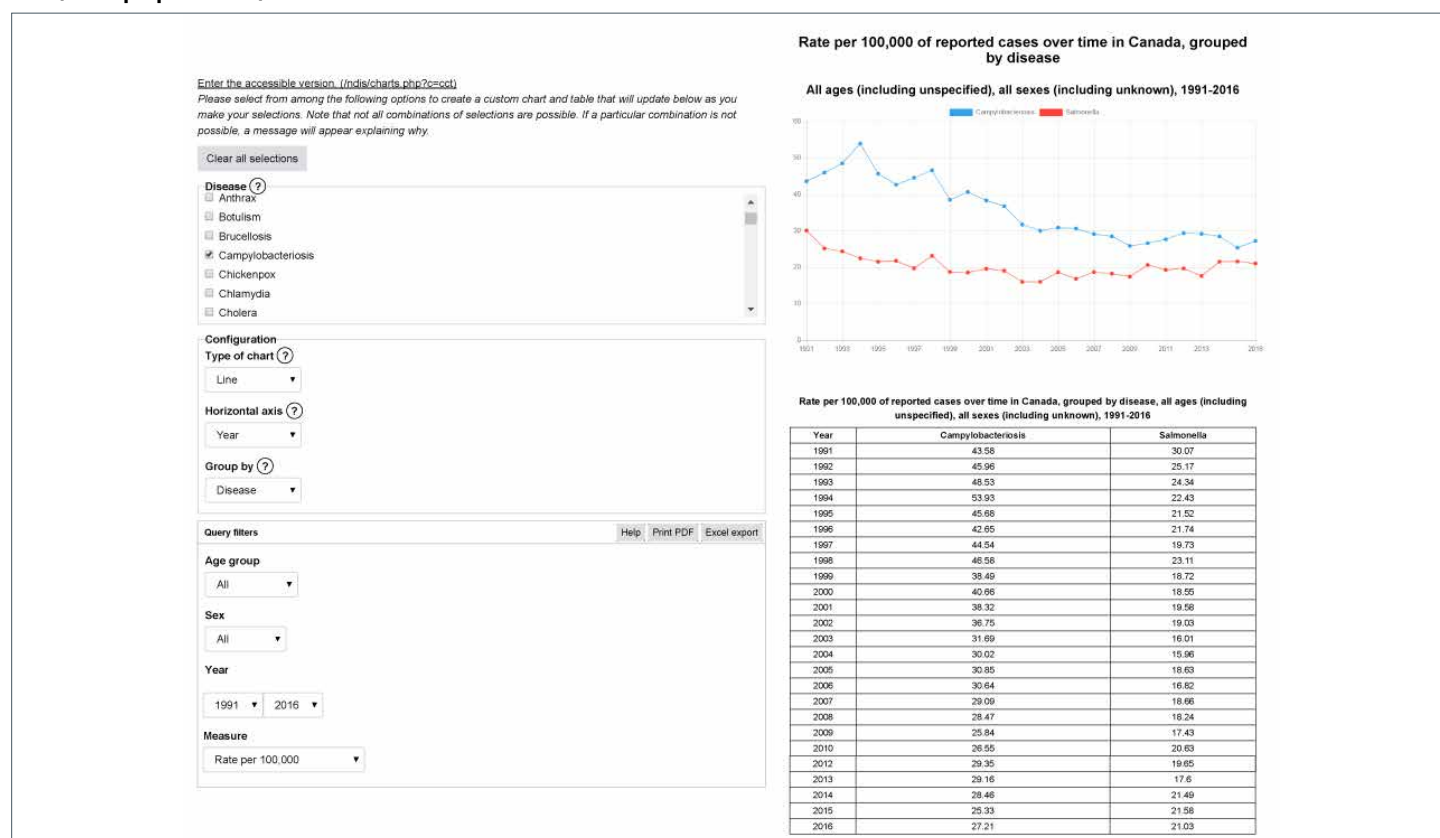
This work was supported by the Public Health Agency of Canada.

