Canadian Joint Replacement Registry Privacy Impact Assessment

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Canadian Institute for Health Information

Institut canadien d'information sur la santé

Who We Are

Established in 1994, CIHI is an independent, not-for-profit corporation that provides essential information on Canada's health system and the health of Canadians. Funded by federal, provincial and territorial governments, we are guided by a Board of Directors made up of health leaders across the country.

Our Vision

To help improve Canada's health system and the well-being of Canadians by being a leading source of unbiased, credible and comparable information that will enable health leaders to make better-informed decisions.

CIHI is pleased to publish the following Privacy Impact Assessment pursuant to its Privacy Impact Assessment Policy:

CANADIAN JOINT REPLACEMENT REGISTRY
PRIVACY IMPACT ASSESSMENT

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Executive Summary

The purpose of this privacy impact assessment (PIA) is to examine the privacy, confidentiality and security risks associated with the Canadian Institute for Health Information (CIHI) Canadian Joint Replacement Registry (CJRR). CJRR serves as the country's leading source of information on hip and knee replacement surgery. The goal of CJRR is to inform decision-making to improve the quality of care and clinical outcomes of joint replacement recipients. CJRR is a voluntary registry with surgeons participating from across Canada.

Orthopedic surgeons have three options for submitting data to CJRR: (a) completing paper-based forms and mailing to CIHI; (b) submitting information using CIHI's secure Electronic Data Submission Service (eDSS); or (c) as of April 2009, entering data in real time through CIHI's web-based data submission and reporting application.

The record-level patient data found in CJRR is collected in its original form from surgeons and facilities in various jurisdictions. The data is provided to CIHI as a secondary data user. Data providers have always obtained patient consent before submitting direct identifiers. In two facilities where patient consent is not obtained, direct patient identifiers are not submitted to CJRR.

In all modes of data submission, CJRR collects personal identifiers such as name, birthdate and health card number to support data validation and eliminate duplicates, which enables in-depth analysis of primary and revision procedures. Detailed patient characteristics are captured in order to profile joint replacement recipients.

A review was undertaken of the 10 privacy principles set out in the Canadian Standards Association's Model Code for the Protection of Personal Information as they apply to CJRR. While some potential privacy risks were identified, this assessment concludes that, except as identified below, the mitigation measures currently in place are such that CIHI and its data providers are prepared to accept and manage any remaining risks.

The PIA sets out the following recommendation:

- CJRR should review the practices around retention of paper questionnaires and, in consultation with Records Management, establish a retention/disposal schedule that takes into account any legal requirements or restrictions and redress mechanisms. CJRR should dispose of documents that no longer have a specific purpose and do so in a way that prevents improper or unauthorized use, access, copying, modification or disclosure and is in accordance with CIHI's policies and procedures.

1 Introduction

The Canadian Institute for Health Information (CIHI) collects and analyses information on health and health care in Canada. Its goal is to provide timely, accurate and comparable information to inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health. CIHI obtains data directly from hospitals, regional health authorities and ministries of health, including personal health information about recipients of health services, registration and practice information about health professionals and health facility information.

The Canadian Joint Replacement Registry (CJRR) is a national registry that collects patient-specific information on hip and knee replacement surgery performed in Canada, including total and partial procedures as well as resurfacing. The CJRR collects information on primary procedures and subsequent revisions. Orthopedic surgeons voluntarily submit data directly to CJRR using either standardized paper data collection forms, an electronic submission system or a web-based data submission and reporting application.

CIHI's Hospital Morbidity Database (HMDB) combined with CJRR data provide pivotal information on the increased demand for total hip and knee replacement surgery in Canada. CJRR data has also proven valuable in demonstrating the effect of obesity on hip and knee replacement rates.

1.1 PIA Objectives and Scope

The purpose of this privacy impact assessment (PIA) is to examine the privacy, confidentiality and security risks associated with CJRR. It includes

a) A review against the 10 privacy principles set out in Canadian Standards Association's *Model Code for the Protection of Personal Information* as they apply to CJRR;

b) A summary of potential privacy risks that have been identified; and

c) Measures currently implemented or to be implemented to avoid or to mitigate identified privacy risks.

This PIA is specific to CJRR. It builds on a PIA carried out in 2004 that evaluated and addressed key data protection issues.

2 CJRR Background and Context

2.1 Background

In 2001, the orthopedic surgeons of Canada, CIHI and Health Canada launched a national relational database to capture information on hip and knee replacement surgery. CIHI and orthopedic surgeons from each jurisdiction, who work under the auspices of the Canadian Orthopaedic Association and the Canadian Orthopaedic Foundation, have upheld this initiative. A number of other key partners have contributed to the successful development and implementation of the CJRR including orthopedic patients, The Arthritis Society and federal, provincial and territorial ministries of health.

Orthopedic surgeons and/or delegated staff collect personal and surgical information from their patients and forward the data on an ongoing basis to CJRR located at CIHI. Orthopedic surgeons began submitting operative data to CJRR in May 2001. On average, CJRR now receives approximately 2,000 hip and knee replacement records on a monthly basis from all jurisdictions performing joint replacements in Canada. The overall participation rate on the part of surgeons is estimated to be 62% (as of January 2010), and the 2007–2008 volume of data captured is approximately 40%.

Previously, CJRR received Ontario data directly from the Ontario Joint Replacement Registry (OJRR). A major impact to CJRR resulted from the decommissioning of the OJRR in March 2006. Rather than obtaining Ontario data directly from OJRR, CIHI must now work with each of the Ontario surgeons and have them provide their data directly to CJRR.

CJRR is expanding its data collection and recruitment efforts in order to enhance value as a leading source of health information for decision-makers. Focused attention continues to be directed toward increasing CJRR participation in provinces such as Ontario and Quebec, which contribute a substantial proportion of national joint replacement data. The web-based data submission and reporting system, introduced in April 2009, is intended to facilitate data submissions to the CJRR.

2.2 Description of CJRR

CJRR is a pan-Canadian information system for hip and knee replacement surgery with a mandate to record and analyze the level of activity, clinical parameters and outcomes of primary and revision hip and knee replacement surgery over time.

CIHI captures administrative and demographic information on all procedures performed in hospitals across Canada, including primary hip and knee joint replacements and revisions, through the HMDB. The HMDB also provides national discharge statistics from Canadian health care facilities by diagnoses and procedures. The CJRR was developed to provide a rich set of additional patient, clinical and surgical information beyond what is captured in HMDB to enable more in-depth analysis of primary hip and knee replacements and revisions. The goal of the CJRR is to provide information designed to help improve the quality of care and clinical outcomes of joint replacement recipients.

