

# Principles and Policies for the Protection of Personal Health Information at Cancer Care Ontario ("CCO's Privacy Policy")

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## Table of Contents

<u>List of Abbreviations</u> .....	4
<u>INTRODUCTION</u> .....	5
<u>Background and Overview</u> .....	5
<u>Legislative Authorities</u> .....	7
<u>CCO's Privacy Program</u> .....	7
<u>CCO's Privacy Policy</u> .....	8
<u>Scope of CCO's Privacy Policy</u> .....	8
Principle 1.1 Delegation of responsibilities .....	10
Principle 1.2 CCO's Privacy Policy .....	10
Principle 1.3 Implementation of CCO's Privacy Policy .....	10
Principle 1.4 Consultants, contractors and third party service providers ("Third-Parties").....	10
Principle 2.1 Documentation of purposes.....	11
Principle 2.2 Notification .....	11
Principle 2.3 Staff awareness .....	11
<u>PRINCIPLE 3: Knowledge and Consent for the Collection, Use or Disclosure of PHI</u> .....	12
Principle 3.1 Knowledge and consent .....	12
<u>PRINCIPLE 4: Limiting Collection of PHI</u> .....	13
Principle 4.1 Limiting collection .....	13
Principle 4.2 Data elements not required .....	13
<u>PRINCIPLE 5: Use, Disclosure and Retention of PHI</u> .....	14
Principle 5.1 Use of PHI.....	14
Principle 5.2 Data access – CCO employees .....	14
Principle 5.4 Data linkage.....	15
Principle 5.5 Data retention .....	15
Principle 5.6 Data destruction.....	15
<u>PRINCIPLE 6: Accuracy of PHI</u> .....	16
Principle 6.1 CCO data quality program .....	16
<u>PRINCIPLE 7: Safeguards for PHI</u> .....	17
Principle 7.1 Physical safeguards.....	17
Principle 7.2 Administrative safeguards – contracts and agreements .....	18
Policy 7.3 Administrative safeguards - privacy training and awareness .....	18
Policy 7.4 Administrative safeguards - privacy impact assessments .....	18
Policy 7.5 Technical safeguards.....	19
<u>PRINCIPLE 8: Openness about the Management of PHI</u> .....	20
Principle 8.1 Availability of information .....	20
<u>PRINCIPLE 9: Individual Access to and Amendment of PHI</u> .....	21
Principle 9.1 <i>PHIPA</i> Section 45 and <i>PHIPA</i> Section 39(1)(c) .....	21
Principle 9.2 Exceptions .....	21
<u>PRINCIPLE 10: Complaints About CCO's Handling of PHI</u> .....	22
Principle 10.1 Complaints related to CCO's information practices.....	22
Principle 10.2 Privacy breach .....	22
Policy 10.3 Whistleblower protection.....	22
<u>APPENDIX A - Definitions</u> .....	24
<u>APPENDIX B - CCO Primary Data Holdings for the Prescribed Entity</u> .....	27
<u>APPENDIX C - CCO Primary Data Holdings for the Prescribed Registry</u> .....	37

## **List of Abbreviations**

ALR	Activity Level Reporting
ATC	Access To Care
ATP	Annotated Tumour Project
CCO	Cancer Care Ontario
CEO	Chief Executive Officer
CIHI	Canadian Institute for Health Information
CIO	Chief Information Officer
CIRT	Colonoscopy Interim Reporting Tool Database
CPO	Chief Privacy Officer
CSP	Cancer Screening Program
CTO	Chief Technology Officer
DAD	Discharge Abstract Database
ERNI	Emergency Room National Ambulatory Reporting System Initiative
HIC	Health Information Custodian
ICES	Institute for Clinical Evaluative Sciences
IPC	Information and Privacy Commissioner / Ontario
IT	Information Technology
MOHLTC	Ministry of Health and Long-Term Care
MOU	Memorandum of Understanding
NACRS	National Ambulatory Care Reporting System
NDFP	New Drug Funding Program
OOP	Out of Province
ORN	Ontario Renal Network
PET	Positron Emission Topography
PHI	Personal Health Information
<i>PHIPA</i>	<i>Personal Health Information Protection Act, 2004 (Ontario)</i>
PIA	Privacy Impact Assessment
PIMS	Pathology Information Management System
PPCIP	Provincial Palliative Care Integration Project
REB	Research Ethics Board
RPDB	Registered Persons Data Base
SCT	Stem Cell Transplant
WTIO	Wait Time Information Office
WTIS	Wait Time Information System

## **INTRODUCTION**

### **Background and Overview**

#### **ABOUT CANCER CARE ONTARIO**

Cancer Care Ontario (CCO) works to improve cancer control and ensure patients receive better cancer care. CCO's mission is to improve the performance of the cancer system by driving quality, accountability and innovation in all cancer-related services. The agency's vision is to work together to create the best cancer system in the world.

As the provincial agency responsible for continually improving cancer services, and the government's cancer advisor, CCO:

- Directs and oversees more than \$850 million in funding for hospitals and other cancer care providers to deliver high quality, timely cancer services and to improve access to care;
- Implements provincial cancer prevention and screening programs designed to reduce cancer risks and raise screening participation rates;
- Works with cancer care professionals and organizations to develop and implement quality improvements and standards;
- Uses electronic information and technology to support health professionals and patient self-care and to continually improve the safety, quality, efficiency, accessibility and accountability of cancer services;
- Plans cancer services to meet current and future patient needs, and works with health care providers in every Local Health Integration Network to continually improve cancer care for the people they serve; and
- Rapidly transfers new research into improvements and innovations in clinical practice and cancer service delivery.

CCO's operations and activities are guided by the following principles: transparency, equity, evidence-based, performance oriented, active engagement and value for money.

Formally launched and funded by the provincial government in 1997, CCO is governed by legislation called *The Cancer Act*. As an operational service agency of government, CCO is accountable to the Ministry of Health and Long-Term Care (MOHLTC). The details of this relationship with the Ministry are laid out in a formal Memorandum of Understanding (MOU) that was signed in December 2009.

#### **Multi-Service Agency**

In addition to cancer, CCO has other core lines of business including supporting and hosting the provincial Access to Care (ATC – the Government of Ontario's Wait Times Information Strategy). We have also worked with renal leadership in Ontario to launch the newly formed Ontario Renal Network (ORN), as well as special access programs such as Positron Emission Topography (PET) for uninsured indications. These activities are mandated through separate accountability agreements between CCO and the Ministry.