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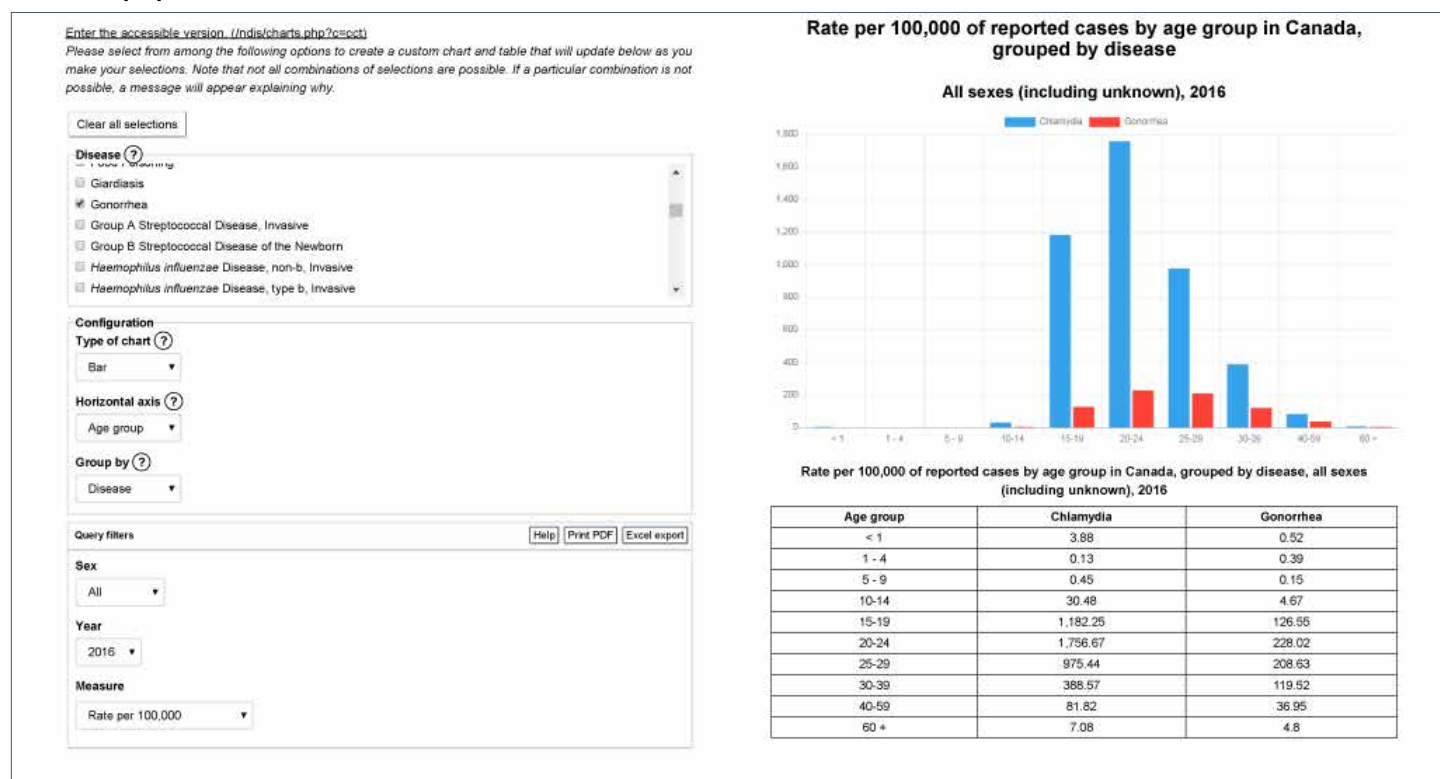
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## Appendix 1a: Example output from Notifiable Diseases Online – campylobacteriosis and salmonella, rate per 100,000 population, 1991 to 2016



## Appendix 1b: Example output from Notifiable Diseases Online – chlamydia and gonorrhea by age group, rate per 100,000 population, 2016





# Community outbreak of hepatitis A disproportionately affecting men who have sex with men in Toronto, Canada, January 2017–November 2018

H Sachdeva<sup>1,2\*</sup>, M Benusic<sup>3</sup>, S Ota<sup>1</sup>, R Stuart<sup>1</sup>, J Maclachlan<sup>1</sup>, V Dubey<sup>1,2</sup>, A Andonov<sup>4</sup>

## Abstract

**Background:** In late 2016 and early 2017, a number of countries began reporting hepatitis A virus (HAV) outbreaks involving person-to-person transmission among men who have sex with men (MSM), people using illicit drugs and homeless or underhoused persons.

**Objective:** To describe the epidemiology and public health response to an outbreak of HAV disproportionately affecting MSM in Toronto, Canada from January 2017 to November 2018.

**Methods:** Following an increase in the number of cases of HAV in MSM being reported in other countries, enhanced surveillance was performed for all non-travel-related cases of HAV reported from June 1, 2017 to November 1, 2018, including a retrospective analysis of cases reported from January 2017 to June 2017. Descriptive analysis and viral sequencing were performed to describe person-to-person transmission patterns and target interventions. Control strategies included interventions to promote the uptake of preexposure HAV vaccination, including social media campaigns geared to MSM, messaging to healthcare providers and vaccine clinics.

