

# The future of health informatics and electronic health records: a look at the Canadian surveillance systems

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## Abstract

In the 21<sup>st</sup> century of information and technological advancement, the emergence of health informatics and use of software applications have in no measure transformed the way surveillance is carried out. The investment in bioterrorism and automated surveillance systems has further stimulated new informatics methods in the public health sector. Thus, it suffices to say that informatics methods and systems have the potential to improve the quality and consistency of clinical preventive services. Importantly, there are wide ranges of applications in use in the aspect of surveillance, epidemiology, prevention and control.

The importance of sharing surveillance data and health data between and among agencies is essential to early warning systems in terms of disease spread and bioterrorism. It is vital to have a comprehensive and effective surveillance system in place so as to monitor disease trend and to ensure that information delivered are accurate, timely and complete; this strategy aims to prevent outbreaks and to protect the health of the public. However, this is not possible without a functional info-technology system in place such as the availability of a computer system to aid in effective tracking, identifying, collecting, validating, and analyzing data; this measure would ensure that the public and other stakeholders are well informed on any possible outbreaks for necessary measures to be put in place.

There is need for other economically advanced countries to take a leave from Canada as the government is internationally recognized not only as a leader in health care prevention and promotion but also a founder of the healthy communities' movement; this could not have been possible without the government's strong commitment to fundamental change towards bringing an enviable healthcare to the door steps of Canadians.

**Key Words:** Electronic health records, Surveillance, Tele-health, Tele-medicine, Syndromic Surveillance, Canada

## 1. Introduction

The concept of public health surveillance has evolved over time; it began in Europe in the 14<sup>th</sup> century through the emergence of scientific thought during the Renaissance spreading to the U.S. by European settlers. During that period, surveillance was done by closely observing persons exposed to infectious diseases through detection of early symptoms so that prompt isolation and control measures could be instituted<sup>1,3</sup>.

Surveillance, a branch of epidemiology has in the last decade developed into a complete discipline within the public health sector with its own objectives, data sources, methodologies and evaluation procedures<sup>1,2,3</sup>. Surveillance could be defined as an ongoing collection of data using methods that are distinguished by their practicability, uniformity, rapidity, and usefulness within the context of timeliness so that information received would be used for action<sup>1,3,4</sup>.

## 2. Health Informatics and Surveillance

Public health informatics is a central systemic application that aims to protect and promote health of a community, and prevent disease, injury and disability<sup>1,3,5</sup>. In achieving this, there is the need to have a comprehensive and effective surveillance system in place so that there would be vigorous monitoring of diseases trends and that any information delivered must be accurate, timely and complete. This is one of the most important ways to prevent outbreaks and also protect the health of the public. Furthermore, there is need to underscore the importance of using computer system to effectively track and inform the public, as well as other stakeholders on disease outbreaks so that necessary measures would be put in place. Additionally, in this 21<sup>st</sup> century of technological advancement, there are different applications in use that supports the public health surveillance systems; these applications often involve programming and use of the database<sup>1,3,5</sup>.

## 3. Issues of Interoperability and Data Sharing

In early 21<sup>st</sup> century, the various health departments that implemented syndromic surveillance systems had greatly transformed data collection and analysis notwithstanding the obstacles that continue to negatively impact interoperability of such systems<sup>1,3,5</sup>. There is no doubt that health informatics has eased up how

surveillance is done hence the need to remind ourselves that the prime objective of surveillance systems is the interoperability of multiple systems at especially the three tiers (e.g. local, state, and federal) so as to effectively track, monitor and create a better understanding of disease across a geographical setting and the globe as a whole<sup>1,5,9</sup>.

It is a fact that advancement in information and telecommunication technology has opened up enormous opportunities and has transformed public health across the globe with the emergence of modern and advanced applications in health informatics and biosurveillance<sup>1,3,5,9</sup>. Importantly and for public health leaders to bring social change to the community, there is need to underscore the importance of sharing surveillance data and health data between and among agencies; this is essential to early warning systems in terms of disease spread and bioterrorism. This effort ensures that various the health institutions on the surveillance network exchanges and shares data with other agencies and organizations to protect the health of the nation as a whole<sup>1,3,5,9</sup>.