#### **Personal Health Information**

CCO collects PHI as defined under *PHIPA*, from healthcare organizations and professionals (also known as health information custodians, or HICs) that are directly involved in the care and treatment of patients. CCO uses this information to plan, fund and report on the performance of our roles in the

healthcare system. Information is also used to facilitating and improving the provision of healthcare services for Ontarians. For example data are used to:

- calculate survival rates,
- estimate cancer and chronic kidney disease incidence and demand for services,
- report wait times for radiation, chemotherapy, and cancer surgery,
- report on the quality of cancer services in Ontario,
- develop clinical guidelines,
- reimburse hospitals for specific cancer drugs,
- manage CCO's Cancer Screening Program,
- advise the MOHLTC on healthcare issues,
- create outreach programs that support early screening activities for the population, and
- support research by CCO scientists and research associates.

PHI is disclosed by CCO, as authorized by law, to organizations such as the Institute of Clinical and Evaluative Sciences (ICES), the Canadian Institute for Health Information (CIHI), Statistics Canada, health information custodians, and to researchers who comply with research requirements set out in *PHIPA*.

All disclosures of PHI must comply with CCO's *Data Use and Disclosure Standard*.

For more information about CCO and its information management practices please see our web site at [www.cancercare.on.ca](http://www.cancercare.on.ca) or contact:

CCO Privacy & Access Office  
Cancer Care Ontario  
620 University Avenue  
Toronto, ON M5G 2L7  
Telephone: 416.217.1816  
[privacyandaccessoffice@cancercare.on.ca](mailto:privacyandaccessoffice@cancercare.on.ca)

Individuals may also submit any concern or complaint about CCO's information practices to the Information and Privacy Commissioner / Ontario (IPC) by contacting:

Information and Privacy Commissioner/Ontario  
2 Bloor Street East, Suite 1400  
Toronto, ON M4W 1A8  
Telephone: 416.326.3333 or 1.800.387.0073  
TDD/TTY: 416.325.7539  
FAX: 416.325.9125  
[www.ipc.on.ca](http://www.ipc.on.ca)

## **Legislative Authorities**

CCO is a provincial government agency responsible to the MOHLTC. CCO is governed by the *Cancer Act*. CCO's mandate is also determined pursuant to a MOU between CCO and the MOHLTC.

### **A Prescribed Entity**

CCO is subject to Ontario's health information privacy legislation, *PHIPA*. In the accompanying Regulations to *PHIPA*, CCO is established as a 'prescribed entity' under section 45 of the Act. This means that CCO has authority to collect, use and disclose PHI for the purposes of health system planning and management.

### **A Prescribed Registry**

CCO is also designated as a "prescribed person" under *PHIPA* with respect to CCO's role in compiling and maintaining the Ontario Cancer Screening Registry ("prescribed registry") as part of Ontario's Cancer Screening Program (**CSP**). This designation grants CCO the authority to collect, use and disclose PHI, without consent, for the purpose of *facilitating or improving the provision of healthcare*.

As a prescribed entity under section 45 of *PHIPA* and a prescribed person under section 39(1)(c) of *PHIPA*, CCO is subject to oversight by the IPC and must have its information practices reviewed and approved every three years by their Office. This review process provides the public with the assurance that CCO's information management practices comply with *PHIPA* and with standards of practice expected from the IPC. CCO's information practices were last formally reviewed and approved by the IPC in respect of the prescribed entity and the prescribed registry, in October 2011. The next IPC review is scheduled to be completed in 2014.

## **CCO's Privacy Program**

CCO is committed to respecting personal privacy, safeguarding confidential information and ensuring the security of PHI within its custody. CCO meets this commitment through its Privacy Program. This Program is overseen by the Chief Privacy Officer (CPO), who reports directly to CCO's President & Chief Executive Officer (CEO). The CPO is supported in carrying out her responsibilities by a network of individuals and committees with specific privacy and security related responsibilities, including:

- A Director, Privacy & Access, who is responsible for the day-to-day operation of privacy processes within CCO and compliance with CCO privacy policies.
- Privacy Specialists who report to the Director, Privacy & Access, and support CCO's Privacy Program.
- Data Stewards, each associated with a specific data-holding, who are responsible for authorizing both internal and external requests for access to CCO data.
- Business Unit Privacy Leads who are responsible for ensuring that the CCO Privacy Program is implemented in their Business Units.
- A Facilities Manager who is responsible for ensuring the physical integrity of CCO premises.
- Systems Security Specialists who report to the Chief Technology Officer (CTO), and oversee IT security safeguards for CCO data.
- A Core Privacy & Security Committee composed of the CPO, Privacy & Access Office staff, Enterprise Information Security Office staff, and key members of CCO's information management team, which provides advice and consultation to the CPO on specific privacy topics.
- A Data Access Committee, supported by an Information Management Coordinator, which is ultimately responsible for reviewing and approving requests for access to CCO data by researchers.

Key components of CCO's Privacy Program include:

- CCO's Privacy Policy and procedures;
- a privacy network comprised of individuals and committees, as described above;
- an employee privacy training, communications and awareness program;
- a privacy audit and compliance program; and
- privacy impact assessments on existing and proposed CCO data holdings.

CCO's Privacy & Access Office is responsible for developing, implementing, and enforcing CCO's Privacy Policy and related policies, standards and procedures.

### **CCO's Privacy Policy**

*PHIPA* governs CCO's collection, use, and disclosure, of PHI. *PHIPA* is based on the 10 privacy principles set out in the Canadian Standards Association *Model Code for the Protection of Personal Information* ("*CSA Model Code*"). The *CSA Model Code*, which became recognized as a national standard for privacy protection in 1996, is used across Canada as the basis for health information privacy legislation, policies and procedures. The *CSA Model Code* includes the following 10 principles:

- Accountability
- Identifying Purposes
- Consent
- Limiting Collection
- Limiting Use, Disclosure and Retention
- Accuracy
- Safeguards
- Openness
- Individual Access
- Challenging Compliance

CCO's Privacy Policy is structured around these 10 privacy principles. This Policy provides a general statement of CCO's position on each of the principles. Each principle is accompanied by related documents that provide additional information on how the principle is operationalized and implemented by at CCO.

The principles and related documents presented in CCO's Privacy Policy reflect:

- CCO's role as a Section 45 prescribed entity under *PHIPA*,
- CCO's role as a Section 39(1)(c) prescribed person under *PHIPA*
- current best practices in privacy and data protection, and
- current information practices at CCO.

CCO's Privacy Policy will continue to evolve over time to reflect current best practices in privacy and data protection and as CCO's program responsibilities evolve.

### **Scope of CCO's Privacy Policy**

This Policy applies to **CCO and all of its agents in respect of CCO's capacity as a Section 45 prescribed entity and a Section 39(1)(c) prescribed person** under *PHIPA* and to the data holdings which CCO operates in this capacity as provided in Appendices B and C.



