



Canadian Institute  
for Health Information

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Institut canadien  
d'information sur la santé

## Canadian Institute for Health Information

### Privacy Impact Assessment of the Therapeutic Abortions Database

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## I. Introduction and Overview

- ◆ Canadian Institute for Health Information (CIHI)
  - CIHI is an independent, national, not-for-profit corporation incorporated on December 10, 1993.
  - CIHI's mandate, set by the Ministers of Health, is to provide accurate and timely information needed to establish sound health policy, effectively manage the Canadian health system, and create public awareness of factors affecting good health. In meeting this mandate, CIHI receives data from the hospital sector and from specific programs.<sup>1</sup>
  - Since respecting personal privacy, safeguarding the confidentiality of individual records, and system security are critical to successfully meeting its mandate, CIHI has created a Privacy Secretariat reporting to the CEO and established principles and policies for the protection of health information (which continue to undergo revision and enhancement in a rapidly changing field).<sup>2</sup>
- ◆ The Therapeutic Abortions Database (TADB)
  - The TADB contains statistical information on the number of therapeutic abortions performed on Canadian residents.
  - The TADB contains very limited personal information and this information is not released to any individual or organization (including Statistics Canada).
  - CIHI follows careful procedures to ensure that the information produced from the TADB cannot be linked back to the individuals who received the abortions.
  - As a result of the 1969 Criminal Code Amendment regarding therapeutic abortions, the Department of Justice requested Statistics Canada to develop the statistical means to monitor the operation of the amendment. The procedure was decriminalized in 1988, however data collection was deemed important for public health reasons and was continued by Statistics Canada under authority of the Statistics Act. When CIHI was formed, Statistics Canada transferred responsibility for collection to CIHI. The transfer was effected in 1996.
  - The TADB integrates de-identified provincial data relating to therapeutic abortions performed in hospitals and clinics on women residing in Canada.
  - CIHI sends an annual TADB file (containing only de-identified data) to Statistics Canada for analysis and release.

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<sup>1</sup> CIHI, "Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information," (April, 2002, 3<sup>rd</sup> ed.), 3.2.

<sup>2</sup> CIHI, "Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information," (April, 2002, 3<sup>rd</sup> ed.), 1.1.

- Statistics Canada protects and safeguards the information received from CIHI under the strict confidentiality obligations of the *Statistics Act*. Statistics Canada also ensures that data, which refer to private clinics and, those provinces and territories that submitted data for 3 or fewer facilities are not disclosed without authorization by the data provider.

## II. Description of the Therapeutic Abortions Database

### ◆ General Goals of the TADB

- Therapeutic Abortion (TA) data are considered important from a social and public health perspective. The data are used for example, to assist in the calculation of teenage pregnancy rates.<sup>3</sup> They are also used to assess the impact of planned parenting initiatives, and to facilitate statistical analysis and research pertaining to the demographic and medical characteristics of Canadian residents obtaining therapeutic abortions in Canada and in neighbouring states of the United States.

### ◆ Current and Intended Scope of the TADB

- The TADB is a national database representing approximately 90% of all abortions performed in Canada involving Canadian residents.
- The TADB does not capture information on all abortions performed on Canadian residents. For example, not all medical (i.e., non-surgical) procedures or drug-induced abortions that are performed in Canada are reported for inclusion in the TA database.
- The data elements collected include: demographic information (i.e., including patient's province of residence and age in years or age groups) and medical information relating to surgical and medical procedures.
- The TADB includes therapeutic abortion data about procedures performed on Canadian residents in Canadian facilities (hospitals and clinics), and in American facilities along the United States-Canada border. Capturing data from these U.S. states provides a more complete picture of the total number of abortions performed on Canadian residents. The reports received from bordering American states in the United States, and from most Canadian clinics, include only aggregate counts with no personal identifiers.
- Reporting of abortion data became non-mandatory for Canadian facilities in the late 1980s, which has affected the comprehensiveness of reporting to the TADB. There is an on-going emphasis on enhancing the quality and timeliness of data in the TADB.

