Data Collection and Use

Reviewed Date		**Number**	*PP0104*
Revised Date		**Approved Date**	*March 5, 2008*

Introduction

Data are collected in the course of daily activities to support the delivery of programs and services. These and other data may also be collected and used for the purposes of disease surveillance, needs assessment, program monitoring, program evaluation and policy analysis. These data collection initiatives contribute to the knowledge base on which we build our programs and services and ensure that we use the most effective and efficient methods to achieve our goals. They are guided by information privacy legislation, research standards and best practice.

Purpose

The purpose of this policy is to guide health unit staff, students, contractors and volunteers in data collection and use and to establish clear review and approval processes for these activities. These parameters have been put in place to ensure the legal and ethical appropriateness and feasibility of the data collection initiatives and to promote the quality and usefulness of data collected.

Legislative Authority

Municipal Freedom of information and Protection of Privacy Act R.S.O. 1990
Personal Health Information Privacy Act R.S.O. 2004

Policy Definitions and Interpretation

This policy applies to the planning and approval of data collection initiatives as well as the use and management of the data. The policy and procedures apply to all data collection initiatives implemented by, through, or on behalf of the health unit, including internal, external and partnership initiatives. The policy and procedures should be interpreted within the framework of policies that define agency rights and obligations in relation to information privacy and access and the policy defining requirements for planning, approval and conduct of public health research.

Data Collection Initiatives: The systematic gathering of information on persons or places that is not mandated by law or required for the routine provision of service directly to that place or person. (Activities such as evaluations and satisfaction surveys **would** fall under this policy. Activities such as the collection of data for the purpose of creating a health record for a client to whom services are being delivered or for outbreak management **would not** fall into this definition.)

Express Consent: See policy A1.043 Information Privacy – Consent.

Health Information Council: The purpose of the Health Information Council is to provide a venue for cross-program information sharing and discussion, team building, brainstorming and the proactive planning, collaboration and coordination of current/future projects regarding health information. A main objective of the council is to develop standards, and to draft and recommend policies and procedures that may be required to improve the collection, use and dissemination of health information in the agency. The committee includes Program Evaluation Specialist, Research

Analysts, Epidemiologists, Library Technician and representatives of Clinical Service and Corporate Service management.

Implied Consent: A "health information custodian…that receives personal health information about an individual from the individual, the individual's substitute decision-maker or another health information custodian for the purpose of providing health care or assisting in the provision of health care to the individual, is entitled to assume that it has the individual's implied consent to collect, use or disclose the information for the purposes of providing health care or assisting in providing health care to the individual, unless the custodian that receives the information is aware that the individual has expressly withheld or withdrawn the consent." (source Personal Health Information Protection Act R.S.O. 2004 S.20(2) . Implied consent is **NOT** a term that applies to the collection of information for purposes other than the provision of health care.

Risk of Harm: Assessing potential harm is a pro-active process to identify, and then assess the magnitude of, possible physical, economic/financial, social, or psychological harms, or harms to people's rights. Potential harms are assessed for individuals or groups participating, providing data, or being studied in initiatives; and also for others affected by data collection, data uses, or other aspects of the research initiative. Potential harms to individuals or groups affected by programmatic decisions directly affected by the research initiative may also be considered.

For each potential harm identified for a relevant group, the level of risk should be assessed for all participants, respondents, and any others that may be affected by data collected or the initiative as a whole. Minimal risk means that the probability and magnitude of possible harms is no greater than those in everyday life.

Vulnerable Persons: persons whose situation or characteristics may make them unable to provide free and informed consent to participate in research. This group includes children, institutionalized persons, those who have cognitive impairments, and those in a position of inferiority.

Policy

A written data collection plan will be developed for all data collection initiatives that includes as a minimum:

- purpose and objectives
- data uses and users
- methods for data collection and analysis
- a listing of the data elements
- identification of intent to collect personal information and strategies to protect privacy and access
- workplan including timelines and resources required to collect, analyze and disseminate the data.

Managers will review and approve all data collection plans within their program prior to initiation of data collection activities to ensure the legal and ethical appropriateness and feasibility of the data collection initiatives and to promote the quality and usefulness of data collected.