2.2.1 Description of CJRR Data

CJRR data is collected using two forms: the Hip Replacement Data Collection Form (153 data elements) and the Knee Replacement Data Collection Form (172 data elements). Copies of the forms are in Appendix B.

The following is a summary listing of the data collected and used in CJRR:

- Surgeon's name (mandatory)
- Patient name (mandatory)
- Provincial health card number
- Chart number
- Patient's home postal code (mandatory)
- Patient height and weight
- Birthdate (mandatory)
- Gender (mandatory)
- Hospital name and province (mandatory)
- Surgery date (mandatory)
- Wait time information
- Diagnosis details (mandatory)
- Surgical and clinical characteristics (some elements are mandatory)
- Surgical types (some elements are mandatory)
- Surgical approaches

2.2.2 Limits on Data Collected for CJRR

The CJRR only collects and receives identification, demographic, medical and technical information about patients and facilities that CIHI, with input from the CJRR Advisory Committee, has identified as relevant to the goals of CJRR.

2.2.3 Personal Information in CJRR

The CJRR captures detailed patient and surgeon identification information. The patient information is used to characterize the profile of joint replacement recipients and enable analysis of the different variables including age, gender, body mass index (BMI), etc. The surgeon is identified as the data provider and location of the health care provision.

2.3 Users of CJRR

Data products and services have been developed to address three categories of users based on their information needs.

2.3.1 General Public

CJRR provides a national view on knee and hip replacement comparative analyses and research studies that benefit the knowledge base of professionals, patients and the general population. The general public has access to published reports of aggregated findings. CIHI makes such information publicly available only in a manner designed to minimize any risk of identifiability and residual disclosure of information about individuals. The latest annual publication is entitled *Hip and Knee Replacements in Canada—Canadian Joint Replacement Registry 2008–2009 Annual Report* (Ottawa, Ont.: CIHI, 2009).

2.3.2 User Community (Data Providers)

CIHI has a user community made up of its data providers. Surgeons and treatment centres use the data to inform decisions to improve quality for treatment and as national standards for comparison.

Aggregate data is published at the provincial or territorial and national levels. There are no comparative reports published that compare one facility with another facility.

2.3.3 Third-Party Data Requesters

CIHI also administers a third-party data request program to facilitate and support statistical health research in Canada and management of the health care system. Aggregated data addresses many of the research needs but not all. Therefore, CIHI discloses de-identified record-level data for approved research purposes subject to CIHI standard practices—so that the identity of individuals cannot be determined by a reasonably foreseeable method—and subject to the requisite security mechanisms outlined in CIHI's third-party data request process.

2.4 Organization and Governance

2.4.1 Organization

CJRR is a program under the CIHI branch of Health Resources Information (HRI).

2.4.2 Governance

Position/Group	Role/Responsibilities
Vice President, Programs	The Vice President, Programs, is responsible for the overall operations and strategic direction of the Health Resources Information branch, including the CJRR.
Director, Health Resources Information (HRI)	The Director is fully accountable for CJRR. The Director is responsible for strategic and operational decisions about CJRR and for ensuring its continued successful development.
Manager, Clinical Registries	The Manager is responsible for on-going management, development and dissemination of CJRR. The Manager makes operational decisions about CJRR, supports the CJRR Advisory Committee and consults internally and with CJRR clients as appropriate.
CJRR Advisory Committee	The external Advisory Committee provides advice on the development and implementation of CJRR and subject matter expertise.
CJRR Program Lead	The Program Lead coordinates activities related to the functioning of CJRR and ensures the timely delivery of results and services that satisfy business and user requirements.
Chief Technology Officer	The Chief Technology Officer is responsible for the strategic direction and overall operation/implementation of CIHI's technological and security solutions.
Chief Privacy Officer	The Chief Privacy Officer is responsible for the strategic direction and the overall implementation of CIHI's privacy program.
Manager, Analytical Systems	The Manager is responsible for ensuring that technical requirements for the ongoing development and maintenance of CJRR are met. The Analytical Systems team is responsible for acting as System Administrator for CJRR.

2.5 Authorities Governing CIHI

CIHI adheres to its *Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010* (Privacy Policy, 2010) and to any applicable privacy legislation and/or agreements.

2.5.1 Legislation and Agreements

Legislation

CIHI is a secondary user of personal health information, specifically for the planning and management of the health system, including statistical analysis and reporting. Data providers are responsible for meeting the statutory requirements in their respective jurisdictions, where applicable, at the time the data is collected initially.

All provinces and territories have public-sector privacy legislation in place. Canadian privacy legislation includes provisions that authorize public bodies covered by the acts to disclose person-identifiable data, without the consent of the individual, for statistical purposes. Alberta, Saskatchewan, Manitoba and Ontario (legislation pending in Newfoundland and Labrador and New Brunswick) also have health information-specific

privacy legislation with express lawful authority to use and disclose personal health information, without individual consent, for purposes of management of the health system, including statistical analysis and reporting.

For example, CIHI is recognized as a prescribed entity under the *Personal Health Information Protection Act* of Ontario. Custodians in Ontario may disclose personal health information to CIHI without patient consent pursuant to section 29 as permitted by section 45(1) of the Act.

Agreements

CIHI has in place the following types of agreements:

- Bilateral and data-sharing agreements between the provinces and territories and CIHI in support of data collection, and any subsequent data sharing with authorized users; and
- Data-sharing and other types of agreements negotiated between other data providers and CIHI, which set out the purpose, use, disclosure and retention requirements, as well as any subsequent data sharing that may be permitted.

2.5.2 Committees

The CJRR Advisory Committee provides advice on the development and implementation of CJRR as well as content expertise. Canadian orthopedic surgeons, through their voluntary participation in the CJRR and CIHI, have been collaborative partners during the implementation stages of CJRR. Orthopedic surgeons from across Canada are represented on the CJRR Advisory Committee, which also includes a patient representative and a representative from The Arthritis Society. Efforts are currently under way to recruit representation from departments of health and regional health authorities.

2.5.3 CIHI Policies

CIHI has in place a suite of privacy and security policies, procedures and guidelines, which is designed to protect personal health information from unauthorized or unintentional loss, theft, access, use, modification or disclosure and which outlines the roles and responsibilities of management and staff at CIHI.

