

The Essential Role of Unique Identifiers in Public Health Practice

Association of Local Public Health Agencies
August 2011

The Essential Role of Unique Identifiers in Public Health Practice

Contents

EXECUTIVE SUMMARY	i
1. PURPOSE	1
2. INTRODUCTION.....	1
The Health Protection and Promotion Act.....	1
Population and Individual Health	2
3. WHY DOES PUBLIC HEALTH NEED TO RELY ON UNIQUE IDENTIFIERS TO COLLECT DATA ON INDIVIDUALS?	3
Uses of Personal Demographic and Health Information	3
4. THE USE OF DATABASES IN PUBLIC HEALTH.....	4
Assessment.....	5
Surveillance	5
Program Evaluation	5
Linkages Among Programs.....	5
Linkages for Research.....	6
Uses of Database Studies	6
Examples of Databases Used By Public Health.....	6
A. The Integrated Public Health Information System (iPHIS).....	6
B. Immunization Reporting Information System (IRIS)	6
C. Oral Health Information Support System (OHISS)	7
5. RESEARCH AND KNOWLEDGE EXCHANGE.....	7
Research Ethics.....	7
6. CONCLUSION.....	7
7. REFERENCES	8

Acknowledgements

The Association of Local Public Health Agencies wishes to thank the members of the Information Privacy Working Group for their contribution to the development of this document.

Information Privacy Working Group Members from Health Units and other Organizations:

Dr. Eileen deVilla, AMOH, Peel Public Health Unit

Dr. Michael Finkelstein, AMOH, Toronto Public Health

Ms. Pat Hewitt, Manager, Public Health Administration, Halton Region Health Department/Performance Management Working Group Representative

Dr. Valerie Jaeger, MOH(A), Niagara Region Public Health Department

Dr. Robert Kyle, MOH, Durham Region Public Health Commissioner & Medical Officer of Health, Durham Region Health Department - alPHa CO-CHAIR

Mr. Bill Mindell, Director of Clinical Services, Simcoe Muskoka District Health Unit

Dr. Lynn Noseworthy, MOH, Haliburton, Kawartha, Pine Ridge District Health Unit

Ms. Jane Speakman, City Solicitor, City of Toronto

Ms. Linda Stewart, Executive Director, alPHa

Dr. Bryna Warshawsky, AMOH, Middlesex-London Health Unit

Provincial Members:

Ms. Mary Lou Daniels, Privacy Officer, Public Health Ontario (PHO)

Ms. Michèle Harding, Manager (A), Public Health Standards, Practice and Accountability Branch - MOHLTC CO-CHAIR

Mr. Paul Kaufman, Counsel, Legal Service Branch, MOHLTC/MHPS

Ms. Shelley Laskin, Senior Advisor, Ministry of Health Promotion and Sport (MHPS)

Mr. Andrew Lefebvre, Senior Analyst, Protection and Prevention Branch, Ministry of Health and Long-Term Care (MOHLTC)

Secretariat Staff:

Ms. Candace AQUI, Mr. Doug Gowans and Ms. Nicole Consitt, Public Health Standards, Practice & Accountability Branch, MOHLTC

Mr. Shawn Hewitt and Ms. Jennifer Dempster, Knowledge Management Branch, MOHLTC

The Essential Role of Unique Identifiers in Public Health Practice

EXECUTIVE SUMMARY

Public health is different from acute care. The primary focus of the 36 public health units in Ontario is the health and well-being of the whole population through the promotion of health and the prevention of illness.

Public health practitioners may and do provide services to individuals, such as immunization and follow-up for a number of reportable diseases, however the purpose of these services is to protect the health of the population. While individuals benefit from immunization, the larger benefit to society, i.e., stemming the spread of communicable diseases, is the focus of immunization as a public health intervention. This is different than the relationship between physicians and patients in, for example, the acute care sector where the focus is on the individual benefit.

To identify and mitigate factors affecting the health of populations (large or small) and to formulate future programs, social policies and public investments, it is often necessary to build or monitor evidence using individual personal information and data. In matters regarding health, the use of a unique personal identifier - in particular the Ontario Health Card Number - provides for objective reliable data, accurate linkage, and ensures efficient follow up for monitoring functions. Indicators and data, such as income level, age, sex and ethnicity, allow policy-makers to assess the distribution of health benefits and risks among the different population groups and to analyze progress towards achieving equity. Unique personal identifiers are the safest, most secure way of disaggregating this broad data for efficient collation, use and research. Without these data, many public health functions are subject to compromised reliability.