**Results:** Based on the outbreak case definitions, 52 confirmed and probable cases of HAV were identified. Over 80% of outbreak cases were male (n=43/52) and, among those for whom data were available, 64% (n=25/39) reported an MSM exposure. Data on hospitalization was available for 51 cases; 56% of confirmed cases (n=23/41) and 40% of probable cases (n=4/10) required hospitalization. Of the cases with serum samples that had HAV sequencing, 83% (n=30/36) had one of the three strains seen circulating in outbreaks among MSM internationally; 72% (n=26/36) were VRD\_521\_2016, which had been detected in recently reported European outbreaks among MSM. Targeted promotion of publicly-funded vaccination using social media platforms popular with MSM and targeted vaccine clinics were developed to promote HAV awareness and vaccine uptake among MSM.

**Conclusion:** Outbreaks of HAV, attributed to person-to-person transmission of strains of HAV that disproportionately affected MSM and were likely to have been imported from international MSM outbreaks, have now occurred in Canada. Genetic sequencing of HAV, risk factor analysis of cases, monitoring trends of vaccine coverage in high-risk groups and initiation of vaccination campaigns that address barriers to HAV preexposure vaccine coverage in the MSM population may prevent future outbreaks.

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## Affiliations

<sup>1</sup> Communicable Disease Control, Toronto Public Health, Toronto, ON

<sup>2</sup> Dalla Lana School of Public Health, University of Toronto, Toronto, ON

<sup>3</sup> Public Health & Preventive Medicine Residency Program, University of Toronto, Toronto, ON

<sup>4</sup> National Microbiology Laboratory, Winnipeg, MB

## \*Correspondence:

[herveen.sachdeva@toronto.ca](mailto:herveen.sachdeva@toronto.ca)

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**Keywords:** HAV, outbreak, men who have sex with men, vaccine promotion, MSM



## Introduction

Hepatitis A virus (HAV) infection is endemic in developing countries and is one of the most common vaccine-preventable diseases in travellers (1). Clinical disease results after a 15–50 day incubation period and typically begins with an abrupt onset of fever, nausea and abdominal pain, followed by jaundice (2). While most cases are self-limiting, 25% of adult cases require hospitalization (1). A case-fatality rate of 2.2% has been observed among those over 60 years of age (3).

The primary source of HAV is contaminated food or water, but person-to-person transmission has also been documented, particularly through sexual anal-oral or digital-anal contact. Men who have sex with men (MSM) have been identified as a higher risk group for person-to-person HAV transmission (4).

In late 2016 and early 2017, a series of HAV outbreaks were reported in countries that had previously had low HAV rates. Specifically, the United States (US), 15 countries in the European Region and Chile documented an increased incidence among MSM (5). In Europe, three co-circulating strains of genotype 1A (VRD\_521\_2016, V16-25801 and RIVM-HAV16-090) were reported with origins linking to importations from Central America and Asia (4). Also during this time period, US outbreaks were being reported involving individuals reporting illicit drug use or homelessness with genotype 1b viral strains (6).

In Ontario, two doses of the HAV vaccine are publicly funded for three groups: MSM; those who use intravenous drugs; and those with pre-existing liver disease (7). Case confirmation of HAV in Ontario requires serology with either compatible symptoms or an epidemiologic link to a confirmed case (8). Toronto Public Health receives, investigates and responds to reports of suspected and confirmed HAV cases. From 2012 to 2016, the average incidence of reported HAV was 32 cases per year (9).

In light of the different high-risk populations being affected by person-to-person HAV transmission internationally (5,6), in June 2017, Toronto Public Health initiated enhanced surveillance of HAV cases, requested hepatitis A genotyping and viral sequencing for all newly reported cases and conducted a retrospective study of the risk factors for cases reported in Toronto since January 2017. Initial analysis in August 2017 showed the number of cases was consistent with the previous five year average for this time period. However, almost 50% of the cases did not report travel during the incubation period, compared with the previous five year average of 30%. Furthermore, almost 40% were MSM, compared with the previous five year average of 4%. Locally-acquired HAV cases among MSM continued to be detected in September 2017 and an outbreak was formally declared in October 2017.

The objective of this report is to describe the epidemiology of locally-acquired person-to-person HAV transmission occurring in Toronto, and the public health response to an outbreak of HAV disproportionately affecting MSM from January 2017 to November 2018.