3 Data Collection and Verification Process

A diagram illustrating the flow from data capture through to verification and dissemination can be found in Appendix C.

There are three data transmission modes for data submission.

3.1 Paper Forms

Paper collection forms are completed by the surgeons and/or their delegated staff, and then the forms are couriered to CIHI in prepaid and labelled envelopes. Authorized CJRR staff enter the data into the CJRR relational database. The collected data is reviewed by CJRR staff, and missing and/or incomplete data elements are communicated back to the surgeon's office for follow-up.

There are three methods for communicating missing or incomplete data elements to clients:

1) Electronic communication
Data quality reports are produced and sent on CDs, which are encrypted, password-protected and accompanied by a cover letter. The CDs are sent via courier to the authorized registered data users for updating, and confirmation of receipt must be obtained by the program area.

A new mechanism and infrastructure to electronically disseminate information back to data providers is being launched in the summer of 2010, which will enhance the validation process by minimizing the use of CDs. The automated approach will see data loaded to a web interface with access granted to only those appropriately authorized. Updating of the data will be done directly to the reports, and they will be resubmitted to CJRR through a web interface, with stringent security features built in as part of the system architecture.

2) Phone communication
CJRR staff call the relevant surgeon's office to obtain missing or incomplete information via the telephone.

3) Return of paper forms

As of 2010, CJRR will return paper forms via courier to the surgeon's office to obtain missing or incomplete information. These forms will be double-wrapped with the surgeon's address placed on both envelopes, and efforts will be made to blank out sensitive fields when feasible.

3.2 Electronic Data Reporting

Electronic data reporting using the CIHI Electronic Data Submission Service (eDSS) system was introduced in 2005–2006. Data is submitted electronically by surgeons' designates/vendors through a combination of two secure applications, namely eDSS and Client Services. Both are accessed through industry standard HTTPS protocol over SSL using trusted secure certificates. Client Services is a common authentication solution used by all externally accessible CIHI applications. Client Services ensures only authorized external users are allowed access. The data providers submit their data in electronic format according to prescribed specifications. The data is verified by CJRR, and problems are communicated back to the provider via email with password-protected reports, or by phone. The provider updates the data and resubmits an updated file.

3.3 Web-Based Submissions and Reporting

A web-based submission and reporting system has been in use since April 2009. Data providers are able to complete the data elements and provide updates online in an industry standard secure web environment. User agreements are in place outlining appropriate system use and protection of data. This tool permits the submission of data to CJRR, and also allows external users to run reports containing own data, as well as download a full copy of all their own data that has been submitted to CJRR, including personal health information.

4 Privacy Analysis

4.1 Principle 1: Accountability for Personal Health Information

CIHI's President and Chief Executive Officer is accountable for ensuring compliance with CIHI's Privacy Policy, 2010. CIHI has a Chief Privacy Officer; a corporate Privacy, Confidentiality and Security team to manage privacy matters at CIHI; a Privacy Subcommittee of its Board of Directors; and an external Chief Privacy Advisor.

Functional responsibility for CJRR falls under the Health Resources Information branch. The Clinical Registries Manager is responsible for CJRR and ensures adherence to the CIHI policies and procedures for protecting privacy of the personal health information.

CJRR clients are subject to the requirements of data protection laws in their respective jurisdictions and the independent oversight of privacy commissioners or their equivalents. They also agree to the terms and conditions as outlined in the CJRR Web-Based Data Submission and Reporting Application User Agreement.

4.2 Principle 2: Identifying Purposes for Personal Health Information

CIHI only collects personal health information once the purpose has been identified in consultation with appropriate stakeholders. The purposes are clearly stated in the CJRR program documentation.

The following are purposes specific to CJRR personal health information:

- *Patient first name, middle initial and last name* are used primarily for data processing and quality purposes (for example, to identify and remove patient and procedure duplicates and help to identify revisions).
- *Birthdate* is collected to analyze the effects of age at treatment. It is also used for data processing and quality purposes.
- *Gender* is collected to identify gender differences in patient outcomes and to facilitate merging a patient's surgery data to hospital stay data.
- *Patient height and weight* are used to calculate BMI, which is an indicator used in measuring the physical load on patient joints. The load has implications on the rate of deterioration of the joint.
- *Patient home postal code* is collected to calculate patient residence and enable comparison of distance from residence to location of surgery.
- *Chart number* may be used to identify patient/procedures and for follow-up with hospitals on data quality related issues.
- *Provincial health card number* is collected to facilitate accurate identification of a record for data quality checks. The number facilitates merging patient's surgery data to hospital stay data and may also be used for longitudinal follow-up.
- *Diagnosis and surgical details* are used to analyze the relative effectiveness of surgical techniques. The information is intended to help determine which implants are most effective in specific circumstances, how best to avoid infection and other complications, and which patients can most benefit from hip and/or knee replacement surgery.

Data dictionaries that are currently referenced list data elements and describe the purpose. These documents are currently being reviewed and revised to conform to CIHI standards and will be made publicly available during 2010.

4.3 Principle 3: Consent for the Collection, Use or Disclosure of Personal Health Information

The data found in CJRR is collected in its original form from the surgeons and facilities in the various jurisdictions. When CJRR was first launched, the data providers obtained the express consent of patients for the collection and use of their data in the CJRR. Currently, consent is obtained by all those providers submitting via paper and web and the vast majority of those submitting via electronic files (that is, more than 95% of the collected cases are consent-based).

4.4 Principle 4: Limiting Collection of Personal Health Information

CIHI limits the collection of personal health information for the CJRR to that which is necessary for its identified purposes, and it collects information by fair and lawful means. The CJRR Advisory Committee of program experts advises on the data elements to be collected.

4.5 Principle 5: Limiting Use, Disclosure and Retention of Personal Health Information

4.5.1 Limiting Use

CIHI publishes a wealth of publicly available, aggregate-level data. Considerable information is made available through analytic reports as a means to address a broad base of information needs. CIHI limits the access to and use of CJRR data to authorized purposes, and only authorized users have access. Staff are only permitted to access and use data holdings containing personal information on a need-to-know basis.

Access to and use of data by CIHI staff outside of CJRR, which may be required to prepare reports or publications, is done in compliance with CIHI's privacy policy and related procedures. These include justification for use, manager approval and auditing. Employee access to specific data holdings is frequently reviewed and validated by the program manager. At CIHI, sensitive data elements such as the health card number are encrypted before the data set is used for analysis or report production. Health card numbers in an unencrypted form are only available to staff when performing application support, data submission and verification activities.