Unique personal identifiers, in particular the Ontario Health Card Number, are absolutely essential to public health for the management and administration of services provided to individuals, especially but not exclusively through immunization programs. Without the unique identifier, individuals receiving immunizations assume some risk of being misidentified and thus not receiving all immunizations, receiving unnecessary additional vaccinations or being inappropriately threatened with suspension from school, especially where large multicultural populations may be involved.

Program delivery, assessment, surveillance, program evaluation, research, and knowledge exchange are the foundations of modern public health. The *Ontario Public Health Standards* establish requirements for fundamental public health programs and services, which include assessment and surveillance, health promotion and policy development, disease and injury prevention, and health protection. The Health Protection and Promotion Act (HPPA, 1990) both requires and allows for the collection of personal and personal health information in the execution of the public health mandate.

Public health units must anticipate issues so that the risk to the health of persons and populations can be prevented, eliminated or decreased. Population health interventions frequently build on evidence found through the analysis of aggregated individual data. The use of personal health information in planning, evaluation and monitoring authorized public health functions or services is vital if Ontario's public health units are to fulfill their role as guardian of population health.

1. PURPOSE

The purpose of this document is to clarify why access to personal health information, including demographic information and unique identifiers such as the Ontario Health Card Number (OHCN), is necessary for the planning, delivery and evaluation of public health programs and services. While it is an absolute requirement that personal health information is protected against theft, loss and unauthorized collection, use or disclosure, and that whenever possible personal health information is subject to strong encryption, this document will highlight the value and significance of personal health information in the public health context, and the integral verification it provides in ensuring quality and equity of service.

2. INTRODUCTION

Public health is a critical component of Ontario's health system and, over the last 100 years, has been responsible for significant advances in human health and wellbeing. Dr. Charles Hastings, Toronto's medical Officer of health from 1910 – 1929, transformed the tragic loss of his daughter to typhoid into public health measures that made Toronto the city with the lowest death rate in North America in 1922. His legacy of population health solutions such as safe water, well baby clinics, childhood immunizations and restaurant inspections continues as a small fraction of what public health does today.

In 1994, the population health approach was officially endorsed by the federal, provincial and territorial Ministers of Health in a report entitled *Strategies for Population Health: Investing in the Health of Canadians*. The report summarized broad determinants of health and laid out a framework for the development of policies and strategies to improve population health.

Public health is different from acute care. The primary focus of public health is the health and well-being of the whole population through the promotion of health and the prevention of illness. In Ontario, 36 boards of health are mandated to carry out public health interventions that bridge between individual and population health services. In turn, the 36 boards of health govern the programs and services provided by 36 public health units across Ontario.

There are three cornerstones of public health:

- protecting communities against health hazards;
- preventing injury and disease; and
- promoting good health.

Public health units address these cornerstones through population level interventions and advocacy for healthy public policy, as well as service to individual clients, particularly those from vulnerable populations who may lack sufficient access to alternative health services. Public health units must create networks and services that reflect community needs and cut across sector or socio-economic boundaries. The collection of personal health information provides the arteries to this complex infrastructure and facilitates the development of a population framework.

The Health Protection and Promotion Act

The Health Protection and Promotion Act (HPPA, 1990) provides a legislative framework for the organization, public funding and delivery of public health programs and services. The HPPA is the most

significant legislation for a board of health, as it mandates the existence and functions of boards of health and medical officers of health. It is also the enabling statute for the regulations and guidelines that prescribe the more detailed requirements that serve the purpose of the Act. That purpose is to “*provide for the organization and delivery of public health programs and services, prevention of the spread of disease and the promotion and protection of the health of the people of Ontario*” (R.S.O. 1990, c. H7, s.2)

Section 7 of the HPPA grants authority to the Minister of Health and Long-Term Care to “publish guidelines for the provision of mandatory health programs and services, and every board of health shall comply with the published guidelines” (R.S.O. 1990, c. H7 s.7(1)), thereby establishing the legal authority for the *Ontario Public Health Standards*.