The advances recorded in public health informatics has greatly transformed surveillance activities across the globe and especially in the world most industrialized countries; this has greatly empowered public health practitioners and the public as well thus enabling them to have access to health information so as to protect and promote good health at a population level<sup>5</sup>. However, these advancements are not without challenges, which are often associated with implementing the electronic disease surveillance system at various government levels. The need for all health departments to work in a coordinated fashion in the interest of public health was highlighted, hence the need for local health departments to keep pace with the modern public health informatics<sup>5,9</sup>.

#### **4. Traditional and Syndromic Surveillance**

Syndromic surveillance is defined as an ongoing, systematic collection, analysis, and interpretation of ‘syndrome’-specific data for early detection of public health aberrations<sup>10</sup>. Information is an important tool in every organization as it aids in the way the organization functions to achieve its aims and objectives. More so, in the field of public health, information enables health officials to forecast outbreaks and study disease trends for prompt action to be taken so as to avoid adverse consequences to the public.

The world is now facing increasing challenges more than ever before both natural and man-made threats hence the need to have a perfect real time online surveillance system in place, as this would ensure timeliness, accuracy, reliability, and completeness. It is on record that disease surveillance has positively transformed especially with the use of different applications that supports disease reporting and tracking notably among which are applications that involve programming and use of database<sup>5,10</sup>. Importantly, there are new disciplines that emerged in the field of public health and importantly this includes public health informatics. Public health informatics, which has a major focus on syndromic surveillance and outbreak detection, is defined as “the systematic application of information and computer science and technology to public health practice, research, and learning.” It aims to protect and promote the health of a community, and prevent disease, injury and disability<sup>5,10</sup>.

In public health, there is the need to have a comprehensive and effective surveillance system in place to enable vigorous monitoring of diseases trends and to ensure that information delivered are accurate, timely and complete. This is one of the most important ways to prevent outbreaks and also protect the health of the public. It is because of the importance of technology in public health disease surveillance that the use of computer system was highlighted in effective tracking, identifying, collecting, validating, and analyzing data so that public and other stakeholders would be well informed of possible outbreaks for necessary measures to be in place<sup>5,10</sup>.

In comparison to public health informatics, traditional disease surveillance has a slow and incomplete reporting system as it often relies on reports from laboratory diagnosis to make inferences which is rather time consuming. It is as a result of this and the increasing threats from bio-surveillance that new breed of public health surveillance systems emerged which has the potential to significantly speed up detection of disease outbreaks<sup>5,10</sup>.

The computer-based surveillance systems that are in place especially in technologically advanced countries clearly offer valuable and timely information to all reporting sites ranging from hospitals to state, local, and federal health officials<sup>10</sup>. The sensitivity of these systems is such that they detect diseases and harmful biological agents, as is the case with bioterrorism, and in a real-time online fashion thus allowing for a prompt public health response.

Furthermore there is need to safeguard surveillance data as it serves as an important source for deriving valuable information for health professionals and policy makers to enable them act accordingly<sup>10</sup>. The task that lies ahead of public health specialists is their ability to validate, filter and judiciously use data and information from what is reported to them to determine what might be considered “actionable intelligence.”<sup>10</sup>

#### **5. Information sharing and Ethics**

Information sharing among these applications enables public health personnel to better understand disease trends that may be difficult to interpret from the examination of a single system. However, a variety of legal, ethical, and practical issues arise as a result of this sharing of information. The potential for problems is magnified when information is available to and shared among multiple systems. There is need to integrate systems as lack of doing so would negatively impact establishing surveillance networks to improve on timely disease detection, so as to protect the health of the public<sup>1,3,5,9</sup>. There is need for public health applications to be user friendly and works without conflicts between the applications to enable them operate smoothly. Thus it is important to avoid issues of simple measurement and network issues, systems incompatibility, and system security that pose significant challenges on interoperability of systems; this could potentially hinder our understanding of the health informatics system and consequently affect health outcomes.