This Policy does not apply to CCO affiliated researchers conducting research studies under the authority of section 44 of *PHIPA*. Nor does it apply to CCO as an IT Service Provider which operates under a separate privacy policy posted on CCO's website ([www.cancercare.on.ca](http://www.cancercare.on.ca)).

**PRINCIPLE 1: Accountability for PHI**

CCO is responsible for ensuring that the PHI within its custody is managed in accordance with *PHIPA*. CCO’s President & CEO is ultimately accountable for ensuring that this occurs at CCO.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 1.1 Delegation of responsibilities</b>  Accountability for CCO’s compliance with applicable privacy legislation rests with the President &amp; CEO.</p> <p>The CEO may delegate an individual to act on his behalf and, accordingly, names the CPO, who reports directly to the CEO, to be responsible for CCO’s Privacy Program.</p>	<p><i>CCO Privacy Organizational Chart</i>  <i>CCO Privacy Governance Framework</i></p>
<p><b>Principle 1.2 CCO’s Privacy Policy</b>  CCO’s Privacy Policy complies with <i>PHIPA</i>. If there is a discrepancy between the Policy and <i>PHIPA</i>, <i>PHIPA</i> takes precedence.</p> <p>CCO’s Privacy Policy is reviewed annually to ensure that it reflects current legislation and practices at CCO.</p> <p>CCO’s Board of Directors will approve any substantive changes to CCO’s Privacy Policy.</p>	<p><i>CCO Privacy Audit and Compliance Standard</i>  <i>CCO Privacy Governance Framework</i></p>
<p><b>Principle 1.3 Implementation of CCO’s Privacy Policy</b>  CCO’s Privacy Policy is implemented throughout the organization using appropriate means to ensure that CCO employees understand and apply the CCO privacy policies in their daily work.</p> <p>The CPO is assisted in implementing CCO privacy policies by the Privacy &amp; Access Office.</p>	<p><i>CCO Privacy and Security Training and Awareness Procedure</i>  <i>CCO Privacy Governance Framework</i>  <i>CCO Data Steward Terms of Reference</i>  <i>CCO Privacy Lead Terms of Reference</i>  <i>CCO Data Access Committee Terms of Reference</i>  <i>CCO Privacy Audit and Compliance Standard</i>  <i>CCO Information Security Policy</i></p>
<p><b>Principle 1.4 Consultants, contractors and third party service providers (“Third-Parties”)</b>  CCO is responsible for PHI that is used by Third-Parties acting on behalf of CCO.</p> <p>CCO uses contractual or other means to ensure that a comparable level of protection is applied when PHI is handled by Third-Parties.</p>	<p><i>Template Consulting Agreement</i>  <i>CCO Confidentiality Policy</i>  <i>CCO Statement of Confidentiality</i>  <i>CCO Data Use and Disclosure Standard</i></p>

**PRINCIPLE 2: Identifying Purposes for PHI**

Consistent with CCO’s designation as a section 45 prescribed entity under *PHIPA*, its authority under the *Cancer Act*, and its Memorandum of Understanding with the MOHLTC, CCO collects PHI from HICs and other entities for the purposes of health system planning and management.

CCO also collects information pursuant to section 39(1)(c) which permits a prescribed person to collect information in compiling and maintaining the Ontario Cancer Screening Registry (OCSR) as part of the CSP.

Principles	Related Documents
<p><b>Principle 2.1 Documentation of purposes</b>            CCO documents the purposes for which it collects PHI for each of its data holdings, and makes these purposes known to entities that disclose PHI to CCO.</p> <p>The CCO Business Unit is responsible for:</p> <ul style="list-style-type: none"> <li>• creating a statement of purposes for data holdings under their responsibility,</li> <li>• ensuring the statement of purposes is up to date</li> <li>• ensuring a copy of the approved statement is provided to the Privacy &amp; Access Office for inclusion in privacy-related documentation and the List of CCO Data Holdings.</li> </ul>	<p><i>List of CCO Data Holdings (Appendices B and C)</i></p>
<p><b>Principle 2.2 Notification</b>            CCO encourages and supports “primary data collectors”, HICs and other organizations, in making the purposes for which PHI is disclosed to CCO known to individuals who provide such PHI.</p> <p>The CPO will ensure that a Statement of Information Practices is published and made available to primary data custodians who disclose PHI to CCO, so that they may use this information in their notification practices.</p>	<p><i>CCO Statement of Information Practices</i>  <i>CCO Privacy FAQs</i>  <i>CSP Privacy FAQs</i></p>
<p><b>Principle 2.3 Staff awareness</b>            CCO employees are aware of the purposes for which PHI is collected for the data holding(s) associated with their Business Unit.</p> <p>CCO Privacy Leads will be responsible for ensuring Business Unit staff are aware of the purposes for which PHI is collected.</p>	<p><i>List of CCO Data Holdings (Appendices B and C)</i>  <i>CCO Privacy Lead Terms of Reference</i>  <i>CCO Privacy Training and Awareness Procedure</i></p>

**PRINCIPLE 3: Knowledge and Consent for the Collection, Use or Disclosure of PHI**

CCO collects PHI in accordance with the authorities set out in *PHIPA*.

Pursuant to section 45 and 39(1)(c) of *PHIPA*, CCO uses information disclosed to it by primary data collectors, without the consent of the patient for programs which support planning and management for, as well as facilitation of the healthcare system.

CCO ensures that its information management practices are easily accessible to primary data collectors and the public.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 3.1 Knowledge and consent</b> The primary data collector is responsible for complying with the knowledge and consent components of <i>PHIPA</i>. However for the CSP, CCO takes a consent based approach to program correspondence (i.e. invitations, results, notifications and screening reminders)</p> <p>CCO will facilitate this awareness by providing both primary data collectors and the public with information related to the authority and purpose for CCO's collection, use and disclosure of PHI.</p>	<p><i>CCO Statement of Information Practices</i> <i>List of CCO Data Holdings (Appendices B and C)</i> <i>CCO Privacy FAQs (posted on website)</i> <i>CSP Privacy FAQs</i> <i>CSP Participant Information Form</i></p>