## Methods

### Outbreak detection and investigation

For this investigation, an outbreak case definition was established to include all locally-acquired cases. Confirmed outbreak cases were defined as residents of, or visitors to, Toronto who:

- Met the provincial case definition for a confirmed case of HAV (8)
- Had a report date on or after January 1, 2017
- Had no travel history during their acquisition period
- Had no epidemiological link to a travel-related case

Probable cases were defined as patients having a report date on or after January 1, 2017 and who:

- Met the provincial case definition for a confirmed case of HAV
- Had travelled during the period of acquisition or were epi-linked with a traveller
- Had a risk factor for person-to-person transmission of HAV (homeless or underhoused, use of illicit drugs or MSM).

### Case and contact management

Case management was initiated through a telephone interview guided by a standardized questionnaire from Public Health Ontario (10). As per routine case management procedures, outreach to healthcare providers, shelter staff and harm reduction staff was used to locate harder to reach individuals. Counselling was provided to decrease the risk of transmission to others. Contacts were interviewed to determine eligibility for postexposure prophylaxis. Case and contact information was entered into the Ontario-wide integrated Public Health Information System (iPHIS).

### Molecular sequencing

Hepatitis A virus genotyping and molecular sequencing is not routinely performed in Ontario, but was performed as part of this outbreak investigation. Serum specimens that were sent to the Public Health Ontario Laboratories were forwarded to the National Microbiology Laboratory in Winnipeg, Manitoba for genotyping and molecular sequencing where possible, depending on availability of a serological sample at the diagnosing laboratory. Sequencing results were compared with strains from international outbreaks.



## Analysis

A line-list of HAV outbreak cases from January 1, 2017 to November 30, 2018 was extracted from iPHIS, and included information on age, gender, address, episode and reported date, risk factors and laboratory results.

Statistical analysis was performed with Stata Statistical Software: Release 15 (College Station, Texas, US: StataCorp LLC). Odds ratios were analyzed using simple logistic regression. Statistical significance was set at  $\alpha < 0.05$ .

Home addresses of confirmed outbreak cases were plotted using ArcMap 10.5 (Redlands, California, US: Environmental Systems Research Institute). A heat map was generated using point density and Global Moran's  $I$  test for spatial autocorrelation was applied to assess randomness of spatial distribution after applying a fishnet grid for aggregation of points.

In Toronto, some publicly funded vaccines, including HAV vaccines, are ordered directly from Toronto Public Health by healthcare providers. Therefore, the number of publicly funded HAV vaccines ordered by healthcare providers per month was known and were accessed through the Immunization Module of Panorama—the Ontario e-health immunization information system. A t-test was performed on the number of HAV vaccines ordered per month during the outbreak from June 2017 to October 2018 when targeted vaccine promotion efforts were implemented as part of the public health response compared with the number of HAV vaccines ordered per month from January 2012 to May 2017, to help evaluate whether vaccine promotion strategies may have affected vaccine ordering. Vaccines used by public health for contacts for postexposure prophylaxis were not included in this analysis.

## Public health response

Early in the outbreak, all HAV case investigators were trained on enhanced surveillance, including asking about sexual risk factors and sexual orientation. They were also trained on exposures related to illicit drug use.

The following initiatives were undertaken to promote preexposure vaccine uptake among MSM:

1. Alerts were sent to healthcare providers through the Toronto Public Health Communiqué, an e-newsletter with approximately 4,200 subscribers (four updates were sent between June 2017 and June 2018).
2. Three social media campaigns, involving Facebook, Instagram, Twitter and Grindr, were held during the outbreak period (November 2017, January 2018 and one in June preceding the Pride Toronto 2018 festival). Facebook and Grindr were both selected as these platforms allow for targeting an audience very specifically and because users connect socially to one another using these platforms. Grindr, a geosocial networking app oriented towards MSM

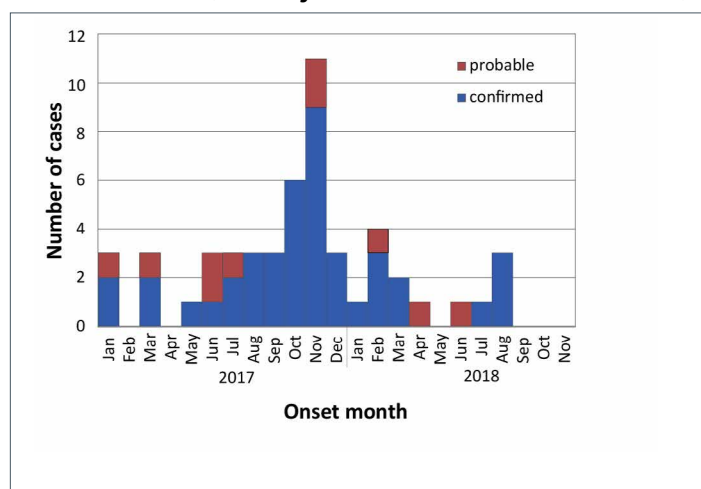
particularly supported highly targeted vaccine promotion to this population. The campaigns were evaluated and included metrics such as monitoring the number of impressions (how often the messages were viewed), engagement (action taken on the message), web traffic to the Toronto Public Health HAV webpage, and monitoring the relative interest in Ontario web searches of 'hepatitis a' through Google Trends, a campaign evaluation metric that provided insight into online search trends during the outbreak period.