In modern public health concept, there is need for all stakeholders to operate within the confines of ethics; this more so when working on or sharing data during daily routines<sup>6</sup>. Furthermore, dealing with data of individuals or groups clearly requires adherence to ethical norms from collection, usage and sharing. Thus in practice, there is need to respect the right of the subjects from research work through data collection of individuals or groups<sup>6</sup>. As a result of ethical considerations with respect to sharing health data, it is important to adhere to the codes and policies for research ethics which include: honesty, objectivity, integrity, carefulness, openness and respect for intellectual property, confidentiality, respect for colleagues, responsible publication, responsible mentoring, social responsibility, non-discrimination, competence, legality, animal care and protection of the human participants<sup>6,7,8</sup>.

There are situations when conflicts could arise on issues that relate to right of individual with that of the state such as sharing of surveillance data on disease condition for action between health institutions and government agencies. It is reassuring to note that the Center for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists (CSTE) has a list of notifiable diseases that reporting is voluntary<sup>1,3,5,9</sup>.

Ethics could be defined as “norms for conduct that distinguish between acceptable and unacceptable behaviour.” It is documented that when dealing with health data or information of individuals, it is important to adhere to ethical norms from collection, usage and sharing. In research there is need to respect the right of the subjects from research work through data collection of individuals or groups<sup>6</sup>.

In relation to research work, the basis of ethics should aim to promote values that are essential to collaborative work, ensure that researchers can be held accountable to the public, help to build public trust and support for research, as well as promote a variety of other important moral and social values<sup>6,8</sup>. As a result of ethical considerations with respect to sharing health data, researchers are required to adhere to the codes and policies for research ethics which include: honesty, objectivity, integrity, carefulness, openness and respect for intellectual property, confidentiality, respect for colleagues, responsible publication, responsible mentoring, social responsibility, non-discrimination, competence, legality, animal care and protection of the human participants<sup>6,7,8</sup>.

However, it is considering the ethical implications associated with sharing or disclosing data source that Institutional Review Boards (IRB) stipulates that researchers need to have their research plan reviewed and also the need for informed consent acknowledging that participants’ right would be protected during data collection<sup>6,7,8</sup>. The challenge that may arise on issue of confidentiality is a situation where data from a specific community with a disease of public health importance being kept confidential and only used for action, that some individuals from the community might not want it to be treated confidentially but rather the data be shared and made public<sup>8</sup>.

When this is compared with use and sharing of surveillance data of a disease condition for action between health institutions and government agencies, this leads to the issue fundamental human right of the individual. It is important to note that although the Center for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists (CSTE) has a list of notifiable diseases, the reporting is voluntary<sup>5</sup>. The U.S. government has no established law requiring health establishments to supply data for syndromic surveillance. The fundamental human right of individual is of utmost importance and thus surveillance systems should not threaten confidentiality of individual or a given population hence the need to create a balance between protecting an individual’s identity on health issues with that of the community<sup>12</sup>.

When there is conflict as to whether protecting individual’s identity takes precedence that protecting health of the public, it suffices to say that consideration should be given to ensuring good health of the public health than that of an individual hence the concept of population health<sup>15</sup>.

It is on record that HIPPA (Health Insurance Portability Accountability Act) establishes privacy rights for the American citizens to protect their private medical information; however, when conflict arises on protecting individual’s identity or protecting health of the public, consideration should be given to protecting the health of the public health hence the concept of population health<sup>13</sup>. There is no doubt that there are laws which

protect individual's privacy and personal identifiable health information and that notwithstanding preference should be given to protecting public health<sup>15</sup>.

## 6. The Canadian Surveillance Systems and Electronic Health Records

Improved communication and healthcare has remarkably transformed the practice of public health and healthcare delivery at a population level spanning from diseases surveillance to health promotion especially through the use of health informatics and electronic health records (EHRs). This is one of the reasons why the Canadian government has committed billions of dollars in the past decade towards the use of EHRs<sup>14,16</sup>.