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<sup>3</sup> Statistics Canada uses data from TADB to determine teen pregnancy rates in Canada. See Sources of Teen Pregnancy in <http://www.statcan.ca/english/freepub/82-221-XIE/01002/defin4.htm>

◆ Conceptual Technical Architecture

- The data submitted by all provinces and territories are stored in a secure segregated database.
- Hospitals in most Canadian provinces and territories use the International Classification of Diseases (ICD) 9<sup>th</sup> revision developed by the World Health Organization (WHO) for reporting purposes. Due to the staggered implementation of the ICD-10-CA/CCI<sup>4</sup> across Canada, the TADB includes procedures coded using more than one coding system. Access to the TADB data is limited to the small number of people working on the TADB. CIHI's practices are designed to ensure the security and confidentiality of the database.

### III. Data Collection for the Therapeutic Abortions Database

◆ Authorities for the Collection, Use, and Disclosure of Information

- CIHI maintains the TADB in accordance with written agreements with Statistics Canada and the provinces and territories that submit therapeutic abortion data to CIHI.
- The data are obtained from provincial and territorial facilities that are covered by various provincial and territorial *Freedom of Information and Protection of Privacy Acts*, *Health Information Acts* (Manitoba and Alberta) and public hospital legislation. These organizations are responsible for complying with the requirements in their jurisdictions.
- CIHI obtained authorization in June 2001, from provinces and territories that submit data through the Discharge Abstract Database (DAD) to deliver a non-identifiable data file to Statistics Canada (STC) in accordance with the STC-CIHI transfer agreement.

◆ Limits on Data Collected/Received by CIHI

- Statistics Canada originally specified the data elements to be collected for the TADB. However, when therapeutic abortion was decriminalized, some provinces chose not to report all data elements.
- The TADB collects a maximum of 15 data elements. There is considerable provincial variation in the data elements reported by hospitals and those reported by clinics. (See Table 1 and Table 2 in Appendix A). The lack of consistency in data collected is recognized as a data quality issue for the TADB.

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<sup>4</sup> ICD-10-CA/CCI - This is the Canadian version of the International Classification of Diseases 10<sup>th</sup> revision and Canadian Classification of Interventions. Though this has been adopted as the Canadian standard for reporting, individual provinces and territories will be adopting this classification system over the next few years, starting in April 2001.

#### ◆ Sources of Data

- The sources of data for the TADB include provincial and territorial ministries of health and individual hospitals and clinics.
- The available data are currently gathered from a variety of sources and data inputs vary accordingly.
- Most Canadian hospitals submit hospitalization data to the Discharge Abstract Database (DAD) maintained by CIHI.
- The submission of data by hospitals to CIHI through the DAD streamlines the data capture process. It provides for greater uniformity of the data elements submitted and for greater control and security in data submission. Reliance on the DAD limits the number of individuals able to view the data at CIHI and ensures that the minimum number of sensitive data elements is included in the TADB.
- As of April 1, 1999, Saskatchewan, Ontario, Nova Scotia, New Brunswick, Newfoundland, Nunavut, the Northwest Territories and the Yukon have authorized TA data to be extracted from the DAD, thereby replacing the need for a separate submission of a data file for the National Therapeutic Abortions Database.<sup>5</sup>
- The following is a summary of TA data submission by facilities in Canada:
  - Data from Quebec comes in two forms, aggregate counts (about two-thirds of total abortions in Quebec) from the Quebec Ministry of Health and Social Services and, record level information submitted on paper forms for the remaining one third of total abortions from select Quebec hospitals. The paper forms are manually keyed in and processed at CIHI. Discussions are underway to move towards electronic data submission to improve security.
  - British Columbia submits only aggregate counts for both hospitals and clinics.
  - Newfoundland, Nova Scotia and New Brunswick have authorized that TA data from hospitals be extracted from the DAD. The clinics in these provinces report data directly to CIHI by aggregate counts. Extraction from the DAD is the preferred approach.
  - Data from Ontario hospitals are extracted from the DAD and information from clinics is obtained from the Ministry of Health and Long-Term Care (MoHLTC). For TA 1999 and 2000, only aggregate counts were reported for Ontario clinics. The Ontario ministry will henceforth provide aggregate counts for TAs performed in clinics.
  - Alberta Health and Wellness submits all data elements for both hospitals and clinics on a cartridge by courier. Although Alberta reports to the DAD, the submission contains only in-patient data. Day-surgery cases are not reported to the DAD by Alberta. Since most abortions are performed as day surgeries, Alberta submits a file of abortion data that includes data from both in-patient and day-surgery settings.