4.5.2 Limiting Disclosure

CJRR data is used for analysis and statistical reporting purposes. As part of its mandate, CIHI publishes aggregated health information only in a manner designed to minimize any risk of identifiability and residual disclosure of information about individuals. This generally requires a minimum of five observations per cell.

CIHI may disclose de-identified data to third parties on a case-by-case basis. For each request, a Third-Party Record Level Data Request Form is completed that addresses all the requirements that must be satisfied prior to the disclosure of personal health information for research purposes. The researchers must also sign a non-disclosure/confidentiality agreement, which requires the individuals to agree to comply with the conditions and restrictions imposed by CIHI relating to the use, security, disclosure, return or disposal of personal health information, and a right to audit. CIHI data disclosures are made at the highest degree of anonymity possible to meet the needs of the request. This means that, whenever possible, data is aggregated. Where aggregate data is not sufficiently detailed for the research purposes, de-identified data may be disclosed. For each record-level request, a unique data file is cut from the CJRR database and only those data elements required for the research are included on the file. As of 2009–2010, one analytical cut of the CJRR data set will be made, and all requests will be generated from this cut. Personal identifiers such as health card number

are suppressed or de-identified through techniques such as encryption, truncation or suppression. Health card number (whether encrypted or unencrypted) is not released in data requests.

4.5.3 Limiting Retention

CJRR electronic data is retained permanently to permit relational retrospective and trend analysis. The most recent paper forms are retained in a secure storage facility located on-site in order to facilitate follow-up reference. Older questionnaires are retained off-site in secure storage.

Recommendation: CJRR should review the practices around retention of paper questionnaires and, in consultation with Records Management, establish a retention/disposal schedule that takes into account any legal requirements or restrictions and redress mechanisms. CJRR should dispose of documents that no longer have a specific purpose and do so in a way that prevents improper or unauthorized use, access, copying, modification or disclosure and is in accordance with CIHI's policies and procedures.

4.6 Principle 6: Accuracy of Personal Health Information

CIHI has a comprehensive data quality program. Any known data quality issues are addressed with the data provider and/or documented in data limitations documentation, which is made available to all users.

4.7 Principle 7: Safeguards for Personal Health Information

CIHI has established physical, technical and administrative security practices to ensure the confidentiality and security of its data holdings.

Paper forms submitted to CJRR are stored in CIHI's controlled-access office in locked cabinets, accessible only to certain CJRR staff. Electronic data is stored on a server, which is part of CIHI's in-house network. Data entry is done by authorized CJRR staff. Access to the database is restricted electronically and requires authorization by the manager responsible for CJRR.

The database used for the CJRR has various features beneficial for both data protection and security. It is password-protected and can be accessed only by programming languages that require specialized expertise. In addition, most of the data is coded. Interpreting the data requires the use of the CJRR database documentation, which is not generally available outside CIHI.

Firewalls and/or other appropriate security technology are employed to protect the system and the data from unauthorized access. Session time-outs are in place, which automatically logout a user after 10 minutes of inactivity. Automated auditing is in place to record and track what changes are made by all users of the system.

Forms collecting CJRR data are transmitted via a secure means. Although paper forms are still being used by surgeons, CJRR has introduced a web-based submission and reporting tool to reduce the risks associated with manual handling and transmission of paper.

The tool allows surgeons and/or their designated assistants to submit data in a secure fashion and to generate real-time reports. The reports consist generally of aggregate data (own data only). One exception is a report showing missing non-mandatory fields, which identifies the patient record through use of the patient name.

A second exception is a report that allows the surgeon or designate to download a full data extraction of the surgeon's own data in a .csv format. All data that has been submitted to CJRR by/on behalf of the surgeon can be downloaded in this feature. The CJRR Web-Based Data Entry and Reporting Application User Agreement is currently being updated to reflect this report.

During the initial set-up of surgeons or their designates in Client Services, CJRR has a double-verification process during which two staff members verify that the correct surgeons/designates are submitted to Client Services for account creation and that the correct surgeons/designates are sent the correct access codes. This ensures that errors are not made in associating the surgeons' or the designates' accounts.

As well, designated users (for example, assistants) may leave the employ of the surgeon and fail to notify CIHI. The user agreement requires that the client notify CIHI if a designated user is no longer employed by the client or hospital or if a designated user's means of access is to be changed or cancelled for any reason or if a designated user's user level is to be changed. Moreover, the CJRR plans to carry out an annual verification of all surgeons' authorized designated users to ensure that CJRR's user list is current.

A 2007 CIHI initiative introduced the de-identification of patient health card numbers in the internal analytical environment. As a result, routine access to, or view of, the health card numbers among internal CIHI users and analysts is no longer possible. Exceptional access to the health card numbers requires a formal review and approval process to determine where temporary access should be granted. The de-identification project began in the spring of 2007 and was completed in March 2009.

In addition, new procedures were implemented in 2008 to improve the transmission of data back to providers for follow-up and validation purposes. Rather than paper forms being mailed out, data files are encrypted, password-protected on CD and sent to the authorized registered data users via courier, accompanied by a cover letter. Confirmation of receipt must be obtained by the program area. In consultation with CIHI's Privacy and Legal Services department, a system of returning paper forms to clients has been developed, due to minimal uptake of the CD option. As of 2010, CJRR will return paper forms via courier to the surgeon's office to obtain missing or incomplete information. These forms will be double-wrapped with the surgeon's address placed on both envelopes, and efforts will be made to blank out sensitive fields when feasible.

A new mechanism and infrastructure to electronically disseminate information has been developed and will be implemented in 2010. Data can be loaded onto a web-based application, and users can have electronic access to their own data for verification and updating.

This data dissemination mechanism, which uses an interface option, will allow CIHI to securely post reports that contain sensitive data, and allow data providers to receive these reports. The interface includes a screen consisting of a listing of external client contact information completed by CIHI. Another screen allows CIHI users to load files to be posted onto Client Services. A third screen consists of a listing of all files posted, which is available to CIHI, and allows users to delete files. When a report is posted, the external client will receive an email inviting him or her to pick up the report.

Once external CJRR clients receive an email indicating a report is available to them, they must log into CIHI's Client Services site with a username and password and select the report. The report is available to the client for 90 days.

