

## Frequently Asked Questions (FAQ) RE: Privacy and Confidentiality of Health Information

The Diabetes Care Program of Nova Scotia (DCPNS) is committed to protecting the privacy of personal information contained in the DCPNS Registry. Management and protection of personal information in this database is under the *Freedom of Information and Protection of Privacy Act (the FOIPOP Act)* and other related laws.

### **Why does the DCPNS collect health information?**

The DCPNS is a program of the Department of Health and has a role in helping health care professionals provide the best care possible for persons affected by or at risk of developing diabetes mellitus. We are authorized by law to collect health information from Diabetes Centres. We use your health information to measure and improve the health of Nova Scotians by setting standards of care and monitoring adherence to these standards, providing education, supporting research, and producing reports that identify important trends in health and health care.

### **What information is in the DCPNS Registry?**

The DCPNS collects select data points from Nova Scotia's Diabetes Centres on persons with diabetes who attend these programs. There are not narrative or clinical notes, nor interpretation of any of the data points. *See page 3 for a complete listing of the data that may be collected.*

### **How does the DCPNS protect my health information?**

The DCPNS has a privacy policy that describes the steps that must be taken to keep your information safe. These include staff orientation to principles of privacy and confidentiality; password protected computer files; restricted access to Registry data to DCPNS employees who need to use health information to perform their job functions, and additional security measures for all electronic files, including user names, passwords, firewall, and antivirus software. All uses of health information are governed by a set of Data Management Principles designed to protect the confidentiality of individuals attending the Diabetes Centre, health care professionals, and health care facilities.

### **How does the DCPNS use my health information?**

The DCPNS uses your information, in combination with the information of many other people, to evaluate care provided, to plan education programs for health professionals, in statistical reports, and approved research projects. If personal health information is used for research purposes, the research request must receive approval from a recognized Research Ethics Board and a Data Access Committee. Individuals will never be identified in any published reports.

### **Can I get access to my personal health information?**

The DCPNS has policies and procedures in place for managing requests. You will be asked to complete and sign a "Personal Information Request Form." In this way, we know that you are requesting the information. You may also need to contact the Diabetes Centre where you received care/education, as these records have more information than the DCPNS Registry records. If you have questions about the health information collected by the DCPNS, please contact the DCPNS Privacy officer at 902-473-3219 or e-mail [info@dcpens.nshealth.ca](mailto:info@dcpens.nshealth.ca). Your right to access your health information applies only to your own information; it does not extend to your family members. You must give your written permission in order for a family member to request your health information.

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**Can I request that my personal information not be collected or be removed from the DCPNS Registry?**

It is very important to the work of the DCPNS that health information about diabetes in the province is as complete as possible. There may be alternatives to removing all of your health information. Please contact the DCPNS Privacy Officer at (902) 473-3219 or e-mail [info@dcpns.nshealth.ca](mailto:info@dcpns.nshealth.ca) to discuss your concerns.

**How do I request a change of information?**

To request a change to your personal health information, you must submit a request to the Privacy Officer, or designate, of the DCPNS. The Privacy Officer, or designate, will assist you in the application process.

## Information collected:

### Demographics:

Health card number                      Gender  
 Date of birth                                Municipality of residence  
 Date of diagnosis                         Co-morbid conditions at time of referral and ongoing  
 Date of referral

### Diabetes Centre: By age grouping, children/youth (< age 19 years) or adults (≥ age 19 years)

Area seen:	Diabetes type:	Treatment	Visit type:
<ul style="list-style-type: none"> <li>• Inpatient</li> <li>• Outpatient</li> <li>• Satellite site</li> <li>• Phone</li> </ul>	<ul style="list-style-type: none"> <li>• Type 1</li> <li>• Type 2</li> <li>• Impaired fasting glucose (IFG)</li> <li>• Impaired glucose tolerance (IGT)</li> <li>• IFG and IGT</li> <li>• Pregnant--preexisting diabetes</li> <li>• Gestational diabetes mellitus (GDM)</li> <li>• Impaired glucose tolerance of pregnancy (IGT Preg)</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Diet only</li> <li>• Oral agents (OAs)</li> <li>• Insulin</li> <li>• Insulin and OAs</li> </ul>	<ul style="list-style-type: none"> <li>• <i>New referral:</i> <ul style="list-style-type: none"> <li>- Newly diagnosed</li> <li>- Not newly diagnosed</li> <li>- Not newly diagnosed re-referral</li> </ul> </li> <li>• <i>Follow-up visit:</i></li> </ul> <p><i>As well, sub categories:</i></p> <ul style="list-style-type: none"> <li>- Insulin start</li> <li>- Pump start</li> <li>- Continuous glucose monitoring (instruct)</li> </ul>

### Indicators of Care Component: Information captured on the Flow Sheet

Clinical Indicators	Self-care Indicators
Weight and Height (BMI) Blood Pressure (including medications) Use of Aspirin Foot assessment risk-rating (L, M, H) Blood glucose: Fasting 2-hr Other (specify) Glycated Hemoglobin (HbA <sub>1c</sub> ) Lipids (including medication): Total Cholesterol (TC) HDL-C (ratio TC:HDL-C) LDL-C Tryglicerides Creatinine (estimated creatinine clearance) TSH Proteinuria/microalbuminuria (albumin creatinine ratio)	Self-blood glucose monitoring: Frequency of testing Use of results Appropriate technique Ketone testing (if applicable) Carries Diabetes ID Smoking status Flu vaccination: Date of last appointment Eye examination: Date of last appointment Dental examination: Date of last appointment
Other	
Date of visit Date of diagnosis Date of birth Date of referral Type of diabetes	Type of treatment (name and dosage): Insulin Oral antihyperglycemic agents (OAA) Meal plan Exercise (also a self-care practice): Type and frequency, in keeping with recommendations