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<sup>5</sup> Letter from CIHI, to provinces submitting TA data *via* the DAD, June 8, 2001.

- The ministry of health in Manitoba also submits all data elements for hospital-based TA on a cartridge. The clinic-based TA information is reported directly to CIHI.
  - Saskatchewan Health reports data from hospitals only, through the DAD, since there are no clinics in this province.
  - The Northwest Territories, Nunavut and Yukon also report data through DAD for hospitals only since there are no clinics in these territories.
  - Abortions are not reported by Prince Edward Island since there are no hospitals or clinics in the province that perform the procedure. The residents of Prince Edward Island are, however, included in the data reported by other provinces.
- The raw data files are stored by CIHI to ensure that any data mappings, manipulations, and corrections can be recreated. These raw data files are also used to run some ad-hoc reports and are necessary for audit trails such as verifying original data reported against any changes made for data quality purposes.
  - CIHI encourages data providers to transfer data by secure means, including *via* secure courier. In addition, submission of all data in a secure electronic form is anticipated in the future. This will further enhance security of information submitted.
  - When data are received via cartridges, they are transferred electronically from the cartridge to CIHI's UNIX environment with the help of an external firm, subject to confidentiality and security provisions. Therefore, no individual other than the program area person can access or view the data.
- ◆ Personal Information Collected
- The TADB collects a maximum of 15 data elements for each procedure (Appendix A).
  - The TADB contains the following sensitive data elements:
    - Residence Code: This is the province/territory code indicating the residence of the patient. This is the only geographic information collected about the patient.
    - Chart / Case Number: This number is assigned by the institution to record the episode of care. This number is used to facilitate error corrections in the record, if necessary, to improve overall data quality. This number is retained at CIHI.
    - Institution Number: This number is assigned to every facility by the respective provincial ministries of health. This number is retained at CIHI and used for data quality purposes only. For example, trending of institutional case volumes over time helps to monitor potentially missing cases, which ensures comprehensive data capture.
    - Age: Age is provided in years or in age groups only. This is used for statistical reporting purposes (e.g., teen pregnancy rates).
    - The remaining data elements pertain to clinical aspects of the procedure.

◆ Location of the Data

- TADB data are located at CIHI's office. TADB data are stored in a locked room and in a secure, segregated database. Both the locked TADB room and the segregated database are only accessible to TADB authorized staff at CIHI.

◆ Data Retention/Destruction

- Diskettes and cartridges are returned in a secure manner to the provinces after the final file is released to Statistics Canada. CIHI's Privacy Policy stipulates that, "CIHI retains personal health information in electronic format permanently for long-term analysis and reporting. CIHI retains paper records of personal health information that have been put into electronic format for as long as is required for the electronic records to be finalized. The length of time may vary depending on the data holding."<sup>6</sup>

◆ Consent Issues

- "CIHI recognizes that data providers must determine what actions are necessary to comply with any consent requirements in their jurisdictions."<sup>7</sup> CIHI relies on primary data collectors to comply with the requirements and laws in place in their jurisdiction for the collection, use and disclosure of personal health information.
- CIHI's Privacy Secretariat carried out a national consultation process in 2001 with provincial and territorial ministries of health. Discussions included the importance of ensuring appropriate legal authority for disclosing data to CIHI and of meeting consent or notice requirements under relevant legislation.

#### IV. Uses and Disclosures of Data

◆ Uses of Data

- Data are used for statistical reporting and research purposes.
- Data are grouped into categories and aggregated to produce total counts for a jurisdiction. For example, "age" is grouped into categories of five-year ranges to form the derived "age group" data element. The aggregate counts of abortion procedures reported by clinics are added to information from other facilities (e.g., hospitals) to produce the total counts within a province or territory. The TADB data are then subject to data quality checks. The grouped, aggregated data are then used to create statistical tables and reports.