The *Ontario Public Health Standards* establish requirements for fundamental public health programs and services, which include assessment and surveillance, health promotion and policy development, disease and injury prevention, and health protection. Specifically, the HPPA both requires and allows for the collection of personal and personal health information.¹ Assessment, surveillance, program evaluation, research, and knowledge exchange are the foundations of modern public health.

As a key component of the Performance Management Framework for public health units in Ontario, the Ministries of Health and Long-Term Care and Health Promotion and Sport have developed the *Ontario Public Health Organizational Standards* to establish the management and governance requirements for all boards of health and public health units. The *Organizational Standards* includes an information management standard that requires boards of health to ensure compliance of the health information custodian with applicable legislation, regulations and policies including the *Municipal Freedom of Information and Protection of Privacy Act* (MFIPPA) and *Personal Health Information Protection Act, 2004* (PHIPA) in the management of all personal information and personal health information.

Population and Individual Health

A dynamic tension exists between population and individual rights and interests when broad public health interventions are involved. Protecting the rights and privacy of individuals is a fundamental public health value; however, to protect the wider population’s health, it may be necessary to limit the privacy and freedoms of individuals. For example: to prevent or limit the spread of communicable diseases, such as SARS or HIV/AIDS; to address preventable diseases, such as those arising from tobacco use or contaminated drinking water and food products; or to mitigate injury and disability, such as those due to falls from bicycles.

At the same time, public health practitioners may and do provide services to individuals, such as immunization and follow-up for a number of reportable diseases. However, the primary purpose of these services is to protect the health of the population. While individuals benefit from immunization, the larger benefit to society, i.e., stemming the spread of communicable diseases, is the focus of immunization as a public health intervention. This is different than the relationship between physicians and patients in, for example, the acute care sector where the focus is on the individual benefit.

¹ This authority is included in several sections of the HPPA, for example Section 25 regarding the duty to report a communicable disease.

To identify and mitigate factors affecting the health of populations (large or small) and to formulate future programs, social policies and public investments, it is often necessary to build or monitor evidence using individual personal information and data.

3. WHY DOES PUBLIC HEALTH NEED TO RELY ON UNIQUE IDENTIFIERS TO COLLECT DATA ON INDIVIDUALS?

“Policy-makers are increasingly encouraged to base health policy, public health and service delivery on reliable knowledge, information and evidence: implementation of ineffective interventions wastes resources and could be counterproductive to individuals and populations.”

(WHO: Gaining Health: The European Strategy for the Prevention and Control of Non-communicable Diseases)

Public health units must anticipate issues so that the risk to the health of persons and populations can be prevented, eliminated or decreased. The use of personal health information in planning, evaluating and monitoring authorized public health functions or services is vital if public health units are to fulfill their role as guardian of population health and service determinants. Population health interventions frequently build on evidence found through the analysis of aggregated individual data.

The Unique Personal Identifier

In matters regarding health, the use of a unique personal identifier - in particular the Ontario Health Care Number (OHCN) - provides for objective reliable data, accurate linkage, and ensures efficient follow up for monitoring functions for individuals and populations. For populations, demographic indicators and data, such as income level, age, sex and ethnicity, allow policy-makers to assess the distribution of health benefits and risks among the different population groups and to analyze progress towards achieving equity. Unique personal identifiers are the safest, most secure way of disaggregating these broad data for efficient collation, use and research. Without these data, many public health functions are subject to compromised reliability. For individuals, the unique personal identifier is the most reliable method of ensuring that a program or service, such as an immunization, is associated with or attributed to the intended person.

Uses of Personal Demographic and Health Information

The value of gathering personal health information in the Public Health context is multi-dimensional. The following are generally regarded as determinants of population level health, and research on these determinants necessitates the use of individual data for database correlation, on-going monitoring and program implementation:

- socio economic and physical factors;
- education;
- early childhood development;
- economic change and dislocation;
- age and gender;
- personal health practices;
- human biology; and
- health services.