3. A small number of HAV vaccine clinics for MSM were held within the area of Toronto where many lesbian/gay/bisexual/transgender/queer and others (LGBTQ+) individuals are known to live and where hepatitis cases were clustered (February 2018).
4. Letters were sent to sexual health clinics as well as general healthcare providers who treat sexually transmitted infections (June 2018).

## Results

Figure 1 shows an epidemic curve of outbreak cases by month of onset from January 1, 2017 to November 30, 2018. In total, there were 42 confirmed and 10 probable cases. The outbreak was declared over on November 1, 2018, two months after the last reported case. During the outbreak, Toronto Public Health also received reports of 46 HAV cases that did not meet the outbreak case definition.

**Figure 1: Epidemic curve of confirmed and probable outbreak cases of hepatitis A in Toronto, Ontario, by month of onset (January 1, 2017–November 30, 2018)**



Note: No outbreak cases were reported to Toronto Public Health in February and April, 2017 and May, September, October and November 2018

Characteristics of confirmed and probable HAV outbreak cases are provided in Table 1. The majority of confirmed outbreak cases were male (79%;  $n=33/42$ ), with a mean age of 38 years. Of the 29 confirmed male cases for which information was available, more than half (59%;  $n=17/29$ ) reported an MSM exposure risk factor, in comparison with the previous five year proportion of



4% of HAV cases reporting an MSM exposure risk factor. Nearly half of the confirmed cases (both males and females) reported illicit drug use (49%;  $n=20/41$ ) and 10% ( $n=4/42$ ) reported being homeless or underhoused. Of the confirmed cases, the majority of those who reported illicit drug use also reported an MSM exposure risk factor (65%;  $n=13/20$ ). Illicit drug use was often reported as a co-risk factor with MSM and very few cases (4%) reported illicit drug use in isolation of other risk factors. More than half of the confirmed cases (56%;  $n=23/41$ ) required hospitalization. No outbreak-related risk factors of interest were reported in 43% ( $n=18/42$ ) of the confirmed cases.

**Table 1: Characteristics of hepatitis A virus cases meeting confirmed and probable outbreak case definitions Toronto, Ontario (January 1, 2017–November 30, 2018)**

Characteristics <sup>a</sup>	Outbreak cases					
	Confirmed (n=42)		Probable (n=10)		Total (n=52)	
	n	%	n	%	n	%
<b>Gender</b>						
male	33/42	79	10/10	100	43/52	83
female	9/42	21	0/10	0	9/52	17
<b>Age</b>						
mean age	38.1	38.1	39.4	39.4	38.4	38.4
<b>Risk factors</b>						
MSM	17/29	59	8/10	80	25/39	64
illicit drug use <sup>b</sup>	20/41	49	3/9	33	23/50	46
illicit drug use <sup>b</sup> with no other risk factors	2/36	6	0/9	0	2/45	4
cannabis use	9/40	23	3/9	33	12/49	24
travel	0/38	0	10/10	100	10/48	21
homeless/underhoused	4/42	10	0/10	0	4/52	8
none reported	18/42	43	0/10	0	18/52	35
<b>Co-infections</b>						
HIV co-infection	6/40	15	3/10	30	9/50	18
previous/current STI	13/40	33	5/10	50	18/50	36
<b>Morbidity</b>						
hospitalization	23/41	56	4/10	40	27/51	53
<b>Strain</b>						
VRD_521_2016	26/32	81	0/4	0	26/36	72
RIVM HAV16-090	1/32	3	2/4	50	3/36	8
V16-25801	0/32	0	1/4	25	1/36	3
non-outbreak strain	5/32	16	1/4	25	6/36	17

Abbreviations: MSM, men who have sex with men; STI, sexually-transmitted infections

<sup>a</sup> Denominators reflect counts of cases where information on each characteristic was collected

