

## Chapter 39

# Notifiable Disease Databases for Client Management and Surveillance

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### ABSTRACT

*The spread of certain infectious diseases, many of which are preventable, is widely acknowledged to have a detrimental effect on society. Reporting cases of these infections has been embodied in public health laws since the 1800s. Documenting client management and monitoring numbers of cases are the primary goals in collecting these data. A sample notifiable disease database is presented, including database structure, elements and rationales for collection, sources of data, and tabulated output. This chapter is a comprehensive guide to public health professionals on the content, structure, and processing of notifiable disease data for regional, provincial, and federal use.*

### INTRODUCTION

Under public health acts in all Canadian provinces, physicians, laboratories, nurses and other health professionals are required to report data on individuals with infections of public health importance to health departments. This chapter reviews legislation that requires the reporting of notifiable infections, the public health reasons behind reporting, and the design, use, and improvement of notifiable disease registries. There are few academic Canadian papers on legislation and implementation of notifiable disease programs. Therefore, this chapter references all of those and some from the United States, United Kingdom, and Europe so as to further elucidate the objectives, philosophy and processes behind disease reporting. The goal is to provide a thorough guide for developing and improving notifiable disease databases in order to accurately document public health surveillance and client management activities. This chapter is aimed at public health staff primarily in Canada, but also in other jurisdictions interested in systematically collecting notifiable disease data, with attendant legal and public health rationales.

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Together with a flexible structure, these data will allow for proper management of cases and contacts, improves surveillance practices, and timely notification of outbreaks. The chapter includes data extraction standards for regular reports and outbreak detection.

The structure and content of notifiable disease registries varies substantially in Canada. As with many health databases, data are frequently collected and stored in a manner preventing easy access or analysis. To substantiate the data requirements, this chapter references various provincial public health acts. As many provincial acts contain the same provisions in similar language, the reader may refer to the relevant one in his/her own jurisdiction.

## **BACKGROUND**

Public health laws stem from the industrial revolution. During that time, states were challenged with diseases emanating from undeveloped infrastructures for concentrated housing, migration to cities, and poor working conditions. Public health laws are an instrument of public health practice enacted through a democratic process which itemize measures to be taken by the government to preserve public health (Chorba, Berkelman, Safford, Gibbs, & Hull, 1989; Gostin, 2004; Sepulveda et al., 1992; Stephen B Thacker & Berkelman, 1988). This section describes the implementation of these laws, regulations, and policies as they affect data collection for the investigation and monitoring of notifiable infections.

### **Public Health Acts in Canada**

In Canada, public health acts are enacted and administered by each province and their jurisdictions. Most start with a purpose clause, allowing the health minister or delegate (usually a medical officer of health) to prevent disease and promote the health of residents (Prince Edward Island Public Health Act, 2014; Quebec Public Health Act, 2016). They contain very broad powers for a minister of health or a delegated medical officer of health to do anything, including forbid or order an action to prevent a hazard (Ontario, 2015; Quebec Public Health Act, 2016).

As part of disease prevention, records of infected individuals are required to be reported to a medical officer or a delegate so that:

1. Sources are investigated (Ontario, 2015) and patients are treated appropriately (Chorba et al., 1989; Northwest Territories Public Health Act, 2011).
2. Incidence of infections are monitored regularly to distinguish unusual frequency, manifestations, demography, and locations with the goal of preventing disease (British Columbia, 2016; Quebec Public Health Act, 2016).
3. Mandated surveillance system is evaluated.
4. Patient management is audited.
5. The control program is evaluated.

The first two goals are most commonly cited in legislation and public health surveillance texts. Goals 3, 4, and 5 are also important for the purpose of quality public health professional practice, government financial accountability, and to clarify health department responsibilities for disease prevention efforts (Campbell, 2004; Gostin, 2000; Jajosky & Groseclose, 2004).

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