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<sup>6</sup> CIHI, "Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information," (April, 2002, 3<sup>rd</sup> ed.), 5.8.

<sup>7</sup> CIHI, "Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information," (April, 2002, 3<sup>rd</sup> ed.), Principle 3.

- External users of aggregate information include government departments, researchers, lobby groups, the general public and the media.
- Record level data are required for analysis, using techniques that cannot be used with the aggregate data contained in typical summary tables.

#### ◆ Disclosures of Data

- The 1994 agreement between Statistics Canada and CIHI specifies that Statistics Canada has the right of access to micro-data from CIHI for former Statistics Canada surveys. In compliance with this arrangement, CIHI sends a clean (error-free) file, excluding identifiable data (such as Chart Number and Institution Number) to Statistics Canada.
- CIHI sends a final file of the TADB data to Statistics Canada containing non-identifiable record-level data. Appendix B lists the data elements that are removed before the final file is sent to Statistics Canada for analysis, release and distribution through national reports. Statistics Canada analyzes the data and, jointly with CIHI, publishes an annual data report through its on-line publication, The Daily.<sup>8</sup>
- CIHI processes ad-hoc requests for aggregate data and special analyses from the TADB. These requests are subject to CIHI's multi-stage review process. Some requests that pertain to sensitive information are forwarded for review and decision to CIHI's Privacy Secretariat and Privacy Team. Particularly sensitive requests may be taken to CIHI's Chief Privacy Advisor for advice.
- CIHI receives up to 4 ad-hoc requests per month for TADB data. From July 2001 to September 2002, there were 31 data requests:
  - 12 requests for information already available publicly from Statistics Canada's web site and publications;
  - 9 requests from researchers for aggregate data;
  - 3 requests from government and non-government institutions for a list of data elements collected in the database;
  - 5 requests from non-governmental organizations for aggregate counts;
  - 2 requests from a member of the media for the number of facilities performing abortions.

#### ◆ Disclosure Avoidance Practices for the TADB

- Data releases and reports are subject to CIHI's standard practices for avoiding residual disclosure. Reports are reviewed for risks of residual disclosure and, where necessary, taken to higher levels of aggregation for disclosure avoidance. For example, CIHI's general guideline requiring a minimum of 5 observations per cell is strictly applied in the case of the TADB. Additionally, prior permission is

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<sup>8</sup> See, for example, March 29, 2003, when the 2000 data were released.

obtained before every media release from those provinces and territories where there are 3 or fewer facilities in the jurisdiction.

- Researchers requesting data are required to complete formal requests for data and to sign non-disclosure agreements wherein they agree not to attempt to re-identify the data.
  - A complete description of all of CIHI's practices is available in *CIHI's Principles and Policies for the Protection of Personal Health Information, 3<sup>rd</sup> edition*.
  - In consideration of the sensitivity of TA data, the data tables and tabulations do not include any facility-level information.
  - CIHI limits the data disclosed to Statistics Canada as previously described in "Disclosures of Data".
  - Further, the following sensitive data elements are removed from the final file before disclosure to Statistics Canada (Appendix B):
    - Data Capture Control Fields - batch number, page number and line number.
    - Hospital Information Fields - hospital number, hospital case/chart number and generated hospital number.
  - Sanctions for clients who violate conditions for disclosure, or who misrepresent the nature of the data supplied to them, include a written complaint to the sponsoring organization, refusal of future access to data, seizure of any data released by CIHI, and legal action.<sup>9</sup> This has never been required.
- ◆ Record Linkages for the TADB
- CIHI does not link the individual records from the TADB with other internal or external databases.
- ◆ Access Rights of Individuals to their Personal Information
- "Upon request, CIHI informs an individual whether CIHI holds personal information about the individual. CIHI indicates the source of this information and refers the individual to the data providers concerned for access to the full personal health information held by them."<sup>10</sup> Requests from an individual for access to his/her specific information will be referred to the data provider (i.e., provincial/territorial ministry of health or facility depending on who supplied CIHI with the data).