Monitoring and tracking of infectious/communicable diseases requires extensive data collection and on-going surveillance. These data are vital to disease prevention and population protection. The spread of illness, diseases and emerging threats must constantly be monitored at the population and community level. The role of public health is to protect the population, as well as the community and the individuals within that defined community. The following examples illustrate that the effectiveness of public health units can often depend on the information available to them.

Example 1. While monitoring the outbreak of a disease, it is imperative to determine if one person is presenting several times with a recurring disease, or if several different people are presenting. Questions must be answered such as: is this a large population outbreak, or are a limited number of persons affected; did ten individuals have pneumonia, or did five individuals each have pneumonia twice. Public health officials need to know the difference. The use of the OHCN ensures the recorded data reflect unique individuals and the right number of individuals.

Example 2. While many residents of Ontario are able to receive a vaccination without presenting an OHCN, the ability to track population adherence, adverse reactions, correct identification, and individual and gross dosage management is compromised without it. A unique personal identifier, such as the OHCN, enables significant and pertinent analysis as well as ensures a level of safety without compromising privacy policies.

Example 3. In many areas of Ontario multi-cultural representation is growing. In regions such as Peel, York and Durham the population landscape has changed dramatically. In certain communities family names and given names are very similar or identical and are commonly used. Public health professionals are faced with significant challenges to identify an individual within large data sets. At an individual level, public health professionals must be able to verify the identity of the person presenting to them in order to confirm eligibility for services (e.g., oral health or universal immunization programs) and to provide quality and effective care. Recent research conducted in Montreal has determined that the use of basic demographics such as postal code, gender and date of birth to identify an individual is accurate 98 percent of the time. This means that in a large database containing one million records, as many as 20,000 records could be interpreted inaccurately. An OHCN, as a unique personal identifier is the safest and most reliable method to both verify identity for the purposes of delivering service and identify individuals in large databases.

Example 4. Administering large legislated public health programs such as those derived from the Immunization of School Pupils Act or the Day Nurseries Act cannot be done efficiently, effectively or safely in many jurisdictions without using the OHCN. Virtually all children in Ontario (which is millions) are covered by these programs which must collect, maintain, add to and act on specific immunization records for each individual child each year. Many children have similar names, birthdays and addresses. They may attend the same school, be in the same class or attend the same daycare. Moreover, a large proportion of this population will change addresses, classes, schools, daycares, health unit jurisdictions, provinces or countries within any given year and over the 17 years that the legislation is applicable. Each child's record must be assessed accurately within the limited time frame allowed and with limited public health resources. This is simply not feasible without the use of the OHCN. The risks of attributing an immunization to the wrong person include: inadequate immunization thus making the individual vulnerable for a disease; over immunization which in some cases may cause significant health risks; suspension or the threat of suspension from school for appearing to not be adequately immunized; or unnecessary exclusion from school in the event of an outbreak or exposure to a case of a vaccine preventable disease.

4. THE USE OF DATABASES IN PUBLIC HEALTH

Population health assessment, surveillance and program evaluation are foundational to the *Ontario Public Health Standards* and underlie the mandate of boards of health. In all of these, the use of large scale databases is required.

Assessment

Population health assessment includes measuring, monitoring, and reporting on the status of a population's health, including determinants of health and health inequities. Population health assessment provides the information necessary to understand the health of populations through the collaborative development and on-going maintenance of population health profiles, identification of challenges and opportunities, and monitoring of the health impacts of public health interventions. In order to get meaningful results from a population health assessment, the OHCN is essential to linking data related to individuals in multiple data sets.

Surveillance

Surveillance is the systematic and on-going collection, collation, and analysis of health-related information that is communicated in a timely manner to all who need to know, so that action can be taken. Surveillance contributes to effective public health program planning, delivery, and management. Dissemination of surveillance analysis may take the form of advisories, alerts or warnings, or healthy public policy reports and recommendations. For surveillance to be accurate, a unique identifier such as the OHCN ensures that individuals are not counted more than once in determining, for example, the extent of an infectious disease outbreak. Surveillance has historically been associated with infectious and communicable disease programs, but its importance has become increasingly recognized for environmental health issues, child health, reproductive health, chronic disease prevention, and injury prevention.