#### **PRINCIPLE 4: Limiting Collection of PHI**

CCO limits the collection of PHI to that which is necessary for identified purposes and in accordance with the requirements set out in *PHIPA*.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 4.1 Limiting collection</b> The PHI collected by CCO will be limited to that which is necessary to fulfill the purposes identified for each data holding. This process may be informed by Program Areas or advisory committees, and may further be guided by data sharing agreements between CCO and other entities.</p> <p>Where a data sharing agreement is required, the CCO Privacy Manager/Specialist will ensure the agreement includes:</p> <ul style="list-style-type: none"><li>• a statement of the authority and purpose for the collection, and</li><li>• a description of data elements required for the collection.</li></ul>	<p><i>CCO Data Sharing Agreement Standard</i> <i>CCO Data Sharing Agreement Procedure</i> <i>CCO Data Sharing Agreement Template</i> <i>CCO Data Sharing Agreement Initiation form</i> <i>CCO Privacy Impact Assessment Standard</i> <i>List of CCO Data Holdings (Appendices B and C)</i></p>
<p><b>Principle 4.2 Data elements not required</b> Where data elements are disclosed to CCO by a data provider that fall outside the purposes identified for a data holding, the CCO Privacy Manager/Specialist will work with the business lead and the data provider to return or destroy the unnecessary data elements, so as to minimize the data elements required to meet the purposes of the identified for a data holding.</p>	<p><i>List of CCO Data Holdings (Appendices B and C)</i></p>

## **PRINCIPLE 5: Use, Disclosure and Retention of PHI**

CCO only uses and discloses PHI for the purposes for which it was collected, or as permitted or required by law. CCO will not use and disclose PHI if other information, namely de-identified or aggregate information, will serve the purpose.

PHI is retained as long as necessary to fulfill the purposes of the data holding and in accordance with *PHIPA*. Generally, given CCO's role as a prescribed entity and prescribed registry PHI will be retained indefinitely to support retrospective analysis for the purposes of planning and management of the provincial healthcare system and to support **OCSR**.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 5.1 Use of PHI</b>            CCO uses data for the purposes of planning and management of the provincial healthcare system, including:</p> <ul style="list-style-type: none"> <li>• determining key indicators such as survival rates, wait times, disease incidence and the demand for services;</li> <li>• creating reports to advise the MOHLTC;</li> <li>• reimbursing hospitals for various services and programs ; and</li> <li>• managing screening and prevention programs.</li> </ul>	<p><i>List of CCO Data Holdings (Appendices B and C)</i>  <i>CCO Privacy Impact Assessment Standard</i>  <i>CCO Data Use and Disclosure</i></p>
<p><b>Principle 5.2 Data access – CCO employees</b>            CCO employees, Third-Parties and volunteers, are authorized to access PHI on a “need-to-know” basis only where it is required to perform official CCO duties.</p> <p>CCO prohibits the access to or use of more PHI than is reasonably necessary to meet the identified purpose.</p> <p>CCO has appropriate processes to be followed upon termination or cessation of the employment, contractual, or other relationship to ensure access privileges are terminated and CCO property is returned.</p>	<p><i>CCO Data Use and Disclosure</i>  <i>CCO Privacy and Security Training and Awareness Procedure</i>  <i>CCO Confidentiality Policy</i>  <i>CCO Statement of Confidentiality</i>  <i>CCO Direct Data Access Procedure</i>  <i>CCO Direct Data Access Audit Procedure</i>  <i>CSP Access Control Procedure</i>  <i>CCO Employee Exit Process</i></p>
<p><b>Principle 5.3 Data disclosure</b>            All data disclosures, including the disclosure of identifiable record level data, de-identified record level data or aggregate data, to persons external and internal to CCO must comply with CCO's Data Use and Disclosure Standard and where required by <i>PHIPA</i>.</p>	<p><i>CCO Business Process for Data Requests</i>  <i>CCO Decision Criteria for Data Requests</i>  <i>CCO De-Identification Guidelines</i>  <i>CCO Data Use and Disclosure Standard</i>  <i>CCO Data Access Committee Terms of Reference</i>  <i>CCO Data Sharing Agreement Standard</i>  <i>CCO Data Sharing Agreement Procedure</i>  <i>CCO Data Sharing Agreement Template</i></p>

<b>Principles</b>	<b>Related Documents</b>
<p>Where a data sharing agreement is required, the agreement must include:</p> <ul style="list-style-type: none"> <li>• a statement of the authority and purpose for the disclosure; and</li> <li>• a description of data elements disclosed to the persons external to CCO.</li> </ul>	<p><i>CCO Guideline on Fax Transmission</i>  <i>CCO Information Classification and Handling Standard</i></p>
<p><b>Principle 5.4 Data linkage</b>  CCO performs data linkage for planning and management purposes.  The CSP performs data linkage for identifying eligible population for screening as well as to conduct planning and management activities.</p>	<p><i>CCO Data Linkage Policy</i>  <i>CCO Data Linkage Procedure</i></p>
<p><b>Principle 5.5 Data retention</b>  CCO retains all mediums of PHI for as long as is required to fulfill the business purpose.</p> <p>CCO holds each data holding containing PHI “separate and apart” from CCO’s other data holdings (<i>i.e.</i>, held in a separate database within the same database management system).</p> <p>The Data Steward is responsible for maintaining an inventory of data holdings that includes information on:</p> <ul style="list-style-type: none"> <li>• the format of the data (paper or electronic);</li> <li>• its physical location;</li> <li>• the time span of the data; and</li> <li>• secure destruction of data when it is no longer required.</li> </ul>	<p><i>CCO Data Steward Terms of Reference (to be developed)</i>  <i>CCO Policy on Retention of Records Containing PHI</i>  <i>CCO Information Security Policy</i>  <i>CCO Business Continuity Plan</i>  <i>CCO Business Continuity Service Framework</i>  <i>CCO Disaster Recovery Plan</i></p>
<p><b>Principle 5.6 Data destruction</b>  All records of PHI, including records of PHI in paper format and in electronic format, no longer required to fulfill the identified purpose, must be destroyed in a secure manner.</p>	<p><i>CCO Enterprise Information Security Policy</i>  <i>CCO Information Security Code of Conduct</i>  <i>CCO Template Agreement for Third Party Service Providers</i>  <i>CCO Operational Security Standard</i>  <i>CCO DBAN Disk Wipe Procedure</i>  <i>CCO Digital Media Disposal Guideline</i>  <i>CCO Hard Copy PHI Disposal Procedure</i></p>

**PRINCIPLE 6: Accuracy of PHI**

CCO maintains the accuracy of PHI as necessary for the activities it conducts in support of its planning and management mandate and to support its activities for OCSR.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 6.1 CCO data quality program</b> CCO uses PHI as necessary for activities related to:</p> <ul style="list-style-type: none"><li>• Planning and management to support healthcare system</li><li>• Facilitate and improve the provision of healthcare</li></ul> <p>The CIO is responsible for establishing a CCO data quality program, practices and processes appropriate to CCO’s programs and services.</p> <p>The CCO Business Unit, in conjunction with the Corporate Data Quality Team and consistent with CCO’s data quality program, will determine the appropriate data submission specifications and other related requirements for the data holdings in their area, and convey these to respective primary data collectors and others with access to the data.</p> <p>The Data Steward or program lead for the data holding is responsible for ensuring compliance with established data quality practices and processes.</p> <p>Some CCO programs, such as CSP will allow individuals to correct the data that applies to them, upon the receipt of the appropriate written authorization.</p>	<p><i>CCO Data Steward Terms of Reference</i></p> <p><i>CSP Participant Information Form</i></p>



**PRINCIPLE 7: Safeguards for PHI**

CCO has physical, administrative and technical systems in place to safeguard PHI in its custody against loss, theft, unauthorized access, disclosure, copying, use, or modification.

