



| <b>DISCLAIMER</b>   |  |
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| <p>This Privacy Code Document has been prepared by CaNIOS for its membership, for the ownership and use of the CaNIOS members, as a general guide to assist each CaNIOS member and centre to meet their obligations under the <i>Personal Information Protection and Electronic Documents Act</i> (PIPEDA) Canada, 2000 and the <i>Personal Health Information Protection Act</i> (PHIPA). Ontario, 2004.</p> |  |
| 1.  | This Privacy Code is designed to provide information to assist in complying with the law and meeting the changing expectations of patients and the public.   |
| 2.  | The material provided in this Privacy Code is for general information purposes only. It should be adapted to the circumstances of each institution or physician using the CaNIOS National Registry.  |
| 3.  | The Privacy Code reflects interpretations and practices regarded as valid when it was published based on available information at that time.   |
| 4.  | The Privacy Code is not intended, and should not be construed, as legal or professional advice or opinion.   |
| 5.  | CaNIOS centres and members concerned about the applicability of privacy legislation to their activities are advised to seek legal or professional advice based on their particular circumstances.  |
| 6.  | In addition, Ontario's Information and Privacy Commissioner has an important role to play in providing further guidance on how the Personal Health Information Protection Act, 2004 is being applied and interpreted. Websites to monitor are:<br><a href="http://www.ipc.on.ca">http://www.ipc.on.ca</a><br><a href="http://www.health.gov.on.ca/english/public/updates/archives/hu_03/priv_legislation.html">http://www.health.gov.on.ca/english/public/updates/archives/hu_03/priv_legislation.html</a> |
| 7.  | This is the first version of the CaNIOS Privacy Code. A second version may be released in due course. Your feedback on this first edition would be appreciated.  |
| 8.  | This first version of the CaNIOS Privacy Code is compliant with the Ontario Privacy Law. Future versions will be released in due course meeting the requirements of other provincial privacy laws.   |

## INTRODUCTION

This Privacy Code for the CaNIOS National Registry is sensitive to the various provinces' own privacy legislation. As all privacy legislation has to be “substantially similar” to the federal code, there will be greater similarity than differences in the code between the provinces.

Principles articulated in this document are based on the ten principles found in the CODE FOR THE PROTECTION OF PERSONAL INFORMATION, CAN/CSA-830-96, which is now Schedule 1 to the *Personal Information Protection and Electronic Documents Act*, (PIPEDA) Statutes of Canada, 2000, c.6.

**These 10 principles include:**

- |   |                            |
|---|----------------------------|
| 1. Accountability                         | 6. Accuracy                |
| 2. Identifying purposes                   | 7. Safeguards              |
| 3. Consent                                | 8. Openness                |
| 4. Limiting collection                    | 9. Individual access       |
| 5. Limited use, disclosure, and retention | 10. Challenging compliance |

This document will discuss each of these principles of fair information practices individually as they apply to the conduct of research at CaNIOS. To help the reader anchor the discussion, CaNIOS uses personal health information for the following purposes:

- To perform research that contributes to the effectiveness, quality, equity, and efficiency of health care for the lupus population of Canada (CaNIOS' mandate);
- To carry out lupus related research in area of clinical and pragmatic relevance from a population-wide perspective;
- To document “Canada-wide” patterns of the evolution of the disease of lupus and of its related medical care on an ongoing basis;
- To implement and evaluate projects in a clinical setting so as to promote more effective and efficient patterns of care;
- To promote collaboration among lupus researchers in Canada, and between researchers and decision-makers;
- To train lupus researchers and to promote a wider understanding of relevant concepts from clinical epidemiology and lupus-related health research.

## **Principle 1    Accountability**

Principles and procedures for ensuring confidentiality and security of data are strictly enforced in order to respect the privacy of users and providers of the health care system, and to protect data against loss, destruction or unauthorized use. CaNIOS as a “disease specific registry” is responsible for all data held in its possession or custody and has designated individuals who are accountable for CaNIOS compliance with the following principles.