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<sup>9</sup> CIHI, "Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information," (April, 2002, 3<sup>rd</sup> ed.), 5.14.

<sup>10</sup> CIHI, "Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information," (April, 2002, 3<sup>rd</sup> ed.), 9.1.

## V. Security Safeguards

### ◆ Security Safeguards

- CIHI maintains the TADB in a segregated database on a password-protected system in a separate room with security locks and restricted access.
- The TADB is subject to data quality edit checks to verify accuracy of data reported. CIHI's Data Quality Framework also applies to the TADB. The Data Quality Framework is a CIHI-developed tool that is designed to provide a common, objective approach to assessing and documenting the data quality of its various data holdings along five general dimensions of quality: accuracy, comparability, timeliness, usability, and relevance.
- Data submission *via* the DAD makes processing of data more secure and efficient. Transmission of data through the DAD permits selection criteria and access rules to be set electronically, thereby limiting human access to TA data.
- For those providers that submit data through a format other than DAD, CIHI strongly encourages secure modes of submission, such as secure prepaid courier service. Data that arrive at CIHI on paper forms or in electronic form are forwarded to the responsible program area person who then updates the TADB in a secure manner.
- CIHI is currently conducting a pilot project on the electronic submission (via diskette) of TA data from Quebec hospitals.
- Access to the TADB is subject to CIHI's highest standards for access and security.

## VI. Conclusions: A Privacy Report Card for TADB

### ◆ Conclusions

- Responsibility for the TADB was transferred to CIHI from Statistics Canada in 1996.
- The TADB is a database of statistical information on the number of therapeutic abortions performed on residents of Canada.
- The TADB holds limited personal identifiers and does not release record level data, except to Statistics Canada.

The practices of TADB in relation to the ten privacy principles set out in *CIHI's Principles and Policies for the Protection of Personal Health Information* are set out below. CIHI's Principles are based on Schedule 1 of the *Personal Information Protection and Electronic Documents Act*.

#### a) Accountability

CIHI's President and Chief Executive Officer is accountable for ensuring compliance with CIHI's *Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection health information*. CIHI also has a Chief Privacy Officer, a Chief Privacy Advisor, and a corporate Privacy Confidentiality and Security team in place to manage privacy matters at CIHI.

#### b) Identifying Purposes

The intended purposes and scope of the TADB are for statistical reporting purposes. The data are used for example, to determine teenage pregnancy rates<sup>11</sup>, to assess the impact of planned parenting initiatives and to facilitate statistical analysis and research pertaining to the demographic and medical characteristics of Canadian residents obtaining therapeutic abortions in Canada and in neighbouring states of the United States.

#### c) Consent

The TADB receives data originally collected by hospitals, clinics and ministries of health for the purpose of administering and managing the health care system. The TADB relies on the data collectors to meet their data collection, use and disclosure rules, including those related to consent and notification. CIHI's focus is on transparency as to its purpose, the uses of its data holdings, data protection practices, and appropriate use of the data.

#### d) Limiting Collection

The TADB collects a maximum of 15 data elements at the highest degree of anonymity possible.

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<sup>11</sup> Statistics Canada uses data from TADB to determine teen pregnancy rates in Canada. See Sources of Teen Pregnancy in <http://www.statcan.ca/english/freepub/82-221-XIE/01002/defin4.htm>

e) Limiting Use, Disclosure and Retention

The TADB data are used only for statistical reporting purposes and research. The TADB data are used and disclosed in accordance with data sharing agreements with the ministries of health and CIHI's strictest privacy practices.

The intent of the TADB is to facilitate statistical reporting and analysis. This may include retrospective studies. CIHI maintains data for as long as necessary to support this requirement.

f) Accuracy

CIHI applies edit checks to the data and the database is subject to CIHI's Data Quality Framework.

g) Safeguards

In addition to CIHI's standard physical, technological, and administrative safeguards, the TA data are kept in a segregated database on a password-protected system in a separate room with security locks and restricted access.

h) Openness

Information about the TADB is set out in this document and is available on CIHI's website as well as from the TA program staff.

i) Individual Access

Individuals requesting access to their information will be referred back to the data provider (i.e., the province/territory or relevant facility as appropriate).

j) Challenging Compliance

The public may challenge CIHI's compliance with its *Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information*. If an individual does not believe that their challenge has been satisfactorily resolved, he or she may appeal to the CIHI's Chief Privacy Advisor who will report to CIHI's President and Chief Executive Officer.