The nature of the safeguards corresponds to the sensitivity of the information collected; the amount, distribution and format of the information; and the method of storage.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 7.1 Physical safeguards</b> CCO provides a secure physical environment for the equipment on which PHI is stored and for the employees who use PHI.</p> <p>The Facilities Manager is responsible for ensuring, that:</p> <ul style="list-style-type: none"><li>• the physical premises are secure;</li><li>• there is controlled access to CCO offices;</li><li>• employees are provided with appropriate identification;</li><li>• visitors are appropriately screened and authorized to be on the premises; and</li><li>• video surveillance is used for forensics purposes and is not monitored.</li><li>• Some operational areas which process PHI may require restricted access with a secondary level of access controls</li></ul>	<p><i>CCO Physical Security Policy</i> <i>CCO Access Card Procedure</i> <i>CCO Visitor Access Policy</i> <i>CCO Video Monitoring Policy</i></p>

Principles	Related Documents
<p><b>Principle 7.2 Administrative safeguards – contracts and agreements and processes</b>            CCO uses confidentiality agreements to reinforce employee and Third-Party understanding of their responsibility to protect PHI and to create a culture of privacy at CCO.</p> <p>The CPO will ensure that there are adequate processes in place to ensure that:</p> <ul style="list-style-type: none"> <li>• appropriate confidentiality agreements and privacy &amp; security training programs in place;</li> <li>• appropriate contracts in place with data providers and Third-Parties; and</li> <li>• appropriate contracts in place with disposal firms for the secure destruction of paper records containing PHI</li> </ul> <p>The Privacy Lead in each Business Unit is responsible for:</p> <ul style="list-style-type: none"> <li>• monitoring and regularly reviewing and testing the effectiveness of safeguards in their Business Unit.</li> </ul>	<p><i>CCO Confidentiality Policy</i>  <i>CCO Statement of Confidentiality</i>  <i>CCO Template Third Party Service Provider Agreement</i>  <i>CCO Privacy Lead Terms of Reference</i></p>
<p><b>Policy 7.3 Administrative safeguards - privacy training and awareness</b>            CCO requires all employees, third parties, researchers, students and volunteers, working for, or on behalf of CCO, to be aware of the importance of maintaining the confidentiality of PHI through its privacy and security training and awareness program. Specifically, where Third-Parties support CCO activities and require access to CCO systems they are subject to the same privacy and security training requirements as CCO employees.</p>	<p><i>CCO Privacy and Security Training and Awareness Procedure</i>  <i>CCO Privacy and Security Acknowledgement form</i>  <i>CCO Information Security Code of Conduct</i></p>
<p><b>Policy 7.4 Administrative safeguards - privacy impact assessments, privacy risk management, and change management</b>            CCO requires that PIAs, including, as appropriate, security analyses and threat risk assessments, be completed for any purposes as listed in the Privacy Impact Assessment Standard.</p> <p>CCO also has a comprehensive privacy risk management program to ensure privacy risks are identified, mitigated and responsibly managed.</p>	<p><i>CCO Privacy Impact Assessment Standard</i>  <i>CCO Privacy Risk Management Policy</i>  <i>CCO Privacy Risk Management Framework</i>  <i>CCO Change Management Policy</i></p>

<b>Principles</b>	<b>Related Documents</b>
<p><b>Policy 7.5 Technical safeguards</b>            CCO adopts industry standards and tests its systems to ensure PHI in its custody, and the equipment and communication systems utilized by CCO are secure.</p>	<p><i>CCO Information Security Policy</i>  <i>CCO Logging, Monitoring and Auditing Standard</i>  <i>CCO Logical Access Control Standard</i>  <i>CCO Information Classification and Handling Standard</i>  <i>CCO Information Classification and Handling Guideline</i>  <i>CCO Cryptography Standard</i></p>

**PRINCIPLE 8: Openness about the Management of PHI**

CCO makes information available to primary data collectors, the public and other stakeholders about its policies and practices relating to the management of PHI.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 8.1 Availability of information</b> CCO makes information about its policies and practices for the collection, use and disclosure of PHI freely available, in paper and electronic form.</p> <p>The Privacy &amp; Access Office ensures that the following are publicly available:</p> <ul style="list-style-type: none"><li>• general information on CCO’s privacy practices;</li><li>• descriptions of CCO’s data holdings of PHI; and</li><li>• contact information for CCO’s Privacy &amp; Access Office.</li></ul>	<p><i>CCO Statement of Information Practices</i> <i>CCO Privacy FAQs</i> <i>CSP Privacy FAQs</i> <i>CCO external website Privacy page</i> <i>List of CCO and CSP Data Holdings (Appendices B and C)</i> <i>CCO Privacy Inquiries and Complaints Procedure</i></p>

**PRINCIPLE 9: Individual Access to and Amendment of PHI**

Under *PHIPA*, CCO is not obligated to grant individuals access to, or correction of, their records. Persons requesting access to, or correction of, their records will be directed to the HIC who originally provided care and/or collected their health information. Exceptions may be made in accordance with the following policy.

<b>Principles</b>	<b>Related Documents</b>
<p><b>Principle 9.1 <i>PHIPA</i> Section 45 and <i>PHIPA</i> Section 39(1)(c)</b> CCO does not hold an individual’s full health record and CCO employees are not medical practitioners involved in interpreting medical information for individuals.</p> <p>As CCO is not the primary data collector, all requests for access to or corrections of an individual’s health record(s) will be directed to the HIC directly involved in their care and treatment.</p> <p>However, the CSP will provide individuals with an opportunity to update information that pertains to them, such as address or telephone number which is stored in the OCSR for cancer screening correspondence purposes.</p>	<p><i>CCO Access and Correction Procedure</i> <i>CSP Participant Information Form</i></p>
<p><b>Principle 9.2 Exceptions</b> Exceptions may be made to granting individuals access to their records in special circumstances, for example where:</p> <ul style="list-style-type: none"><li>• an individual (or authorized next-of-kin) is researching the individual’s family’s cancer history, or</li><li>• a genetic counselor is researching an individual’s family’s cancer history on behalf of the individual, or</li><li>• no other source of the record is available.</li></ul>	<p><i>CCO Access and Correction Procedure</i></p>

**PRINCIPLE 10: Complaints About CCO’s Handling of PHI**

Any individual can challenge CCO’s information practices and its handling of PHI.