CaNIOS’ Chair, the Chair of the Data Access subcommittee and designated personnel are responsible for the Network’s compliance with the principle of accountability, among other principles and for ensuring that all research studies are implemented in accordance with the current standards for ethical acceptability and that they adhere to the principles of privacy, confidentiality and security. These individuals are accountable to the CaNIOS Board of Executives.

1.1 Designated CaNIOS personnel are responsible for the day-to-day collection and processing of health information.

1.2 CaNIOS has implemented the following policies and practices to give effect to the above principles:

- The establishment of procedures to protect personal information;
- Orientation and training of new staff about CaNIOS policies and procedures;
- Reinforcement of staff sensitivities to privacy protection on a regular basis;
- The establishment of procedures to receive and respond to complaints and inquiries;
- The development of public information to explain CaNIOS policies and procedures;
- The establishment of procedures to be able to access data for future research purposes.

## Principle 2 Identifying Purposes

CaNIOS will identify the purposes for which its scientists use personal health information. Research proposals and study designs/plans will be developed *before* the information is used (or at the time of collection). Collected data will be used for research and statistical purposes only.

- 2.1. CaNIOS uses and/or collects personal information to conduct research that contributes to the effectiveness, quality, equity, and efficiency of health care for the Canadian lupus population, as part of its unique mandate and partnership with its scientists.
- 2.2. Identifying the purposes for which CaNIOS uses and/or collects personal information before use and/or collection allows careful determination of the information needed to fulfill these purposes. CaNIOS uses and/or collects only information that is necessary to meet pre-defined purposes.

Personal data is transferred from one responsible keeper (such as the MUHC lupus cohort) to CaNIOS National Registry with a chain of accountability for data protection. It is the responsibility of the primary collector to obtain consent from participants to transfer the collected data; to have the legal authority to transfer data; and to follow CaNIOS' research agreements.

- 2.3. The identified purposes for primary data collected in the context of the clinical trials and epidemiological studies will be specified to the individual from whom personal information is sought before it is collected. This may be done verbally (i.e. by telephone) or in writing (ie. by consent form) depending on the way in which information is collected.
- 2.4. If a new purpose is subsequently identified for the use of anonymous health information data, for which CaNIOS has stewardship responsibility, the new purpose will be identified prior to use. For example, if studies reveal increasing poor health during pregnancy in women with SLE, an underlying question “do their newborn infants have increasing poor health as well?” may also be addressed by the collected data.

If a new purpose is identified from the use of health information that CaNIOS has collected in the context of a clinical trial, the new purpose will be identified prior to use. This may be done at the time of original consent. If potential future use of data from a clinical trial is hypothesized, the consent will include a statement articulating the possibility of using the data for further studies. An “opt-out” clause will be located at the end of the consent form.

Unless a new purpose is required by law to be identified in the original consent, the new purpose is required by law, only the approval of the Research Ethics

Board [REB]~~REB~~ is required before information can be used for ~~that~~the new purpose. If new information is to be gathered, the consent of the individual is required before information is collected or used for that purpose.

- 2.5. CaNIOS personnel collecting personal information for clinical research projects will fully explain to individuals the purposes for which the information is being collected as part of the consent process. They will also discuss the possibility of future projects with an “opt-out” method of consent.

### Principle 3 Consent

The individual CaNIOS centers, supplying the personal health information to the CaNIOS National Registry, will be responsible for obtaining consent from patients. As well, the individual CaNIOS center's cohort consent will contain a section describing the sharing of selected minimum personal health information with the CaNIOS National Registry in an anonymized fashion.