With the introduction of the web-based data dissemination mechanism, the process of returning data to the provider for purposes of data quality follow-up (that is, review and update/correction of errors) could result in reports for one facility being mistakenly posted for access by other facility. Although care is taken to ensure the correct file is chosen and posted, the process is not foolproof, and inappropriate disclosure could result, as with any other dissemination mechanism (for example, paper-based data dissemination).

To address this, the design of the new web-based data dissemination mechanism for data quality follow-up reports uses an interface option. Measures that have been implemented to ensure that the wrong file is not inadvertently posted for access by a facility include

- Implementation of a file-naming convention that checks the client ID in the file name versus the client ID in the contact list prior to a file being sent to the client; files that do not meet this naming convention will not be sent;
- Auto-population of the Client Services user ID in the contacts page; the means of linking this data dissemination mechanism to Client Services (where the files are picked up by the client) is the Client Services user ID;
- Pop-up message confirming that the user wishes to upload the file selected; and
- Importing of client information to the dissemination tool directly from the CJRR database to avoid risk of transcription errors.

Additionally, even after the file has been sent, CIHI staff have the ability to delete files from the dissemination mechanism.

The tool has been constructed to allow the dissemination of other surgeon-specific information (that is, surgeon comparative reports) and non-surgical reports (that is, continuing professional development credits). This functionality also requires the program area (that is, CJR) and facility/surgeon (that is, 12345 or E1234) identifiers in the file name and application of the same validation rules.

4.8 Principle 8: Openness About the Management of Personal Health Information

CIHI makes information available about its privacy policies, data practices and programs relating to the management of personal health information on its corporate website. As well, this PIA is accessible on CIHI's website (www.cihi.ca).

4.9 Principle 9: Individual Access to, and Amendment of, Personal Health Information

CIHI recognizes that individuals have a right to access their personal health information. Sections 60 to 63 of CIHI's Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010 state that when an individual requests an amendment to or correction of his or her personal health information, CIHI refers the individual to the data provider. When a data provider notifies CIHI that the individual has successfully demonstrated the inaccuracy or incompleteness of personal health information, CIHI amends the information as required

4.10 Principle 10: Complaints About CIHI's Handling of Personal Health Information

As set out in CIHI's *Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010*, complaints about CIHI's handling of personal health information are investigated by the Chief Privacy Officer. If an individual does not believe that his or her challenge has been satisfactorily resolved, he or she may appeal to CIHI's Chief Privacy Advisor who will report his findings to CIHI's President and Chief Executive Officer. If a complaint is found to be justified, CIHI takes appropriate corrective measures.

5 Conclusion

This PIA summarizes CIHI's assessment of the privacy implications of CJRR. It makes only one recommendation, which relates to the establishment of a retention/disposal schedule for the paper questionnaires submitted to CJRR. It is felt that this recommendation can be met with minimal impact on the operations of the CJRR.

Appendix A—Glossary of Terms

Term	Definition
data provider	An organization, health care provider or other individual that discloses health information to CIHI, which may include ministries of health, regional health authorities and similar bodies, hospitals, other health care facilities and professional colleges.
de-identified data	Personal health information that has been modified to the fullest extent possible using appropriate methodologies, so that the identity of the individual cannot be determined by a reasonably foreseeable method.
health information	A broad term including but not limited to financial information about health and health care, personal health information, de-identified data and aggregate data.
meta data	Summary information that assists data users in the interpretation and use of data.
micro data	Detailed individual record-level information pertaining to a specific patient.
mitigation measures	Means of reducing the possibility of privacy risks.
organization-identifiable information	Information that includes the identity (that is, name or number) of any health organization, health facility, local health integration network, government ministry, continuing care facility, acute care hospital, specialty hospital, long-term care home, ambulatory agency such as an outpatient clinic, rehabilitation centre, community health centre, home care agency, mental health facility, regional health authority or local health authority.
personal health information	Health information about an individual that • Identifies the individual; or • May be used or manipulated by a reasonably foreseeable method to identify the individual, or may be linked by a reasonably foreseeable method to other information that identifies the individual. Personal health information does not include health workforce information or health facility information as defined in CIHI's *Policy on Health Facility Identifiable Information*.
primary replacement	The first replacement procedure in which the natural bone is replaced with an artificial joint prosthesis.
privacy impact assessment	A tool used to assess the possible privacy-related consequences of systems and practices for the collection, use and disclosure of personal information, including personal health information.
privacy risk	An undesirable event with the potential to compromise privacy or breach data confidentiality.
record-level data	Data in which each record is related to a single individual or organization (sometimes referred to as micro data).
residual disclosure	The combination of publicly released health information with other available information that reveals previously unknown information about an individual.
secondary use	For purposes of CJRR, the use of personal health information for purposes that fall outside of direct health care delivery—for example, statistical and analytical purposes.

Term	Definition
revision	Modification or replacement made to an existing artificial hip or knee joint prosthesis component. A revision procedure may be necessary when an existing old or worn-out hip or knee component needs to be removed and replaced with a new or improved prosthesis. This may include the removal of one or more hip or knee components as necessary.
residual risk	The remaining risk after the mitigation measures have been applied to the identified privacy risks.

Appendix B—Data Collection Forms

Canadian Institute for Health Information

Institut canadien d'information sur la santé

For CIHI use only

Unique Identifier

CANADIAN JOINT REPLACEMENT REGISTRY

Hip Replacement Data Collection Form

Addressograph

Surgeon First Name

Surgeon Last Name

Has Patient Consent Been Obtained? ☐ Yes ☐ No **If no, please complete only surgeon first/last name and hospital name, and forward to CIHI.**

Patient First Name | Middle Initial | Patient Last Name

Provincial Health Card Number **Province Code**

Birth Date Y Y Y Y M M D D

Home Postal Code

Gender ☐ Male ☐ Female

Patient's Height (cm) •

Weight (kg) •

Hospital Chart Number

Hospital Province

Hospital Name _____

Surgery Date Y Y Y Y M M D D

Admission Date (If different from surgery date) Y Y Y Y M M D D

Wait Time Information

Referral Date **(New Patients Only)** Y Y Y Y M M D D

Date of First Consult **(New Patients Only)** Y Y Y Y M M D D

Date of Decision for Surgery **(All Patients)** Y Y Y Y M M D D

Please Complete This Form by Checking (√) the Appropriate Box(es)