Principles	Related Documents
<p><b>Principle 10.1 Complaints related to CCO’s information practices</b>            Any person may submit a concern or complaint regarding CCO’s information practices or the purposes for which PHI is collected to CCO’s Privacy &amp; Access Office. They can do so by writing to:</p> <p>CCO Privacy &amp; Access Office            Cancer Care Ontario            620 University Avenue            Toronto, ON M5G 2L7</p> <p>or by emailing:            privacyandaccessoffice@cancercare.on.ca</p> <p>All complaints will be reviewed. A log of complaints will be maintained by the Privacy &amp; Access Office</p> <p>A person may also submit a concern or complaint to the IPC. They can do so by writing to:</p> <p>Information and Privacy            Commissioner/Ontario            2 Bloor Street East, Suite 1400            Toronto, ON M4W 1A8</p>	<p><i>CCO Privacy Inquiries and Complaints Procedure</i>  <i>CCO Statement of Information Practices</i>  <i>CCO Privacy FAQs</i>  <i>CSP Privacy FAQs</i></p>
<p><b>Principle 10.2 Privacy breach</b>            Any privacy breach, suspected privacy breach, or privacy risk will be investigated according to the relevant Privacy Breach Management Procedure by the Privacy &amp; Access Office.</p> <p>A log of privacy breaches, suspected privacy breaches, and privacy risks will be maintained by the Privacy &amp; Access Office.</p>	<p><i>CCO Privacy Breach Management Procedure</i>  <i>CCO Health Information Network Provider (HINP) Privacy Policy</i></p>
<p><b>Policy 10.3 Whistleblower protection</b>            CCO extends “whistleblower” protection to CCO staff, consultants and contractors who (a) report privacy breaches, suspected privacy breaches, or privacy risks or (b) refuse to perform a transaction that they believe will result in a privacy breach or a privacy risk.</p>	<p><i>CCO Privacy Breach Management Procedure</i></p>



## **APPENDIX A**

### **DEFINITIONS**

**Aggregate Data** means summed and/or categorized data that is analyzed and placed in a format that precludes further analysis (i.e. in tables or graphs) to prevent the chance of revealing an individual's identity; individual record cannot be reconstructed. Aggregate data does not include PHI.<sup>1</sup>

**CSA Model Code:** CCO's Privacy Policy is based on the 10 privacy principles set out in the Canadian Standards Association *Model Code for the Protection of Personal Information* ("CSA Model Code").<sup>2</sup>

**Collect** has the meaning set out in section 2 of *PHIPA*. In relation to PHI, "**collect**" means to gather, acquire, receive or obtain the information by any means from any source, and "**collection**" has a corresponding meaning.

**Data Element** is a category used to identify a data type.

**Data Holding** is a full collection of data, categorized by data element, and relied upon to support specific business purposes.

**Data Linkage** is the process by which personal health information about an individual from one data holding is combined with that of another data holding, to create new information about the individual, which may include new PHI.

**Data Provider** is any person from whom CCO collects one or more Data Set(s).

**Data Set** means a subset of a Data Holding made up of populated Data Elements, which could be Identifiable Record-Level Data, De-identified Record-Level Data, Aggregate Data or Published Data.

**Data Sharing Agreement (DSA)** means an agreement which outlines the terms and conditions for a data exchange, which may include the disclosure of one or more Data Sets by CCO to an External Party, or the collection of one or more Data Sets by CCO from an External Party.

**Data Steward** is a person who is accountable for ensuring that privacy, security, and data quality requirements are met for data holdings under his/her stewardship and for maintaining an inventory of all CCO data holdings. A Data Steward will be assigned for each data holding to monitor all uses of PHI and ensure the uses are consistent with CCO's mandate and the purposes for the data holding.

**Disclose** has the meaning set out in section 2 of *PHIPA*. In relation to PHI in the custody or under the control of a HIC or other person such as CCO, "**disclose**" means to make the information available or to release it to another HIC or to another person, but does not include to use the information, and "**disclosure**" has a corresponding meaning.

**External Party** means (a) a person that has requested a data set from CCO for transfer to the person; or (b) a person from which CCO has requested a data set, for transfer to CCO. An external party may include CCO, in its capacity as a prescribed entity under section 45 of *PHIPA*, where it is transferring a data set to or from CCO in its capacity as a prescribed registry under section 39(1)(c) of *PHIPA*. An external party may also include CCO, in its capacity as a prescribed registry, where it is transferring a data set to or from CCO in its capacity as a prescribed entity.

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<sup>1</sup> See the CCO Data Use and Disclosure Standard

<sup>2</sup> Canadian Standards Association, "CAN/CSA – Q830-96, Model Code for the Protection of Personal Information," March 1996.



**Health Information Custodian (HIC)** is a listed individual or organization under section 3 of *PHIPA* that, as a result of their power or duties, has custody of personal health information. Examples of health information custodians include:

- Health care practitioners (i.e. doctors, nurses, pharmacists, psychologists, and dentists);
- Hospitals (public or private);
- Psychiatric facilities;
- Pharmacies;
- Laboratories;
- Nursing homes and long-term care facilities;
- Retirement homes and homes for special care;
- Community Access Centres;
- Ambulance services;
- Ministry of Health and Long-Term Care.

**Information and Privacy Commissioner / Ontario (IPC):** The Commissioner plays a crucial role under *PHIPA* and *FIPPA*. In general terms, the Commissioner's mandate is to:

- Independently review the decisions and practices of government organizations concerning access and privacy;
- Independently review the decisions and practices of health information custodians in regard to personal health information;
- Conduct research on access and privacy issues;
- Provide comments and advice on proposed government legislation and programs;
- Review the personal health information policies and practices of entities and prescribed persons under *PHIPA*; and
- Educate the public about Ontario's access, privacy, and personal health information laws and related issues.

**Memorandum of Understanding (MOU)** means the agreement between the Minister of Health and Long-Term Care (MOHLTC) and CCO, dated December 2, 2009, which details the relationship between CCO and the MOHLTC.