CaNIOS scientists and staff do not have a direct relationship with most of the individuals on whom it holds data. CaNIOS, as a recipient of personal health information in accordance with the provisions of the Ontario Freedom of Information and Protection of Privacy Act (PHIPPA), is not required under its research agreements to seek individual consent for data used for research and statistical purposes. CaNIOS is responsible for ensuring that the personal health information CaNIOS receives into the CaNIOS National Registry has been consented by the individual. A copy of institutional REB approval and annual review will be kept at the CaNIOS Coordinating Centre.

All projects using the CaNIOS National Registry for research and statistical purposes must be vetted and **approved** by the Research Ethics Board of the individual CaNIOS collaborators and by the CaNIOS ad-hoc Data Access committee and /or the Scientific committee.

Knowledge and informed consent of the individual are required for the collection, use, and/or disclosure of primary clinical information. Individuals can give consent in different ways.

- A. A study-specific customized form will be used to seek consent. It will outline: the purpose of the study, the information to be collected, the risks and benefits of study participation, and a description of the intended use of the information (i.e. The 1000 Canadian Faces of SLE project). All the study components will be comprehensively described to the individual by the investigator/designate, with opportunities to pose questions and seek further information at any time. Consent forms always provide the name of investigators and associated contacts and telephone numbers where they may be reached. By completing and signing the form, the individual is giving explicit consent to the collection of their data and its specified use(s).
- B. Researchers will explicitly request the consent of study participants to the transfer of personal information obtained in the context of clinical trials to third party researchers. This is identified on the consent form – at times in the form of a check-off box. The decision to agree (or not to agree) to the transfer of personal health information is the choice of the study participant. [NB: Third party researchers (usually CaNIOS- affiliated scientists) sign confidentiality agreements, have approved research proposals and institutional REB approval

where required, and use data for research and statistical purposes only, as mandated by agreements with CaNIOS].

C. Consent may be given verbally when appropriate to study methodology;

NOTE: All consent forms, which are submitted with the study proposal, **must be approved** by the institutional REB.

- 3.1 CaNIOS requires consent for the transfer of personal clinical information in the context of its mandate and future clinical studies and surveys that it conducts and the subsequent use of this information. CaNIOS researchers will seek consent for the use of the information at the time of the collection. In certain circumstances, consent with respect to use for a new purpose may be sought *after* the information has been collected (for example, CaNIOS wants to use information for a purpose not previously identified) but *before* it is used again for the new purpose.
- 3.2 The consent principle requires “knowledge and consent”. CaNIOS personnel will advise an individual of the clinical research purposes for which the information will be used. To make the consent meaningful, the purposes will be stated in such a manner that the individual can reasonably understand how the information will be used or disclosed. If record linkages are to be carried out on the collected data, the individual will be informed in advance as to which additional data source will be used to augment the research project. Specific consent for these linkages will be sought at the time the original consent is signed (i.e. the Lupus and Malignancy study).
- 3.3 In obtaining consent, the reasonable expectations of the individual are relevant; consent will not be obtained through deception.
- 3.4 Withdrawal of consent by a study participant involves only prospective data. Withdrawal from the CaNIOS National Registry will not affect the data collected and consented to in the past.
- 3.5 Any person may change their decision to withdraw from the CaNIOS National Registry. Collection of data after the consenting process is completed may resume from the date of the new consent.
- 3.6 Any person may refuse to answer any question at any time. Their refusal to answer some specific questions will not preclude the collection of the remaining minimum dataset.

**Principle 4 Limiting collection**

CaNIOS will limit the collection of personal health information to that which is necessary for the purposes of its mandate.

- 4.1 CaNIOS will not collect personal health information that does not have a purpose. Both the amount and the type of information collected will be limited to that which is necessary to fulfill the research purposes needed to complete its mandate.
- 4.2 CaNIOS will not use other data to enrich the research data unless such processes have been clearly identified within the purpose section of a research consent document.