Side (Location)	***If bilateral, complete ONE form PER SIDE*** Unilateral ☐ Right ☐ Left Bilateral ☐ Right ☐ Left
Type of Replacement	***Check ONE only:*** ☐ Primary ☐ R1 ☐ R2 ☐ R3 ☐ >R3 ☐ Excision (not a revision)
Diagnosis Grouping (for primary replacement only)	***Check MOST RESPONSIBLE diagnosis to involved hip:*** ☐ Degenerative OA ☐ Inflammatory Arthritis ☐ Post Traumatic OA ☐ Osteonecrosis ☐ Childhood Hip Problem ☐ Old Hip Fracture ☐ Acute Hip Fracture ☐ Tumour ☐ Infection ☐ Other _____
Reason(s) for Revision ☐ N/A **or** ➔ ➔	***Check ALL that apply to involved hip:*** ☐ Aseptic Loosening ☐ Infection—Single Stage ☐ Infection—Two Stage ☐ Poly Wear ☐ Osteolysis ☐ Instability ☐ Implant Fracture ☐ Bone Fracture ☐ Pain of Unknown Origin ☐ Leg length discrepancy ☐ Other _____
Previous Operations ☐ None **or** ➔ ➔	***Check ALL that apply to involved hip:*** ☐ Fracture Fixation ☐ Surface Replacement ☐ Pelvic Osteotomy ☐ Femoral Osteotomy ☐ Arthrodesis ☐ Resection Arthroplasty ☐ Hemiarthroplasty ☐ Total Hip Arthroplasty ☐ Other _____
Surgical Approach	***Check APPROACH:*** ☐ Smith/Peterson ☐ Anterolateral ☐ Posterolateral ☐ Direct Lateral ☐ 2-Incision ☐ Other _____ ***Minimally Invasive (MIS)?*** ☐ Yes ☐ No
Special Techniques ☐ None **or** ➔ ➔	☐ Trans-trochanteric (includes trochanteric slide) ☐ Extended Trochanteric ☐ Other _____
Antibiotic Use	***Will antibiotics be administered prophylactically?*** ☐ Yes ☐ No ***If yes, duration?*** ☐ ≤24 hours ☐ >24 hours
DVT Prevention	***Will DVT prophylaxis be given in hospital?*** ☐ Yes ☐ No ***If yes, check ALL that apply:*** ☐ Warfarin ☐ LMW Heparin ☐ ASA ☐ SC Heparin ☐ Pneumatic Stockings ☐ Foot Pump ☐ Other _____
O.R. Environment	***Check ALL that apply:*** ☐ Laminar Air Flow ☐ No Laminar Air Flow ☐ Body Exhaust ☐ Ultraviolet

CANADIAN JOINT REPLACEMENT REGISTRY **HIP REPLACEMENT DATA COLLECTION FORM**

Femoral Component **Replaced/ Resurfaced?** ☐ Yes ➔ ☐ No ➔	**Surface Replacement?** ☐ Yes ☐ No **Cemented?** ☐ Yes ☐ No **If Cemented:** Porosity Reduction: ☐ Yes ☐ No **If Cementless, *Check ALL that apply*:** ☐ Porous In-growth ☐ H. A. Coated ☐ Grit Blasted **Modular Stem?** ☐ Yes ☐ No	**Manufacturer** See Legend Below Femoral Component	*Affix sticker(s) or catalogue and lot number beside the specific component. Do not include stickers for screws.* Sticker for Femoral Component
Femoral Head **Replaced?** ☐ Yes ➔ ☐ No ➔	**Modular Head?** ☐ Yes ☐ No **Outside Diameter:** _____ mm **Material:** ☐ Cobalt Chrome ☐ Ceramic Zirconia ☐ Ceramic Alumina ☐ Oxinium ☐ Other ☐ Stainless steel **Hemiarthroplasty?** ☐ Yes ☐ No ***If Yes,*** ☐ **Monopolar** ☐ **Bipolar**	Manufacturer Femoral Head	Sticker for Femoral Head
Acetabular Component **Replaced?** ☐ Yes ➔ ☐ No ➔	**Cemented?** ☐ Yes ☐ No **If Cemented:** Same cement used for femoral component? ☐ Yes ☐ No **If Cementless, *Check ALL that apply*:** ☐ Porous In-growth Screws? ☐ Yes ☐ No ☐ H.A. Coated Screws? ☐ Yes ☐ No ☐ Trabecular metal Screws? ☐ Yes ☐ No Outside Diameter: _____ mm **Tripolar Revision?** ☐ Yes ☐ No **Constrained Cup?** ☐ Yes ☐ No	Manufacturer Acetabular Component	Sticker for Acetabular Component
Acetabular Insert/Liner Replaced? ☐ Yes ➔ ☐ No ➔	**Material: *(Check ONE only)*** ☐ Polyethylene standard ☐ Ceramic Alumina ☐ Polyethylene cross-linked ☐ Metal ☐ Other **Modular?** ☐ Yes ☐ No	Manufacturer Acetabular Liner	Sticker for Acetabular Liner
Ring/Cage Used? ☐ Yes ☐ No		Manufacturer Ring/Cage	Sticker for Acetabular Ring/Cage

Trabecular Metal Augment for Acetabulum used? ☐ Yes ☐ No

Cement Details (Femoral Component) **Cement Used?** ☐ Yes ➔ ☐ No	***For each item, Check ONE only:*** **Cement Name:** ☐ Simplex ☐ Zimmer ☐ CMW ☐ Versabond ☐ Palacos ☐ Osteobond ☐ Cerafix ☐ Other _____ **Antibiotics added by manufacturer?** ☐ Yes ☐ No **Antibiotics added by surgeon?** ☐ Yes ☐ No ***If Yes,*** **Antibiotic Name:** ☐ Tobramycin ☐ Vancomycin ☐ Gentamicin ☐ Erythromycin ☐ Other **Mixing Method:** ☐ Vacuum-mixed ☐ Centrifuge ☐ Manually Mixed	Sticker for Cement Type

Bone Graft Used—Femur
☐ Yes ➔
☐ No

Check ALL that apply:

	Autograft			Allograft	Bone Graft Substitute
	Iliac crest	Femoral head	Other		
Structural	☐	☐	☐	☐	☐
Strut/Onlay	☐	☐	☐	☐	☐
Morselized	☐	☐	☐	☐	☐

Bone Graft Used—Acetabulum
☐ Yes ➔
☐ No

Check ALL that apply:

	Autograft			Allograft	Bone Graft Substitute
	Iliac crest	Femoral head	Other		
Structural	☐	☐	☐	☐	☐
Strut/Onlay	☐	☐	☐	☐	☐
Morselized	☐	☐	☐	☐	☐

Legend of Manufacturer Codes: 01 Biomet 02 Ceraver 03 J&J/DePuy 04 Sulzer/Centerpulse 05 Zimmer 06 Wright Medical 07 Smith & Nephew Richards 08 Stryker/Osteonic/Howmedica 99 Other

Formulaire disponible en français

Canadian Institute for Health Information

Institut canadien d'information sur la santé

For CIHI use only

Unique Identifier

CANADIAN JOINT REPLACEMENT REGISTRY

Knee Replacement Data Collection Form

Addressograph

Surgeon First Name

Surgeon Last Name

Has Patient Consent Been Obtained? ☐ **Yes** ☐ **No** **If no, please complete only surgeon first/last name and hospital name, and forward to CIHI.**

Patient First Name | Middle Initial | Patient Last Name

Provincial Health Card Number

Province Code

Birth Date (Y Y Y Y M M D D)

Home Postal Code

Gender ☐ Male ☐ Female

Height (cm) •

Weight (kg) •

Hospital Chart Number

Hospital Province

Hospital Name _____

Surgery Date (Y Y Y Y M M D D)

Admission Date (if different from surgery date) (Y Y Y Y M M D D)

Wait Time Information

Referral Date **(New Patients Only)** (Y Y Y Y M M D D)

Date of First Consult **(New Patients Only)** (Y Y Y Y M M D D)

Date of Decision for Surgery **(All Patients)** (Y Y Y Y M M D D)

Please Complete This Form by Checking (√) the Appropriate Box (es)

Side (Location)	***If bilateral, complete ONE form PER SIDE*** Unilateral ☐ Right ☐ Left Bilateral ☐ Right ☐ Left
Type of Replacement	***Check ONE only:*** ☐ Primary ☐ R1 ☐ R2 ☐ R3 ☐ >R3 ☐ Excision (not a revision)
Diagnosis Grouping (for primary replacement only)	***Check MOST RESPONSIBLE diagnosis to involved knee:*** ☐ Degenerative OA ☐ Inflammatory Arthritis ☐ Post Traumatic OA ☐ Osteonecrosis ☐ Infection ☐ Tumour ☐ Acute fracture ☐ Other _____
Reason(s) for Revision ☐ N/A **or** ➔ ↓	***Check ALL that apply to involved knee:*** ☐ Aseptic Loosening ☐ Infection—Single Stage ☐ Implant Fracture ☐ Poly Wear ☐ Instability ☐ Pain of Unknown Origin ☐ Infection—Two Stage ☐ Bone Fracture ☐ Osteolysis ☐ Unispacer ☐ Unresurfaced Patella ☐ Patella Maltracking ☐ Patella Failure ☐ Other _____
Previous Operations ☐ None **or** ➔ ↓	***Check ALL that apply to involved knee:*** ☐ Total Knee Arthroplasty ☐ Unicompartmental Arthroplasty ☐ Tibial Osteotomy ☐ Femoral Osteotomy ☐ Open Menisectomy ☐ Arthroscopic Menisectomy ☐ Patellectomy ☐ Ligament Repair ☐ Fracture Fixation ☐ Arthroscopic Debridement ☐ Other _____
Joint Deformity ☐ None **or** ➔ ↓	***Check ALL that apply to involved knee:*** ☐ Varus ☐ Valgus ☐ Flexion contracture ☐ If Any ≥15°
Surgical Approach	***Check APPROACH:*** ☐ Medial Parapatellar ☐ Lateral Parapatellar ☐ Intravastus ☐ Subvastus ☐ Other _____ ***Minimally Invasive (MIS)?*** ☐ Yes ☐ No
Special Steps ☐ None **or** ➔ ↓	***Check ALL that apply to involved knee:*** ☐ Lateral Retinacular Release ☐ Rectus Snip ☐ Quadriceps Turndown ☐ Tubercle Osteotomy ☐ Other _____
Antibiotic Use	***Will antibiotics be administered prophylactically?*** ☐ Yes ☐ No ***If yes, duration?*** ☐ ≤24 hours ☐ >24 hours
DVT Prevention	***Will DVT prophylaxis be given in hospital?*** ☐ Yes ☐ No ***If yes, check ALL that apply:*** ☐ Warfarin ☐ LMW Heparin ☐ ASA ☐ SC Heparin ☐ Pneumatic Stockings ☐ Foot Pump ☐ Other _____
O.R. Environment	***Check ALL that apply:*** ☐ Laminar Air Flow ☐ No Laminar Air Flow ☐ Body Exhaust ☐ Ultraviolet

CANADIAN JOINT REPLACEMENT REGISTRY **KNEE REPLACEMENT DATA COLLECTION FORM**

Femoral Component

Replaced?

☐ Yes ➔

☐ No ➔

Unicompartmental Prosthesis?

☐ Yes ☐ No

If yes,

☐ Medial ☐ Lateral ☐ Patellofemoral

Cemented? ☐ Yes ☐ No

If Cemented:

Porosity Reduction: ☐ Yes ☐ No

If Cementless, *Check ALL that apply*:

☐ Porous In-growth ☐ H. A. Coated

☐ Press-fit

Manufacturer See Legend Below

Femoral Component

Affix sticker(s) or catalogue and lot number beside the specific component. Do not include stickers for screws.

Sticker for Femoral Component

Tibial Component

Replaced?

☐ Yes ➔

☐ No ➔

Unicompartmental Prosthesis?

☐ Yes ☐ No

If yes,

☐ Medial ☐ Lateral ☐ Patellofemoral

All Polyethylene? ☐ Yes ☐ No

Mobile Bearing? ☐ Yes ☐ No

Cemented? ☐ Yes ☐ No

If Cemented:

Porosity Reduction? ☐ Yes ☐ No

If Cementless, *Check ALL that apply*:

☐ Porous In-growth Screws? ☐ Yes ☐ No

☐ H.A. Coated Screws? ☐ Yes ☐ No

☐ Trabecular Metal Screws? ☐ Yes ☐ No

PCL Retaining Or PCL Sacrificing

☐ Standard ☐ Post & Cam ☐ Constrained

☐ Medial Pivot ☐ Deep Dished ☐ Hinged

☐ Medial Pivot

Manufacturer Poly Insert

Tibial Base Plate

Sticker(s) for Poly (Insert)

Sticker(s) for Tibial Base Plate

Patellar Component

Resurfaced?