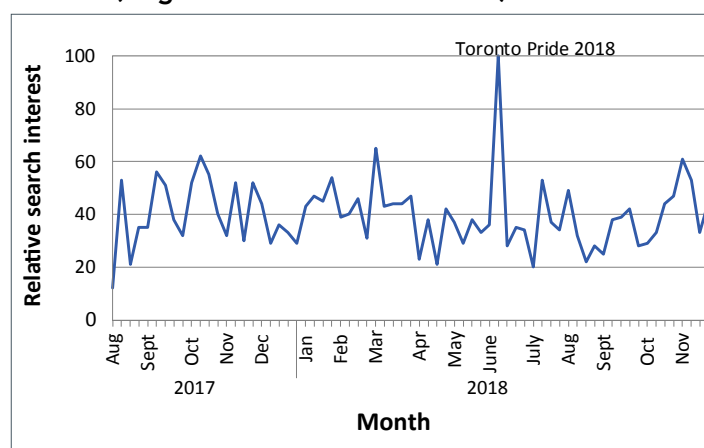
<sup>b</sup> Reported illicit drugs included cannabis, G liquid, 3,4-methylenedioxymethamphetamine (MDMA, ecstasy), opioids/fentanyl, non-injection cocaine, crystal methamphetamine, heroin and crack

Sequencing results were received for 36 cases (confirmed and probable). Of these, 83% ( $n=30/36$ ) had one of the three strains seen circulating in outbreaks among MSM internationally. The majority (72%;  $n=26/36$ ) were the VRD\_521\_2016 strain. This outbreak strain was noted as the most common strain in the MSM outbreaks reported in the European Union (4) and was also reported in South American outbreaks affecting MSM and in New York City (11,12). An outbreak strain was significantly more likely to be sequenced among confirmed cases where at least one risk factor was reported as compared with those where no risk factor of interest was reported (odds ratio: 8.14; 95% confidence interval: 1.32-50.3).

Home addresses were obtained and mapped for 38 confirmed outbreak cases. Global Moran's I test for spatial autocorrelation showed that spatial distribution was statistically not random (Moran's Index: 0.15,  $p$ -value <0.001) and there was relative clustering observed in one of the areas in downtown Toronto popular with MSM and LGBTQ+ communities.

Evaluation of the social media campaigns showed that messaging timed with the Pride Toronto 2018 festival may have had the most impact in terms of number of views and engagement with the campaign. **Figure 2** shows a graph of the Google search term for 'hepatitis a' for Ontario over time relative to the highest point of interest, which coincided with the Pride Toronto festival in June 2018.

**Figure 2: Number of Google searches on 'hepatitis A' in Ontario (August 2017–November 2018)**



Notes: Y-axis reflects search interest over time (x axis). The highest point on the chart coincided with Toronto Pride in June 2018

Orders for HAV vaccine increased during the peak of the outbreak (June 2017 to November 2018) compared with before the outbreak. The monthly mean number of HAV vaccines ordered from June 2017 to October 2018 was 348, compared with a monthly mean of 257 from January 2012 to May 2017 ( $t=4.72$ ,  $p<0.001$ ). A total of 105 vaccines were given at the six MSM preexposure clinics that were held by Toronto Public Health in early 2018.



## Discussion

To our knowledge, this is the first published report of a sustained HAV outbreak disproportionately affecting an MSM population in Canada in over twenty years. Several outbreaks from the 1990s have been summarized (13). Then in 2016 and 2017, multiple HAV outbreaks affecting MSM were reported internationally (4,5,11,12). In the 2017–2018 outbreak we described, clustering was observed in an area of Toronto where many people live who identify as being part of the MSM and LGBTQ+ communities. Viral sequencing of the strains of this outbreak matched those of the international outbreaks. Social media and other outreach strategies used in similar outbreaks (e.g. New York City, US) were used in the Toronto outbreak to develop targeted vaccine promotion.

All three HAV strains originating in recent international MSM outbreaks (5) were detected in this outbreak, with VRD\_521\_2016 being the most common. VRD\_521\_2016 was also the first strain noted to be circulating in the European Union MSM outbreaks (5). Based on the epidemiological curve, sequencing information and travel information collected from cases reporting MSM exposure, it is possible that importation of the strains circulating outside of Canada occurred prior to and during Pride Toronto 2017. This suggests importation of these strains into Toronto in June 2017 and subsequent local transmission through to mid-2018. As other recent outbreak reports in low endemic areas have concluded, a combination of international travel and sexual networks can sustain a large outbreak of HAV within a susceptible population (4).