For example: In order to link with the Canadian Cancer Registries, the original consent for the SLE Malignancy Study is required to contain a statement indicating such a link will occur between the two databases. In the same manner, if such a statement was not on the original consent, then study participants will be required to re-consent to allow a link of their information already on-hand to the Canadian Cancer Registries.

## **Principle 5 Limiting Use, Disclosure, and Retention**

All individual CaNIOS centres' cohort data received by the CaNIOS National Registry will be used only for the purposes outlined in the introduction of this code. All primary data is to be used only for the purposes identified prior to the collection of the data. If a new purpose is identified and required, law requires institutional REB approval and consent of the individual before the information can be used for that purpose.

**(If a new purpose is identified and required, law requires institutional REB approval before the information can be used for that purpose. If the new purpose requires additional information not contained in the cohort data than the participants will need to re-consent to this collection.)**

CaNIOS *does not disclose* individual-level information that it uses or collects **under any circumstances**. Such an act would contradict its research agreements.

CaNIOS presents data in an *anonymized and aggregated* fashion; in other words, data is “collective” and grouped together to be used for research purposes. For example, CaNIOS has studied data on more than 3,000 SLE patients in Canada. SLE patients are followed routinely at individual CaNIOS lupus clinics to assess the kind of care received by SLE patients and how improvements to care can be made to prevent treatment-associated complications.

Personal health information collected in the context of clinical trials and epidemiological studies will not be used for purposes other than those for which it was collected, except with the consent of the individual or as required by law.

Personal health information retained is securely archived for clinical research projects for periods varying from five to fifteen years. The length of retention may be less or more depending upon the project-specific research agreement/requirements.

- 5.1 CaNIOS has developed guidelines and implemented procedures with respect to the retention of personal clinical information. CaNIOS is subject to legislative requirements with respect to retention periods.
- 5.2 Personal health information that is no longer required to fulfill the identified purposes will be destroyed or erased after the agreed-upon retention period has been met. CaNIOS has developed guidelines and implemented procedures to govern the destruction of personal health information (e.g. shredding of documents in-house, data tape erasure).

## Principle 6 Accuracy

The registry data that has been made anonymous cannot be updated at the level of the CaNIOS National Registry, *unless the individual CaNIOS centre collecting the data verifies and updates the information.*

In the context of clinical trials and epidemiological studies, personal information will be as accurate, complete and up-to-date as possible, at the time of the collection.

Importantly, this information is treated as a “snap shot” of a single point in time. The data collected is not to be used in the context of future clinical health care decision-making for the individual patient and therefore does not require updating.

- 6.1 CaNIOS will not update personal health information collected in the context of clinical trials and epidemiological studies, unless such a process is necessary to fulfill the research purposes for which the information was collected initially with the patient’s consent.
- 6.2 CaNIOS takes steps that are reasonable in the given circumstances to ensure that personal health information collected for clinical trials and epidemiological studies is accurate, complete and up-to-date **at the time of the collection**. This is a requirement of these types of studies, in order to ensure the information derived from the project is valid. However, because these projects typically feature a pool of information from a large number of persons, small errors in the data are tolerable and do not influence overall findings.

The information gathered for CaNIOS’ research at any time, will never effect or influence decisions relating to the future health care of an individual. All data are used for research and statistical purposes only.

## Principle 7 Safeguards

CaNIOS will protect **all data** within its custody. CaNIOS personnel consider all data to be highly sensitive; thus information protection is paramount and accomplished with security safeguards appropriate to the sensitivity of the information.