A review and approval of the data collection plan by the Service Director is required for initiatives where:

- the collection of information includes any collection of information that could be perceived as harmful, sensitive, or offensive;
- personal information is collected or accessed (i.e. use of data within client records);
- youth under 18 years of age or other vulnerable persons are the subject of data collection or engaged as participants in the initiative;
- schools or other institutions are engaged as sites for data collection or their clients as participants; and/or
- there is a significant investment of human or financial resources.

The Service Director will request a Research Review under policy PP0103 if in his or her assessment the initiative poses greater than minimal risk of harm for participants, respondents, and/or any others that may be affected by data collected or the initiative as a whole or where the director deems there to be a significant investment of human or financial resources.

The Health Information Council is responsible for establishing and reinforcing the standards for data collection, use, analysis and dissemination by recommending agency policy and providing training and orientation to best practice theories and concepts.

Procedures

A. Data Collection Plan

1. Staff member or external partner proposes a data collection initiative to a Program Manager.
2. The Program Manager makes a preliminary assessment of the value and feasibility of the proposed initiative, in consultation with stakeholders. For initiatives initially deemed by the Manager to be of value and feasible, the Manager clarifies the nature of the health unit's relationship to the initiative using one of the following categories:

   INTERNAL: authored, proposed and implemented by the health unit alone, working with no external organizations or groups

   EXTERNAL: initiative proposed and implemented by an external party, with no health unit funding, leadership, staffing, or responsibility other than providing access to information/data or opportunities for data collection.

   PARTNERSHIP: initiative proposed and/or implemented by the health unit and at least one other external party. Any of the following aspects of health unit involvement may apply:

   - The initiative will be conducted by a coalition of agencies/organizations of which the health unit is a member.
   - Health unit staff are designing and implementing the data collection/research.
   - An external partner is designing and implementing the data collection/research.
   - The initiative is supported by health unit funds or in kind resources.
   - The initiative is funded from grant or external funds administered through the health unit.
3. The Manager works with staff to develop the data collection plan or to facilitate the development of a plan in the case of external or externally led partnership initiatives using the Data Collection Plan Template (PP0103 F 1) Managers involve relevant internal or external stakeholders in proposal development for any activities in which they will be involved or have a substantial interest.

   Managers and staff are encouraged to consult with an Epidemiologist, Evaluation Specialist, Research Analyst or other research staff in the development of their data collection plans.

4. Once data collection plans are complete, the Program Manager reviews and endorses the plan using the checklist and signature page integrated within the Data Collection Plan Template.
5. If one or more of the following apply, the Manager forwards a data collection plan to the Service Director for review and approval:
    - the collection of information includes any collection of information that could be perceived as harmful, sensitive, or offensive;
    - personal information is collected or accessed (i.e. use of data within client records);
    - youth under 18 years of age or other vulnerable persons are the subject of data collection or engaged as participants in the initiative;
    - schools or other institutions are engaged as sites for data collection or their clients as participants; and/or
    - there is a significant investment of human or financial resources.
6. The Service Director(s) reviews and documents his/her assessment of the data collection plan against a standard set of criteria.
7. If in the Service Director's assessment, the initiative poses **no greater** than minimal risk of harm for participants, respondents, and/or any others that may be affected by data collected or the initiative as a whole and **does not** require a significant investment of human or financial resources, the director signs off on the plan.
8. Once the plan is approved, the Manager is responsible for ensuring the data collection initiative is implemented in accordance with the approved plan.
9. The data collection plan is maintained on file within the service forming part of the record of the initiative and shared or referenced as required to guide collection, use, information management and dissemination.
10. If in the Service Director's assessment, the initiative poses **greater** than minimal risk of harm for participants, respondents, and/or any others that may be affected by data collected or the initiative as a whole and **requires** a significant investment of human or financial resources, the Service Director(s) requests a an agency-level review in accordance with agency policy PP0103.