Program Evaluation

Program evaluation is the systematic gathering, analysis, and reporting of data about a program (or set of interventions) to assist in decision-making. Program evaluation produces the information needed to support the establishment of new programs and services (needs assessment); assess whether evidence-informed programs are carried out with the necessary reach, intensity, and duration (process evaluation); or document the effectiveness and efficiency of programs and services (outcome evaluation). For program evaluation to be effective, a unique identifier such as the OHCN is essential. For example, in evaluating the success of its sexual health counselling program, a public health unit may use a unique identifier to link records from its reportable disease list with clients who are seen in their sexual health clinics to determine if counselling is effective to reduce the risk of future sexually transmitted infections.

Linkages Among Programs

Public health units have an ethical responsibility to maximize the use of the information that it collects in order to optimize the effectiveness and quality of programs and services. Boards of health use comprehensive and integrated approaches for the planning and delivery of programs. These include linkages, where possible, among the appropriate programs within the *Ontario Public Health Standards*.

Guided by PHIPA, public health unit policies and information technology systems govern, restrict and monitor the use of personal information beyond its initial purpose for collection and supports linkages when necessary, utilizing identifiers in a methodical, logical way. Replacing potentially identifying data elements, e.g., a name and demographic data, with a unique personal identifier, i.e., a number like the OHCN, can minimize the collection or sharing of potentially identifying data elements. Public health units are committed to data stewardship in the form of mechanisms for responsibly acquiring, storing, safeguarding and using data.

Linkages for Research

A unique identifier such as the OHCN is essential to linking databases for important research. Results of recent epidemiological studies in British Columbia, Australia and Britain support the case of record linkage and unique identifiers. In these studies, valid and reliable data in multiple databases was linked to paint a picture of socio-economic determinants in the fields of environmental, early childhood, and occupational health that informed social policy and resource investment decisions. For example, one study found evidence of increased suicide and mental health risks among the children of British Columbia sawmill workers who were affected by economic instability in the forest industry. The linking of databases led to the development of a program to provide support to the families of British Columbia saw mill workers.

Uses of Database Studies

The following are further examples of database uses with important implications for public health planning and evaluation:

- compiling statistics on population trends;
- conducting health and epidemiological research to improve screening and treatment programs for diseases;
- researching data between diseases and risk factors such as diet, tobacco use, physical activity level, education, income, environment or gender;
- determining cost-effectiveness and efficacy of screening programs;
- tracking and assessing the benefits of provincial services for defined populations, for example, children and seniors; and
- assessing the long-term effectiveness and adverse effects of standard and emerging treatments.

Examples of Databases Used By Public Health

A. The Integrated Public Health Information System (iPHIS)

The HPPA requires that each public health unit in Ontario collect information about people with reportable diseases in their jurisdiction and report it to the MOHLTC. Physicians are required to report cases that fulfill laboratory or clinical case definitions to their local public health unit and this information is used for local, provincial and national surveillance. iPHIS is the database used by public health unit staff to report information on cases of reportable diseases to the MOHLTC as required in the Control of Infectious Diseases program standard under the *Ontario Public Health Standards*. Including a unique identifier such as the OHCN is essential to ensure that cases are not counted more than once.

B. Immunization Reporting Information System (IRIS)

Each child attending a school or licensed day care centre in Ontario must have an up-to-date and complete immunization record or a legal exemption form on file. Ontario health units monitor the vaccination status of children within their jurisdiction under the terms of the *Day Nurseries Act*, the *Immunization of School Pupils Act*, and in accordance with the *Ontario Public Health Standards*. Health unit staff receives immunization information from parents or guardians and physicians to be entered into IRIS. The information is then reviewed according to the system programming to determine which children are up to date with their immunizations and which may receive suspension notices until they become up to date. The inclusion of the OHCN in each immunization record ensures accurate aggregation of an immunization record for each specific child. This in turn enables the public health unit to ensure the health and safety of the population of children attending day care or school settings in their region.

C. Oral Health Information Support System (OHIS)

The Children in Need of Treatment (CINOT) program provides emergency dental care and out-of-hospital anesthetic coverage for low-income children age 17 and under. Costs are covered by the Ontario government and the government eligibility criteria states that children must be residents of Ontario and possess a valid OHCN to receive service. The OHCN is collected by the dentist providing service and the child's parent or guardian is required to sign a consent form which authorizes the dentist to release the OHCN and other confidential health information to the managing health unit. The public health unit is responsible for case validation and the payment of claims to service providers. They are also required to use the Ministry of Health Promotion and Sport's OHIS to conduct case management (i.e., tracking cases from initial screening until the case is completed or closed) and for CINOT administration.