- 7.1 *Without exception*, all personal health information data are considered to be sensitive.
- 7.2 Security safeguards protect personal health information against loss or theft, as well as unauthorized access, disclosure, copying, use, or modification. CaNIOS will protect personal information regardless of the format in which it is held.
- 7.3 The nature of the safeguards will vary depending on the amount, distribution, format of the information, and the method of storage. The methods of protection in place include:
  - (A) **Physical measures:** e.g., locked facility with tracked key access, locked filing cabinets and restricted access to offices, internal/external video monitoring of the institute;
  - (B) **Organizational measures:** e.g., strict employee confidentiality agreements (with immediate dismissal as a sanction) and limiting access on a “need-to-use” basis;
  - (C) **Technological measures:** e.g., two-stage firewall (device & software), secured socket layer encryption user/id password authentication (capability for fingerprint ID), intruder detection, passwords; and
  - (D) **Anonymization** of data by stripping conventional identifiers.
- 7.4 The methods of protection of the CaNIOS National Registry situated at the SoftWorks office include:
  - (A) **Physical measures:** e.g., secure hosting facility, 24-hr surveillance, keypad entry & auditing, bullet-proof encasement around the machine room, access limited by changing security locks, appropriate attention to flooding and fire threat;
  - (B) **Organizational measures:** e.g., strict employee confidentiality agreements (with immediate dismissal as a sanction) and limiting access on a “need-to-use” basis;
  - (C) **Technological measures:** e.g., secure (https;) access to the internet, actively maintained firewalls, ongoing virus/worm surveillance, “moating” of data making it inaccessible externally, passwords, and encryption of data, regular backup and restore procedures; and
  - (D) **Anonymization** of data by stripping conventional identifiers, “private – public key encryption” process: random scrambling of identifiers with algorithm.

- 7.5 CaNIOS requires, as a condition of membership, a signed confidentiality agreement from **all members**, including CaNIOS scientists, adjunct scientists, fellows and students. Research staff involved in any aspect pertaining to the CaNIOS National Registry will also be required to sign the confidentiality agreement. This agreement will be reviewed and re-signed when the CaNIOS Chair changes.
- 7.6 On an ongoing basis, CaNIOS makes all members aware of the importance of maintaining the confidentiality of personal information.
- 7.7 CaNIOS policies and procedures are in place pertaining to the disposal or destruction of personal information to prevent unauthorized parties from gaining access to the information.

## **Principle 8 Openness**

CaNIOS will make information about its policies and practices relating to the management and protection of personal health information readily available upon request. This information is available in printed form and on its corporate web site – [www.canios.ca](http://www.canios.ca). (*NB: this website is not yet in existence*). This information will be made available in a form that is understandable to the general population.

- 8.1 The information made available includes:
- (A) The name or title and address of the person who is accountable for CaNIOS' policies and practices and to whom complaints or inquiries can be forwarded;
  - (B) A description of the type of information held by CaNIOS, including a general account of its use;
  - (C) A copy of any brochure or other general information that explains CaNIOS' policies, standards or codes of practices.

## **Principle 9 Individual access**

In the context of clinical studies and surveys, and upon request, an individual will be informed of the use of his/her personal health information and may be given access to that personal information by the CaNIOS investigator associated with the study.

Upon a request for access to one's personal information held by CaNIOS, CaNIOS will indicate to whom and where the request should be made. The CaNIOS investigator can provide the individual with a duplicate copy of his/her signed consent to participate form, outlining the study plan and principles, which was signed at the time the individual was approached to participate in the study.

CaNIOS cannot provide access to anonymized personal health information of the individual CaNIOS centres registry data within its National dataset. Such an act, in and of itself, might compromise others.

## Principle 10 Challenging compliance

An individual will be able to challenge compliance with the above principles to the designated individuals whom are accountable for CaNIOS' compliance. These individuals will generally include the Chair of CaNIOS, secondly the Chair of the Privacy Compliance subcommittee, and designates.

- 10.1 CaNIOS has put procedures in place to receive and respond to complaints or inquiries about its policies and practices related to the handling of personal health information. These procedures are easily accessible and simple to use.
- 10.2 The Privacy Compliance subcommittee can be reached at (*yet to be determined*) for inquiries and complaints concerning CaNIOS' policies and practices related to the handling of personal health information.
- 10.3 CaNIOS will inform individuals who make inquiries or lodge complaints, of the existence of relevant complaint procedures.
- 10.4 CaNIOS will investigate all complaints. If a complaint is found to be justified, CaNIOS will take appropriate measures including, if necessary, amending its policies and practices.