It is encouraging to note that Canada is recognized internationally as a leader in health care prevention and promotion, and also a founder of the healthy communities' movement; this is due to the government's strong commitment to fundamental change towards bringing an enviable healthcare to the doorsteps of Canadians<sup>17</sup>. Furthermore, the Canadian government has been able to maintain an extensive partnerships among various decision-makers spanning from the federal, provincial, and territorial governments; chronic disease and health promotion alliances; researchers; public health practitioners and public health organizations and non-governmental organizations all working together across the country at all times<sup>19</sup>.

The two Canadian disease surveillance systems considered here are the notifiable diseases online (NDO) and chronic disease infobase (CDI). The designing and development of these two systems was a collaborative effort spearheaded by the Public Health Agency of Canada (PHAC) and with the end-user in mind<sup>5,19</sup>. The systems were designed to be user friendly and such that there is the handler, the processor, the analyzer and the presenter<sup>5,19</sup>.

The NDO is a web-based application of the Public Health Agency of Canada developed by the notifiable diseases section so as to enhance dissemination of surveillance data on all notifiable diseases collected across Canada. Here reporting is made based on the agreed criteria (from consensus among provincial, territorial and federal health authorities) and in accordance with list of notifiable diseases at the federal level. This aims to facilitate tracking of notifiable diseases for adequate control measures to be in place and also promote uniformity in the reporting channels in conformity with the international standards of reporting. The system has information on number of cases reported and rate for each province and territory from 1989; this information and data depends on what the provinces and territories reported. Furthermore, case definitions and confirmatory tests are also subject to change by the reporting channels and this could affect the rates over time<sup>20</sup>.

The chronic disease infobase (CDI), which operates on advanced infotech, provides access to an updated and extensive database on records non-communicable diseases (especially cancers, cardiovascular and respiratory diseases). The information and data contained in the system is based on reports from health units from across the provinces, territories and regions in Canada. Furthermore, users of this system could also access information on demography, mortality, morbidity, risk factors and related health care data of these diseases<sup>18</sup>.

## 7. Conclusion

In spite some ethical issues, the future holds bright for health informatics and electronic health records. Hence, integrating informatics methods into traditional surveillance is of paramount importance in the modern public health concept. This is with a view to effectively protect and promote the health of a community, and prevent disease, injury and disability. The shift from traditional surveillance methods to syndromic surveillance especially in the economically advanced countries clearly reminds us the importance of bio-surveillance, as there is increasing threat from both human and natural sources. It is clear that there is need to have unhindered access to flow of electronic information of public health importance so as to collect, synthesize, analyze and effectively disseminate the information to safe guard the health of the public.

Additionally, and looking at the future of health informatics, there is need to integrate data from all stakeholders, create a unique or improve on global surveillance systems through collaboration and sharing of technologies between developed and developing countries to avoid computer system application conflict, and to agree on standards for data sharing to create a database for all diseases. In the case of developing economies, there is future in the use of health informatics though with enormous challenges that are all centered on lack of resources and poor political commitment. Furthermore, there is need for countries across the globe to copy from the government of Canada so that improvement in the systems would yield tangible results that would improve on preventive healthcare; create additional economic stimulus through job creation; improve healthcare delivery by harmonizing records; as well as improve on syndromic surveillance<sup>14,17</sup>.

In developing countries, the adoption of the EHRs would help in transforming healthcare delivery especially in the preventive and curative areas; this would also create economic stimulus through job creation, improved healthcare delivery by harmonizing records, saving patient's lives, saving physician and patient's time, improve access to care by patients, as well as save the taxpayers money. However, this is not without some challenges more especially the lack of adequate resources, poor infrastructural facilities, lack of man-power, lack

of stable electricity supply, lack of government commitment on healthcare delivery, insecurity from insurgents, massive corruption by the political class.

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