Terms of Reference – Expedited Reviewer

Terms of Reference – Research Review Committee

Appendix A

Privacy Consent Statement for Collection of Information

Forms

PP0104 F1) – Sound Project Criteria

PP0104(F2) - Data Collection Plan Minimum Requirements

PP0104(F3) – Management Assessment for Data Collection Initiatives

PP0104(F4) – Service Director Assessment for Data Collection

PP0103(F1) – Data Collection Plan Template

PP0103(F2) – Research Reviewer Assessment

PP0103(F3) – Research Review Decision

PP0103(F4) – Data Request Form

PP0103(F5) – Research Project Status Report Template

PP0103(F6) – Research Project Amendment Form

Related Policies

Policy IM0101 Personal Information Including Personal Health Information Privacy – Principles
Policy IM0102 Personal Information Including Personal Health Information Privacy – Accountability
Policy IM0103 Personal Information Including Personal Health Information Privacy – Consent
Policy IM0104 Personal Information Including Personal Health Information Privacy – Collection & Use
Policy IM0105 Personal Information Including Personal Health Information Privacy – Disclosure
Policy IM0106 Personal Information Including Personal Health Information Privacy – Access
Policy IM0107 Personal Information Including Personal Health Information Privacy – Correction
Policy IM0108 Personal Information Including Personal Health Information Privacy – Privacy Breach
Policy PP0103 Public Health Research Planning, Approval and Conduct

Final Approval Signature: _____

Review/Revision History:
September 2010 Policy re-numbered, previous number A1.021

Appendix A

Privacy Consent Statement for Collection of Information

Verbal Consent Requirements (Policy IM0104):

Health Unit agents will:

1. *Inform clients that a record of information is being maintained, and under what authority, at the time a record is established.*
2. *Identify the specific purposes for which the information is being collected.*
3. *Seek the individual's consent of the collection of the information.*
4. *Collect and document only that information which is necessary to serve the purpose.*
5. *Restrict the collection of information to that for which they have consent, are required by law to collect or required to provide healthcare to the client.*

Forms Requirements (Policy IM0104):

Forms developed for the collection of personal information and personal health information will include a privacy statement that indicates:

1. *The authority under which the information is being collected (be as specific as possible i.e. Act and section).*
2. *The purpose for collecting the information – how the information will be used.*
3. *The position and contact information for directing questions related to agency information practices.*

Data Collection Requirements for Surveys, Focus Groups etc. (Tri Council Policy Statement – Ethical Conduct for Research Involving Humans)

Researchers shall provide, to prospective subjects or authorized third parties, full and frank disclosure of all information relevant to free and informed consent. Throughout the free and informed consent process, the researcher must ensure that prospective subjects are given adequate opportunities to discuss and contemplate their participation. Subject to the exception in Article 2.1(c), at the commencement of the free and informed consent process, researchers or their qualified designated representatives shall provide prospective subjects with the following:

a. *Information that the individual is being invited to participate in a research project;*
b. *A comprehensible statement of the research purpose, the identity of the researcher, the expected duration and nature of participation, and a description of research procedures;*
c. *A comprehensible description of reasonably foreseeable harms and benefits that may arise from research participation, as well as the likely consequences of non-action, particularly in research related to treatment, or where invasive methodologies are involved, or where there is a potential for physical or psychological harm;*
d. *An assurance that prospective subjects are free not to participate, have the right to withdraw at any time without prejudice to pre-existing entitlements, and will be given continuing and meaningful opportunities for deciding whether or not to continue to participate; and*

e. The possibility of commercialization of research findings, and the presence of any apparent or actual or potential conflict of interest on the part of researchers, their institutions or sponsors.

Generic Standard Statements

1. Standard statement on a form when there **is identifying information collected** (i.e. name and address, health card number, SIN number etc.

   This personal information is collected under the authority of the (insert legislated authority and be specific with Act, Regulation, Section and/or article).

   The information will be used to (insert statement of specific use such as conduct investigations, and for purposes of monitoring and surveillance of rabies activity).

   Documents are maintained pursuant to the Municipal Freedom of Information and Protection of Privacy Act, 1991 and the Personal Health Information Protection Act, 2004.

   Questions regarding the collection, use and disclosure of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

2. Standard statement on a form or script when there **is identifying information collected** such as a survey or focus group. This would also pre-suppose that the survey or focus group had an introductory component that addressed all the requirements of informed consent or that the survey or focus group was implemented by someone who verbally reviewed this information and sought consent.

   This personal information is collected under the authority of the (insert legislated authority and be specific with Act, Regulation, Section and/or article. In this case the most likely statement will be the Health Protection and Promotion Act, 1990 s.5.)

   The information will be used to (insert statement of specific use such as conduct investigations, and for purposes of monitoring and surveillance of rabies activity. Again the most common statement would be: "the information will be used for the purposes of program planning and service delivery").