This Privacy Code is based upon:

CODE FOR THE PROTECTION OF PERSONAL INFORMATION, CAN/CSA-830-96, which is now Schedule 1 to the *Personal Information Protection and Electronic Documents Act*, (PIPEDA) Statutes of Canada, 2000, c.6.

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## **Appendix I. About CaNIOS**

The Canadian Network for Improved Outcomes in SLE (CaNIOS) is an independent, non-profit research organization, mandated to conduct health research in the disease of systemic lupus erythematosus (SLE) and related auto-immune diseases that contributes to the effectiveness, quality, equity, and efficiency of health care in the Canadian lupus population.

CaNIOS governance includes a Board of Executives, a Scientific committee, a Telematics committee transformed to the Data Access committee and the Data Standardization committee in summer 2005, a Membership committee and a Privacy Compliance committee to be struck in summer 2005. A Fund raising/Finances committee (disbanded spring 2005) and Authorship committee (disbanded spring 2003) have been part of the CaNIOS governance structure.

The CaNIOS Network uses research methodologies in innovative ways to probe the interface of clinical practice and health services research in order to create a blueprint for better health care for the Canadian lupus population. Imbedded in its mandate is a commitment to research that can serve as a catalyst for change. Other important features of CaNIOS' research activities include advocacy for a system-wide approach to health care which is knowledge-based and evidence-oriented; translation, dissemination and transfer of research findings to varied audiences in appropriate, accessible language; and a commitment to facilitate the care of Canadian lupus patients in a variety of jurisdictions.

CaNIOS provides a broad view of the health, pattern of disease progression, and pattern of disease of the Canadian lupus population, which contributes valuable information to researchers, clinicians, stakeholders, the public, policy and decision-makers. Since its establishment in 1995, CaNIOS has become recognized for its unique and growing interdisciplinary approach to lupus and related diseases research and for its contribution of new insights to the integration of the variety of lupus scientists.

CaNIOS has a team of respected researchers and support personnel with diverse talents and rich backgrounds. The "virtual" existence of CaNIOS allows for ease of cross-Canada collaborations among scientists of varied disciplines.

Recognizing the necessity to build partnerships to achieve positive change, CaNIOS has assembled a diverse external network of associate scientists (Glinda Cooper at NIEHMS), stakeholder organizations (Lupus Canada and Ontario Lupus Association), representatives of key provincial and national health care organizations (The Arthritis Society, Canadian Arthritis Network, Canadian Rheumatology Research Consortium [CRRC]), and international research organizations (Lupus Clinical Trials Consortium [LCTC]) to collaborate on initiatives with CaNIOS. This inclusive approach helps create support for evaluation and positive change; it also builds on capacity for lupus research in Canada.

CaNIOS has received minimal core funding from the LCTC for a period of 2 years (2004-2005). Its continued existence is primarily based on operating grants from CIHR, TAS, NCIC. The partnership of Lupus Canada and a private donor through AARC has aided in the employment of a National Coordinator and recently a National Registry Administrator. Many CaNIOS and related group projects receive funding or “in-kind” support from stakeholder organizations. These collaborative initiatives have produced relevant and timely research that can serve as a catalyst for change.

CaNIOS researchers have published approximately 9 articles in peer-reviewed journals, as well as more than 25 working papers/technical reports. With more than 5 projects under way at one time, major contributions to the peer-reviewed medical and health services literature in major journals such as the *Lancet*, *New England Journal of Medicine (NEJM)*, *Journal of the American Medical Association (JAMA)*, *Journal of Rheumatology*, *Arthritis Care and Rheumatism*, and *Lupus* are published on a regular basis.