## APPENDIX A

Table 1. Data Elements Submitted by Provinces and Territories (for Hospitals) in Calendar Year, 2000

Data Elements	NFLD	PEI <sup>1</sup>	NS	NB	QC <sup>2</sup>	ON	SK	MB	AB	BC <sup>3</sup>	YK	NWT	NU
Province of Report	√		√	√	^	√	√	√	√	*	√	√	√
Province of Residence	√		√	√	^	√	√	√	√		√	√	√
Institution Number	√		√	√	^	√	√	√	√	*	√	√	√
Age (√) / Age group (*)	√		√	√	^	√	√	√	√	*	√	√	√
Marital Status	√		√	√	^	√	√	√	√		√	√	√
First day of last Menses	√		√	√	^	√	√	√	√		√	√	√
Date of Abortion	√		√	√	^	√	√	√	√		√	√	√
Inpatient Days of Care	√		√	√	^	√	√	√	√		√	√	√
Number of Previous Deliveries	√		√	√	^	√	√	√	√		√	√	√
Number of Previous Spontaneous Abortions	√		√	√	^	√	√	√	√		√	√	√
Number of Previous Induced Abortions	√		√	√	^	√	√	√	√		√	√	√
Initial Surgical Procedure	√		√	√	^	√	√	√	√	*	√	√	√
Subsequent Surgical Procedure	√		√	√	^	√	√	√	√		√	√	√
Sterilization (If any)	√		√	√	^	√	√	√	√		√	√	√
Complication/s (up to 3, if any)	√		√	√	^	√	√	√	√		√	√	√

<sup>1</sup> Prince Edward Island (PEI) does not report abortions.

<sup>2</sup> Only one-third of total Quebec counts contain all data elements. The remaining are aggregate counts by age group only.

<sup>3</sup> The BC ministry of health provides aggregate counts by age groups, procedure and facility.

(√ All data elements, ^ All data elements for one-third of total Quebec counts, \* Aggregate counts)

## APPENDIX A

Table 2. Data Elements Submitted by Provinces and Territories (for Clinics) in Calendar Year, 2000

Data Elements	NFLD	PEI <sup>1</sup>	NS	NB	QC	ON	SK <sup>1</sup>	MB	AB <sup>2</sup>	BC	YK <sup>1</sup>	NWT <sup>1</sup>	NU <sup>1</sup>
Province of Report	*		*	*	*	*		*	√	*			
Province of Residence	*		*	*				*	√				
Age (√) / Age group (*)					*	*			√	*			
Institution Number					*				√	*			
Marital Status									√				
First day of last Menses									√				
Date of Abortion									√				
Inpatient Days of Care									√				
Number of Previous Deliveries									√				
Number of Previous Spontaneous Abortions									√				
Number of Previous Induced Abortions									√				
Initial Surgical Procedure									√	*			
Subsequent Surgical Procedure									√				
Sterilization (If any)									√				
Complication/s (up to 3, if any)									√				

<sup>1</sup> There are no clinics in Prince Edward Island (PEI), Saskatchewan (SK), Yukon (YK), Northwest Territories (NWT) and Nunavut (NU).

<sup>2</sup> Alberta is the only province that reported detailed information.

Note: Prince Edward Island does not report abortions.

(√ All data elements, \* Aggregate counts, ■ No clinics in these provinces and territories, ■ Alberta provides all data elements, ■ These provinces provide aggregate counts only)

**APPENDIX B****Table 3. Suppressed Fields in the Final File to Statistics Canada**

Data Capture Control fields	<ul style="list-style-type: none"><li>• Batch number</li><li>• Page number</li><li>• Line number</li></ul>
Institution Information fields	<ul style="list-style-type: none"><li>• Institution number</li><li>• Institution case number</li><li>• Generated institution number</li></ul>