   Documents are maintained pursuant to the Municipal Freedom of Information and Protection of Privacy Act, 1991 and the Personal Health Information Protection Act, 2004.

   Questions regarding the collection, use and disclosure of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

3. Standard statement on a form or script (phone survey) when there is **NO identifying information collected** such as a survey. This would also pre-suppose that the survey had an introductory component that addressed all the requirements of informed consent or that the survey was implemented by someone who verbally reviewed this information and sought consent.

   This information is collected under the authority of the (insert legislated authority and be specific with Act, Regulation, Section and/or article. In this case the most likely statement will be the Health Protection and Promotion Act, 1990 s.5.)

   The information will be used to (insert statement of specific use such as conduct investigations, and for purposes of monitoring and surveillance of rabies activity. Again the most common

statement would be: "the information will be used for the purposes of program planning and service delivery").

Questions regarding the collection, use and disclosure of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

Examples of Standard WRITTEN Statements <u>with</u> Personal Information

A. Rabies

This personal information is collected under the authority of the Health Protection and Promotion Act, 1990 s. ____ and O.Reg. 557 s.2. The information will be used to conduct investigations, and for purposes of monitoring and surveillance of rabies activity. Documents are maintained pursuant to the Municipal Freedom of Information and Protection of Privacy Act, 1991 and the Personal Health Information Protection Act, 2004. Questions regarding the collection, use and disclosure of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

B. Immunization

This personal information is collected under the authority of the Health Protection and Promotion Act, 1990 s.____ the Day Nurseries Act, 1990 s.___ and the Health Cards and Numbers Control Act, 1991 s.2. The information will be used to maintain immunization records and to monitor the use of vaccines for public health purposes. Documents are maintained pursuant to the Municipal Freedom of Information and Protection of Privacy Act, 1991 and the Personal Health Information Protection Act, 2004. Questions regarding the collection, use and disclosure of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

OR

This personal information is collected under the authority of the Health Protection and Promotion Act, 1990 s. ___and the Immunization of School Pupils Act, 1990 s.___. The information will be used to provide immunizations to students, to maintain immunization records and to monitor the use of these vaccines for public health purposes. Documents are maintained pursuant to the Municipal Freedom of Information and Protection of Privacy Act, 1991 and the Personal Health Information Protection Act, 2004. Questions regarding the collection and use of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

C. Car Seat Clinics

This personal information is collected under the authority of the Health Protection and Promotion Act, 1990 s.5. The information will be used for the purposes of program planning and service delivery. Documents are maintained pursuant to the Municipal Freedom of Information and Protection of Privacy Act, 1991 and the Personal Health Information Protection Act, 2004. Questions regarding the collection and use of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

Example of Standard WRITTEN Statements with <u>NO</u> Personal Information:

A. Behavioural Risk Factor Survey

This information is collected under the authority of the Health Protection and Promotion Act, 1990 s.5. The information will be used for the purposes of program planning and service delivery.

Questions regarding the collection and use of personal information should be directed to the Office of the Privacy Officer, Simcoe Muskoka District Health Unit, 15 Sperling Drive, Barrie ON L4M 6K9, (705) 721-7520 or 1-877-721-7520.

Example of Standard VERBAL Statements with Personal Information:

A. Rabies

Verbal - This is a disclaimer that would be used to inform people. I believe that the health unit has the legislated authority to disclose the information as outlined and therefore, consent is not being requested. The intake form would have a check box indicating that the statement had been read to the client.

- *This information is collected under authority of the Health Protection and Promotion Act, 1990 section ___and Ontario Regulation 567/90 Rabies section_____*
- *The information will be kept confidential, and will be used for rabies program case investigation, enforcement, planning, and statistical purposes only. For the purposes of rabies prevention and monitoring, some information may be shared with outside agencies including the Canadian Food Inspection Agency regarding rabies testing; or municipal and animal control officers, and pound facilities.*
- *Documents are maintained pursuant to the Municipal Freedom of Information and Protection of Privacy Act, 1991 and the Personal Health Information Protection Act, 2004.*
- *Questions regarding the collection, use and disclosure of personal health information should be directed to the Privacy Officer for the Simcoe Muskoka District Health Unit*.

☐ *Privacy Statement was reviewed with the Victim or the Parent/Guardian*