In Ontario, MSM can access the publicly funded HAV vaccine for preexposure prophylaxis. This program has been in place since 1997; however, this recent outbreak demonstrates that immunity levels among MSM were not sufficient to avert an outbreak. Currently, to obtain the publicly funded HAV vaccine, healthcare providers need to document MSM, drug use or other risk factors, and to offer safer sex counselling. The need for disclosure of these risk factors may reduce the effectiveness of the high-risk HAV vaccination program and may be a barrier to maintaining sufficiently high preexposure vaccination coverage. Prior modelling studies have estimated that immunity levels of 70% or more would be needed among MSM to prevent an outbreak (14). Illicit drug use among cases was monitored, and there was significant overlap in cases who reported an MSM exposure and a drug use exposure. This finding may be related to prior research among MSM that has shown a relationship between substance use and increased sexual risk behaviors (15).

Alerts to healthcare providers, social media and traditional communication campaigns were used to increase awareness of the outbreak and promote vaccination and these were followed by a significant increase in HAV vaccine orders by Toronto

healthcare providers. Only four new cases were reported after the Pride Toronto 2018 campaign, and the outbreak was declared over in November 2018. The use of social media campaigns appeared to be an effective strategy to raise awareness of HAV among MSM in Toronto.

## Limitations

This analysis, based only on HAV cases that were reported, likely underestimates the true extent of this outbreak. The hospitalization rate observed in this outbreak was higher than typically quoted for this disease; 56% of confirmed cases required hospitalization during this outbreak. However, this is similar to another report that hypothesised the higher hospitalization rate may be due to increased case ascertainment (4).

For 18 confirmed cases, a risk factor of interest for locally-acquired person-to-person transmission could not be ascertained; their epidemiologic link to the outbreak remains unknown. These cases were significantly less likely to have an outbreak viral sequence and, therefore, may be unrelated to the outbreak. Cases with the outbreak viral sequence may represent local transmission into the general population, as reported in other outbreaks (16,17). Or, these cases may have been misclassified due to reluctance of cases to disclose sexual activities, orientation or illicit drug use. As the outbreak progressed, Toronto Public Health staff changed their interview practices to more specifically ascertain risk factor information for local HAV cases. Therefore, comparisons to prior years should be interpreted with caution.

An online vaccine ordering platform was introduced during the outbreak time period and may have contributed to higher vaccine orders. Further, the data pulled from Panorama did not enable us to separate out vaccine orders for MSM compared with other high-risk groups. The extent of the baseline vaccination coverage of MSM in Toronto is unknown; therefore, the degree to which this population is protected is also unknown.

## Conclusion

Outbreaks of HAV, caused by person-to-person transmission of strains of HAV that disproportionately affect MSM have now occurred in Canada. These strains were likely to have been imported from international MSM outbreaks. At-risk populations were identified using a combination of HAV sequencing results and descriptive analysis of risk factor information—facilitating targeted vaccine promotion. The use of targeted social media campaigns appears to be an effective strategy to promote HAV awareness and vaccine uptake among MSM during the outbreak period. Periodic assessment of vaccine coverage rates in MSM and further study on how best to ensure they are maintained at high levels may help to mitigate future outbreaks.



## Authors' statement

HS oversaw the outbreak management and the writing of the manuscript  
 MB conceived the first draft of this manuscript  
 SO and MB analyzed the epidemiological data  
 JM oversaw and evaluated the social media campaigns  
 VD, JM, RS, and SO were involved in the outbreak management  
 AA provided viral sequencing and interpretation  
 All authors were involved in the editing and revisions of the manuscript

## Conflict of interest

None.

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M Finkelstein and CC Hui (the latter on behalf of the Toronto Public Health men who have sex with men workgroup) helped edit the manuscript.

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# SPREAD THE WORD ABOUT FLU PREVENTION

[illegible]



# A farewell and a welcome: Passing the baton

P Huston<sup>1\*</sup>

It has been a pleasure and a privilege to be the Editor-in-Chief of the *Canada Communicable Disease Report* (CCDR) from 2013 to 2019. Over this time, the journal saw enormous growth in terms of readership and number of scientific articles, two redesigns and the introduction of new features, such as author checklists, Rapid Communications, infographics and visual abstracts. In addition, CCDR was reestablished on PubMed a few years ago. In 2013, the Editorial Office started with desks, computers, and a few back issues of the journal. The former office had closed when the Public Health Agency of Canada (PHAC) was created in 2004, following the retirement of the former Editor-in-Chief, Eleanor Paulson. For almost a decade, there were no peer-reviewed articles and CCDR published primarily Advisory Committee Statements and summaries of FluWatch. There had been calls to reinstate the journal, including from the Public Health Network Council. In the spring of 2013, the journal office was reinstated as a two-year pilot project. With the unanimous support from all the Centres in the Infectious Disease Prevention and Control Branch, ongoing funding for the journal was secured in 2014.