5. RESEARCH AND KNOWLEDGE EXCHANGE

When collecting personal health information in all aspects of research, Ontario public health policies and practices reflect the values of security and privacy. Research ethics, as prescribed by provisions of PHIPA are followed by public health unit staff and govern the use of personal health information in areas of collection, analyzing and aggregating.

PHIPA allows the use or disclosure of aggregate personal health information for research without consent in specific circumstances. However, where personal health information is being directly collected from research subjects/participants, consent of the affected individuals is always required. Aggregate data would serve the research objectives in some circumstances (e.g., data on individuals grouped by age or other useful variables) while unique personal identifiers (e.g., OHCN) would provide objective reliable data, accurate linkage, and ensure efficient follow up monitoring if required.

Public health unit staff uses secure methods to conduct data linkages requested by external researchers such as the data holder conducting the linkage and providing linked data sets to the researcher without direct identifiers and with the minimum level of identifiability necessary for the research purpose.

Research Ethics

In the area of ethics, one of the key objectives for the health research community is to protect the privacy of individuals and the confidentiality of personal information, while allowing research in transparent domains with secure ease of transfer and accessibility. Obtaining consent for the collection of personal health information is adhered to, and governed by Section 41: (CIHI) *Privacy Policy on the Collection, Use, Disclosure and Retention of the PHI and De-Identified Data*, 2010.

Release of personal information tied to an individual is only allowed when the individual consents or it is permitted by law. The latter speaks to exceptional circumstances, but in all other areas of concern the OHCN, used with multi-levels of security and de-identifying processes, is employed as the safest and most secure method of harbouring personal health information.

6. CONCLUSION

To identify and mitigate factors affecting the health of populations (large or small) and to formulate future programs, social policies and public investments, it is often necessary to build or monitor evidence using individual personal information and data. In matters regarding health, the use of a unique personal identifier -

in particular the Ontario Health Card Number (OHCN) - provides for objective reliable data, accurate linkage, and ensures efficient follow up for monitoring functions. Indicators and data, such as income level, age, sex and ethnicity, allow policy-makers to assess the distribution of health benefits among the different population groups and to analyze progress towards achieving equity. Unique personal identifiers are the safest, most secure way of disaggregating these broad data for efficient collation, use and research. Without these data, many public health functions are subject to compromised reliability. The OHCN is also essential in the efficient, effective and safe administration of public health services provided to individuals on a large scale population basis.

7. REFERENCES

Caldicott Committee Report, Department of Health, UK 1997

Gaining Health, World Health Organization, The European Strategy for the Prevention and Control of Noncommunicable Diseases

The NHS Care Record Guarantee, Department of Health, UK 2009

Notice of Privacy and Information Practices (PHIPA) Collection of Personal Health Information, Ontario Information and Privacy Commission, Canada, 2010

Ontario Ministry of Health Promotion and Sport: www.mhp.gov.on.ca

Ontario Public Health Organizational Standards, 2011, Ontario Ministries of Health and Long-Term Care and Health Promotion and Sport

Ontario Public Health Standards, 2008, Ontario Ministry of Health and Long-Term Care

Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data Canadian Institute for Health Information (CIHI) 2010

Privacy Policy: Protecting Personal Health Information at the Niagara Health System, Niagara Health System

Public Health Agency of Canada: www.publichealth.gc.ca

Population Data BC Privacy Impact Assessment, University of British Columbia, September 2009 (revised February 2010)

Population Health and Public Health, The Royal Australian College of General Practitioners 2007

The Re-identification Risk of Canadians from Longitudinal Demographics, El Emam et al 2011

Toward a Healthy Future, Prepared by the Federal, Provincial and Territorial Advisory Committee on Population Health for the Meeting of Ministers of Health, Charlottetown, P.E.I. September 1999

Waterloo Region Public Health Policy & Procedure Manual, Section #13, Policy/Proc. #5