**Personal Health Information (PHI)** is "identifying information" collected about an individual as defined in section 4 of *PHIPA*. It includes both identifying information (i.e. name, date of birth, or address) and the information related to one's health or health care history (i.e. family medical history, diagnosis, or health card number). Information is "identifying" when it identifies an individual or when it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify the individual. Anything that links a person's health information to their identity is considered personal health information.

**Personal Health Information Protection Act, 2004 (PHIPA)** is Ontario's health-specific privacy legislation, which applies to health information custodians. *PHIPA* governs the manner in which personal health information may be collected, used, and disclosed within the health care system.

**Prescribed Entity** is an entity that is prescribed in the regulations, pursuant to *PHIPA*, section 45, to which a health information custodian is permitted to disclose personal health information for the purpose of analysis or compiling statistical information for the management, evaluation, or monitoring of the allocation of resources to, or planning for, all or part of the health system, including the delivery of services. As a prescribed entity, CCO has the authority to collect, use, and disclose PHI for the purposes of health system planning and management ("planning and management purposes").

**Privacy Breach** refers to the unauthorized access, collection, use, and/or disclosure of personal information or personal health information, whether accidental or intentional. These include uses or

disclosures of personal health information that contravene CCO's *Privacy Policy*. This term is explained in further detail in CCO's *Privacy Breach Management Procedure*. See also the following related terms: "**Privacy Risk**" and "**Suspected Privacy Breach.**"

**Privacy Impact Assessment (PIA)** is a formal risk management tool used to identify the actual or potential effects that a proposed or existing information system, technology, or program may have on personal health information. It is used to identify potential privacy risks of new or redesigned programs or services. It also helps to eliminate or mitigate those risks. The PIA examines how personal health information is collected, stored, used, and disclosed.

**Privacy Leads** are the primary point of contact for the CCO Privacy & Access Office on privacy-related matters in CCO's program areas and business units. Their responsibilities include ensuring privacy-sensitive work habits, providing subject-matter expertise on their program area, promoting training and awareness and assisting in breach management activities.

**Privacy Risk** arises where a CCO staff member has reasonable grounds to believe that a Privacy Breach (as defined above) may occur in the future. This term is explained in further detail in CCO's *Privacy Breach Management Procedure*.

**Suspected Privacy Breach** arises where a CCO staff member has reasonable grounds to believe that a Privacy Breach (as defined above) has occurred. This term is explained in further detail in CCO's *Privacy Breach Management Procedure*.

**Third-Party**, as used in this Policy, includes consultants, contractors and third-party service providers.

**Use** has the meaning set out in section 2 of *PHIPA*. In relation to PHI in the custody or under the control of a HIC or other person (such as CCO), "**use**" means to handle or deal with the information, subject to section 6(1); but does not include to disclose the information, and "**use**", as a noun, has a corresponding meaning.

**APPENDIX B**

**CCO PRIMARY DATA HOLDINGS FOR THE PRESCRIBED ENTITY as at JUNE 2014**

<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>SAMPLE</b>	<ol style="list-style-type: none"> <li>1. The purpose of the data holding</li> <li>2. The need for the PHI contained in the data holding in relation to the identified purpose</li> </ol>	<p>This data holding contains the following categories of data: -e.g. clinical data, demographic data, etc.</p>	e.g. CIHI, MOHLTC, etc.	Name, Title and Department of Data Steward
<b>Dyspnea Management Program</b>	<ol style="list-style-type: none"> <li>1. The purpose of the data holding is to securely store data (including PHI) collected from 6 hospital sites for the dyspnea management pilot project.</li> <li>2. PHI is collected to evaluate the impact that dyspnea management has on lung cancer patients, whether a subset of patients benefit from counselling and to determine if counselling results in any secondary impacts on the health system.</li> </ol>	<p>This dataset contains: -Clinical data -Demographic data</p>	-Hospitals	<b>Nathalie Assouad</b> , Program Manager, Disease Pathway Management Secretariat
<b>Stem Cell Transplant (SCT)</b>	<ol style="list-style-type: none"> <li>1. The purpose of the SCT data set is to support planning, funding and forecasting of stem cell transplants within Ontario.</li> <li>2. PHI is collected to calculate specific indicators and measures that are required to support the Goals and Objectives framework for the SCT project</li> </ol>	<p>This dataset contains: -Patient Demographic data -Clinical / Stem Cell Transplants data -File Descriptor data</p>	-Hospitals	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>Brachytherapy Funding Program</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to provide reimbursement for eligible prostate cancer patients that meet the program guidelines.</li> <li>2. PHI is collected to ensure there is no duplication of cases, to reimburse eligible patients and to confirm products used when issues/ questions arise.</li> </ol>	<p>This dataset contains: -Clinical data -Demographic data</p>	-Referring physicians	<b>Eric Gutierrez</b> , Program Manager, Radiation Treatment Programs, Clinical Programs

<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>Ontario Cancer Symptom Management Collaborative (OCSMC) Symptom Management Reporting Database</b>	<ol style="list-style-type: none"> <li>1. The Symptom Management Reporting Database was developed in order to assess the goal of OCSMC, which is to improve symptom management and collaborative palliative care planning through earlier identification, documentation and communication of patients' symptoms and performance status.</li> <li>2. PHI is collected to evaluate the provision of symptom management and palliative care planning for cancer patients in Ontario.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>-Demographic data</li> <li>-Clinical data</li> </ul>	-Hospitals	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>New Drug Funding Program (NDFP)</b>	<ol style="list-style-type: none"> <li>1. The NDFP database stores patient and treatment information about systemic therapy drug utilization at Ontario hospitals, for which reimbursement is being sought through the NDFP according to strict eligibility criteria.</li> <li>2. PHI is collected for CCO NDFP to reimburse hospitals for those patients who have met the eligibility criteria.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data (eligibility criteria)</li> <li>- demographic data</li> </ul>	-Hospitals	<b>Scott Gavura</b> , Director, Provincial Drug Reimbursement Programs
<b>Evidence-Building Program (EBP)</b>	<ol style="list-style-type: none"> <li>1. The EBP database stores patient and treatment information about systemic therapy drug utilization at Ontario hospitals, for which reimbursement is being sought through the EBP according to strict eligibility criteria.</li> <li>2. PHI is collected for CCO EBP to reimburse hospitals for those patients who have met the eligibility criteria.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data (eligibility criteria)</li> <li>- demographic data</li> </ul>	-Hospitals	<b>Scott Gavura</b> , Director, Provincial Drug Reimbursement Programs