Publishing a journal is much like raising a child—it takes a village. CCDR is the result of a small dedicated team. My deep thanks to the Editorial Coordinator, Production Editor and Web Advisor who put together the issue month after month with help from many peer-reviewers, copy-editors, translators, students, a consulting graphic designer and, increasingly, the Associate Scientific Editors. Different Managing Editors have joined as a developmental assignment and have made unique contributions. Many thanks to the CCDR Editorial Board: initially members were enthusiastic colleagues from PHAC and then, as the Board matured, it morphed into the international Board we have today. All through the years, the advice and support of Board members has been incredibly sustaining. Dr. John Last, who recently passed away at the age of 93 years, was an important mentor. In the early 1990s, he encouraged me to become an Editor and continued to provide his friendship and sagacity for many years after he formally retired. One of the joys that we shared of being an Editor-in-Chief was the opportunity to work with authors to transform manuscripts from “diamonds in the rough” to articles that readers find succinct, illuminating and useful. I have learned so much in the process of this work.

And now it is time to become the Editor Emeritus and pass the baton.

I would like to welcome Dr. Michel Deilgat as CCDR's new Editor-in-Chief. Dr. Deilgat is a public health physician who, after decades with the Canadian Armed Forces as a military physician, has a wealth of experience in operational, occupational and preventive medicine. Dr. Deilgat has been a medical advisor at the Centre for Food-borne, Environment and Zoonotic Infectious Diseases (CFEZID) at PHAC since July 2011, and has helped develop a new generation of public health professionals as a preceptor for Western University's Master of Public Health program. Dr. Deilgat has a Master's degree in Public Administration (École nationale d'administration publique; Université du Québec), a Master's degree in Health Professions Education (M.Ed.; University of Ottawa) and is currently completing a Master's degree in Information Studies (University of Ottawa). Dr. Deilgat has been an Editorial Board member since 2014. I am confident the journal will continue to flourish with Dr. Deilgat's strong links to academia and his commitment to lifelong learning.

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## Affiliation

<sup>1</sup> Office of the Chief Science Officer, Public Health Agency of Canada, Ottawa, ON

## \*Correspondence:

[phac.ccdr-rmtc.aspc@canada.ca](mailto:phac.ccdr-rmtc.aspc@canada.ca)





## Challenges of Open Science

**Source:** Rockhold F, Bromley C, Wagner EK, Buyse M. Open science: The open clinical trials data journey. Clin Trials. 2019 Jul 26;1740774519865512. DOI. [Epub ahead of print].

Open data sharing and access has the potential to promote transparency and reproducibility in research, contribute to education and training, and prompt innovative secondary research. Yet, there are many reasons why researchers don't share their data. These include, among others, time and resource constraints, patient data privacy issues, lack of access to appropriate funding, insufficient recognition of the data originators' contribution, and the concern that commercial or academic competitors may benefit from analyses based on shared data. Nevertheless, there is a positive interest within and across the research and patient communities to create shared data resources. In this perspective, we will try to highlight the spectrum of "openness" and "data access" that exists at present and highlight the strengths and weakness of current data access platforms, present current examples of data sharing platforms, and propose guidelines to revise current data sharing practices going forward.

## Making Open Science Work

**Source:** Elliott KC, Resnik DB. Making Open Science Work for Science and Society. Environ Health Perspect. 2019 Jul;127(7):75002. DOI. Epub 2019 Jul 29.

**Background:** The open science movement is transforming scientific practice with the goal of enhancing the transparency, productivity, and reproducibility of research. Nevertheless, transparency is a complex concept, and efforts to promote some forms of transparency may do relatively little to advance other important forms of transparency.

**Objectives:** Drawing from the literature in history, philosophy, and sociology of science, we aim to distinguish between different forms of scientific transparency. Our goal is to identify strategies for achieving forms of transparency that are relevant not only to scientists but also to decision makers and members of the public.

**Discussion:** We draw a distinction between "scientifically relevant transparency" and "socially relevant transparency." Most of the prominent strategies associated with the open science movement (e.g. making data publicly available and registering studies) are designed primarily to promote scientifically relevant transparency. To achieve socially relevant transparency, which is particularly important in fields like environmental health, further steps are needed to provide scientific information in ways that are relevant to decision makers and members of the public.

**Conclusion:** Promoting socially relevant transparency will require a range of activities by many different individuals and institutions. We propose an array of strategies that can be pursued by scientists and other scholars, journals, universities, funders, government agencies, and members of the public.



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Public Health Agency of Canada  
130 Colonnade Road  
Address Locator 6503A  
Ottawa, Ontario K1A 0K9  
[phac.ccdr-rmtc.aspc@canada.ca](mailto:phac.ccdr-rmtc.aspc@canada.ca)

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