Practical care solutions can be constructed through CaNIOS’ network because the traditional silos of care are being broken down, patients are being tracked anonymously across an integrated continuum of services, and health evaluation is being shifted to outcomes of care evaluation. By CaNIOS’ benchmarking of care, there is new understanding of the needs of the Canadian lupus population and how resources should flow to provide the best care for persons living with lupus.

## Appendix 2. Description of Data Held at CaNIOS

There are distinct types of data collected by CaNIOS – registry, survey, primary clinical, and abstracted data – which are used in different ways. These data types help to answer specific research questions about the health care that Canadian lupus patients are receiving *as a population*, not individually.

### (a) Registry Data

CaNIOS holds clinical *registry* databases, which contains minimal information on persons with lupus who have participated in studies and consented to being included in the registry. An ‘annual’ review collects the following participant information: disease activity, damage, quality of life measures, current medications, changes over the previous year, and changes in the demographic make-up of the population. This data provides a snapshot picture of the Canadian lupus population on a yearly basis; as well as, a baseline comparison of the ‘natural’ history of the progression of the disease (changes and similarities that occur from year to year) both individually (although anonymously) and as an entity.

### (b) Primary Data

*Primary data* is collected to answer specific research questions. Such data may be obtained from subjects by interviews, chart abstractions or reviews, questionnaires or thorough observation and intervention studies.

CaNIOS scientists collect *primary clinical data* within the context of clinical trials and epidemiological studies. These studies require development of a research proposal, review and approval through the appropriate institutional and/or university Research Ethics Board [REB]. Collection of primary personal data only occurs after individual informed consent is sought and obtained. It is the responsibility of the CaNIOS investigator to obtain consent from participants. Patients who agree to participate in clinical trials are to be fully informed as to the risks and benefits of the research project; the type of information that will be gathered; and, their freedom to withdraw from the research project at any time without prejudice to their care. Each study participant/patient is assigned a study number or code that is used in research records, opposed to using names, in order to ensure that personal clinical information is made anonymous. Patients also receive a copy of their signed consent for their own records.

Data abstracted from medical records (*chart abstraction*) is collected to augment, supplement, and validate administrative and registry research projects. It also provides a method to assess quality and processes of care – providing an audit function – and thus a way to improve care. This secondary collection of data is performed only after REB approval. Data collected from charts is de-identified and made anonymous and are used only for research and statistical purposes.

**(c) Augmented data through linkage**

Personal information that has been made anonymous and assigned a unique number can be linked across administrative datasets, allowing evaluation of treatments and patient outcomes. This linkage of information is highly important to the understanding of the effectiveness of health care being delivered.

For example, anonymous records of a large group of lupus patients who have had a cancer could be linked to cancer administrative datasets to study whether they have received diagnostic testing, corrective or removal surgeries, chemotherapy, radiotherapy, or a combination of any of the above treatments. By knowing the outcomes of the patients who had these health services provided, researchers can decide which treatment method(s) provide lupus patients with the most benefit.

### Appendix 3. CaNIOS Privacy Commitment

CaNIOS' mandate to perform research that contributes to the effectiveness, quality, equity, and efficiency of health care for the Canadian lupus population is complimented by its promise to respect personal privacy, safeguard the confidentiality of data and provide a secure environment for the databases under its management.

#### CaNIOS meets this commitment by having:

- ✓ Ensured data anonymity;
- ✓ Principles and policies in place for the protection of health data;
- ✓ Strict policies which limit access to anonymized data;
- ✓ Heightened security measures: organizational, technological and physical;
- ✓ Processes for review and approval of research proposals;
- ✓ An active Privacy Compliance subcommittee, at the working and governance levels;
- ✓ Mandatory staff training to keep health information protection matters a constant priority;
- ✓ Requirements that **all staff** sign a pledge of confidentiality;
- ✓ Regular review of its policies to ensure they are in line with current health information legislation and protection practices.