☐ Yes➔

☐ No➔

Cemented? ☐ Yes ☐ No

Type: ☐ Inset ☐ Onlay

Manufacturer Patellar Component

Sticker for Patellar Component

Modular Stem

☐ Yes ➔

☐ No ➔

Stems	**Femoral**	**Tibial**
Cemented	☐	☐
Cementless	☐	☐

Metal Augments

☐ Yes ➔

☐ No ➔

Augments	**Femoral**	**Tibial**
Metal	☐	☐
Trabecular metal	☐	☐

Manufacturer Femoral Stem

Tibial Stem

Sticker(s) for Modular Femoral Stems

Sticker(s) for Modular Tibial Systems

Cement Details

Cement Used?

☐ Yes ➔

☐ No ➔

For each item, Check ONE only:

Cement Name:

☐ Simplex ☐ Zimmer ☐ CMW ☐ Versabond

☐ Palacos ☐ Osteobond ☐ Cerafix ☐ Other _____

Antibiotics Added by Manufacturer? ☐ Yes ☐ No

Antibiotics Added by Surgeon? ☐ Yes ☐ No

***If Yes*, Antibiotic Name:**

☐ Tobramycin ☐ Vancomycin ☐ Gentamicin ☐ Erythromycin ☐ Other

Mixing Method: ☐ Vacuum-mixed ☐ Centrifuge ☐ Manually Mixed

Sticker for Cement Type

Bone Graft Used—Femur

☐ Yes ➔

☐ No ➔

Check ALL that apply:

	Autograft			Allograft	Bone Graft Substitute
	Iliac crest	Local bone	Other		
Structural	☐	☐	☐	☐	☐
Strut/Onlay	☐	☐	☐	☐	☐
Morselized	☐	☐	☐	☐	☐

Bone Graft Used—Tibial

☐ Yes ➔

☐ No ➔

Check ALL that apply:

	Autograft			Allograft	Bone Graft Substitute
	Iliac crest	Local bone	Other		
Structural	☐	☐	☐	☐	☐
Strut/Onlay	☐	☐	☐	☐	☐
Morselized	☐	☐	☐	☐	☐

Legend of Manufacturer Codes: 01 Biomet 02 Ceraver 03 J&J/DePuy 04 Sulzer/Centerpulse 05 Zimmer 06 Wright Medical 07 Smith & Nephew Richards 08 Stryker/Osteonic/Howmedica 99 Other

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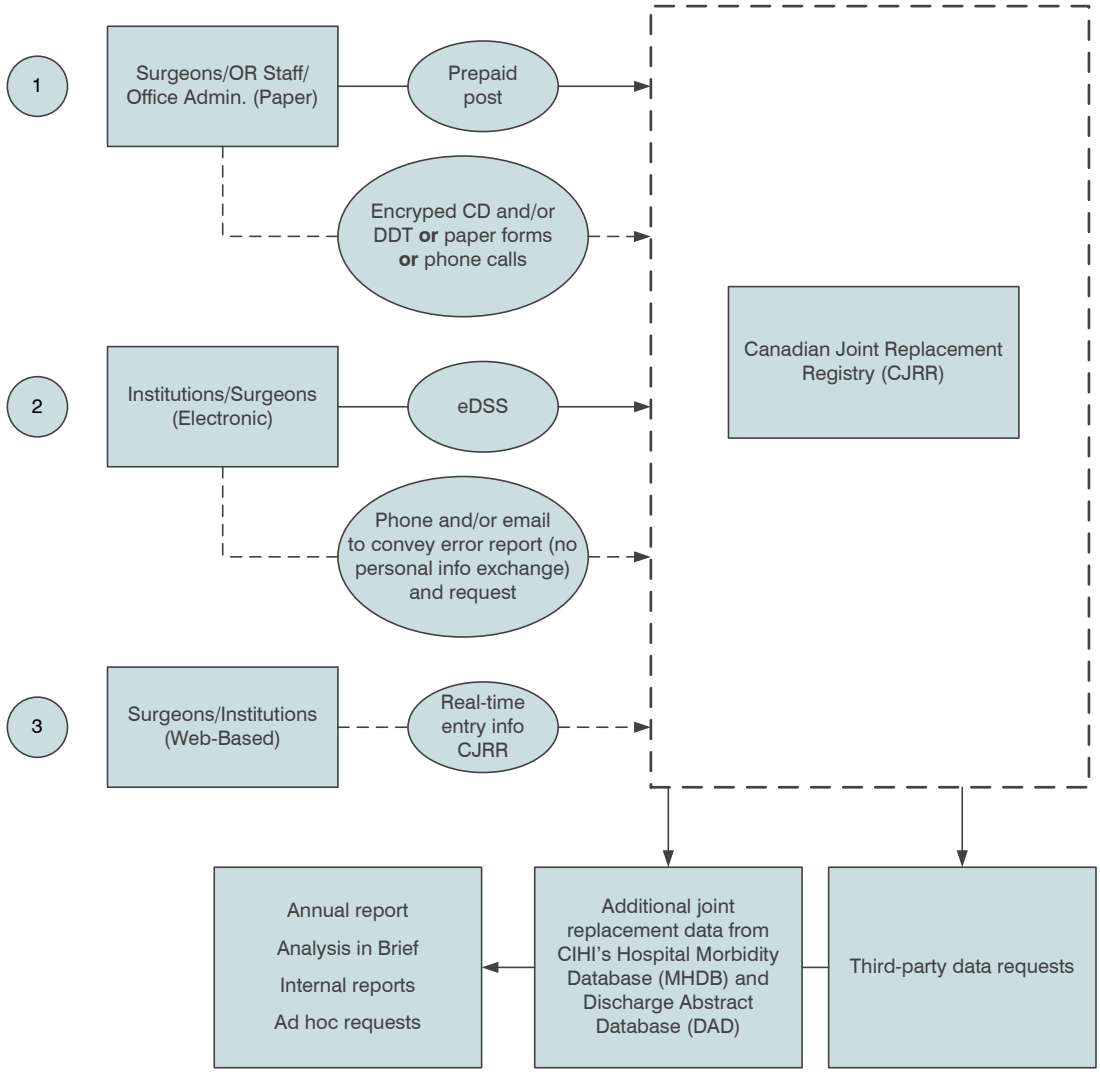
Appendix C—Data Flow Diagram



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