<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>Case-by-Case Review Program (CBCRP)</b>	<ol style="list-style-type: none"> <li>1. The CBCRP database stores patient and treatment information about systemic therapy drug utilization at Ontario hospitals, for which reimbursement is being sought through the CBCRP according to strict eligibility criteria.</li> <li>2. PHI is collected for CCO CBCRP to reimburse hospitals for those patients who have met the eligibility criteria.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data (eligibility criteria)</li> <li>- demographic data</li> </ul>	-Hospitals	<b>Scott Gavura</b> , Director, Provincial Drug Reimbursement Programs
<b>Ontario Positron Emission Tomography Scan Evidence-Based Program (EB-PET Program)</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to carry out CCO's mandate to operate the evidence-based PET Scans Ontario Program <ul style="list-style-type: none"> <li>• Information to PET Access Reviewers for adjudication of scans</li> <li>• Reimbursement to PET Centres and PET Access Reviewers</li> <li>• Provision of information to PET Steering and/or MOHLTC</li> </ul> </li> <li>2. PHI is collected by CCO to: <ul style="list-style-type: none"> <li>• Communicate approved PET scan requests to designated PET Centres.</li> <li>• Provide sufficient information for the adjudication process (some demographic and clinical data).</li> <li>• Link to other data holdings for reporting and analysis for the evaluation and management of the PET Scans Ontario Program.</li> </ul> </li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>-Clinical data</li> <li>-Patient demographic data</li> <li>-Physician demographic data</li> <li>-Administrative data</li> </ul>	-Referring physicians -Diagnostic centres	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence

<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>Collaborative Staging</b>	<p>1. The Collaborative Staging dataset is a standardized set of data elements that describe how far a cancer has spread at the time of diagnosis. It contains patient, tumour and additional disease-site specific factors that together derive the stage of the patient at the time of diagnosis.</p> <p>2. CCO submits provincial stage data annually to NAACCR and Statistics Canada. Along with data from the Ontario Cancer Registry, cancer stage data is necessary to support cancer system surveillance, planning and management. PHI is necessary to enable comprehensive analysis and for linking to the Ontario Cancer Registry, screening, and treatment data.</p>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data</li> <li>- demographic data</li> <li>- facility data</li> </ul>	<ul style="list-style-type: none"> <li>-Ontario Cancer Registry</li> <li>-Pathology Datamart</li> <li>-Hospital patient health records</li> </ul>	<b>Mary Jane King,</b> Manager, Data Management and the Ontario Cancer Registry
<b>Diagnostic Assessment Program (DAP)</b>	<p>1. The purpose of the data holding is to securely store data (including PHI) collected from all regional cancer programs for DAP oversight.</p> <p>2. PHI is collected to evaluate the impact DAPs have on patients in the diagnostic phase of the cancer journey.</p>	<p>This data holding contains the following categories of data:</p> <ul style="list-style-type: none"> <li>- clinical data,</li> <li>demographic data,</li> <li>wait times data,</li> <li>usage data,</li> <li>administrative data</li> </ul>	- Hospitals	<b>Haim Sechter,</b> Manager, Cancer Informatics

<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>ePath</b>	<p>1. The Pathology Database is comprised of patient and tumour information for cancer and cancer-related pathology reports (tissue, cytology), submitted from public hospital (and some commercial) laboratories. ePath documents patient, facility, and report identifiers, and tumour identifiers, such as site, histology and behaviour.</p> <p>2. PHI is used to support management decision-making, planning, disease surveillance and research, as well as contributing to resolved incidence case data in the Ontario Cancer Screening Registry.</p>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data</li> <li>- demographic data</li> <li>- facility data</li> </ul>	<ul style="list-style-type: none"> <li>-Hospitals</li> <li>-Some commercial laboratories</li> </ul>	<b>Mary Jane King</b> , Manager, Data Management and the Ontario Cancer Registry
<b>National Ambulatory Care Reporting System (NACRS)</b>	NACRS contains summary diagnostic and treatment information about patients who have received outpatient surgery or selected other treatments (chemotherapy, emergency department visits, dialysis and cardiology) in Ontario hospitals.	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- demographic data</li> <li>- clinical data</li> </ul>	-Canadian Institute for Health Information (CIHI)	<b>Haim Sechter</b> , Manager, Cancer Informatics
<b>Discharge Abstract Database (DAD)</b>	DAD contains summary diagnostic and treatment information about patients who have received healthcare services as an inpatient (including acute care, chronic care and rehabilitation care) in Ontario hospitals.	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- demographic data</li> <li>- clinical data</li> </ul>	-Canadian Institute for Health Information (CIHI)	<b>Haim Sechter</b> , Manager, Cancer Informatics

Data Holding	Purpose	Data	Source	Data Steward
<b>Ontario Cancer Registry Information System (OCSRIS)</b>	<ol style="list-style-type: none"> <li>The Ontario Cancer Screening Registry (OCSR) is a computerized database of information on all Ontario residents who have been newly diagnosed with cancer ("incidence") or who have died of cancer ("mortality"). All new cases of cancer are registered, except non-melanoma skin cancer. This information is used to support management decision-making, planning, disease surveillance and research.</li> <li>PHI is collected to link records and establish which records belong to which patient. The PHI is frequently required by internal and external researchers. The Canadian Cancer Registry MOU contains the requirement that PHI be included in CCO annual submissions of newly diagnosed patients.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data</li> <li>- demographic data</li> </ul>	<ul style="list-style-type: none"> <li>-CIHI (DAD, NACRS)</li> <li>-ALR (Regional Cancer Centre and Princess Margaret Hospital reporting through Databook)</li> <li>-PIMS, anatomical pathology reports from Ontario public and private laboratories</li> <li>-Ontario Registrar General's Office, Mortality files enhanced by death certificate notifications from Statistic Canada for Ontario residents</li> <li>deaths in other provinces/territories</li> <li>-Out of Province, notifications from other provinces/territories of Ontario residents diagnosed or treated in the notifying P/T</li> </ul>	<b>Mary Jane King,</b> Manager, Data Management and the Ontario Cancer Registry, Cancer Informatics
<b>Mortality Data</b>	<ol style="list-style-type: none"> <li>The purpose of this data holding is for CCO to receive mortality data which contains the date of death and cause of death for Ontario residents who have died in Ontario for planning and management purposes.</li> <li>PHI is collected to measure cancer survival.</li> </ol>	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- demographic data</li> </ul>	<ul style="list-style-type: none"> <li>-Ministry of Government Services</li> <li>-Office of the Registrar General</li> </ul>	<b>Mary Jane King,</b> Manager, Data Management and the Ontario Cancer Registry, Cancer Informatics



<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>Out of Province (OOP) Data</b>	<ol style="list-style-type: none"> <li>1. This data holding contains persons with OCSR reportable diseases. The purpose of these records is to serve as source records to create incident cases for the Enterprise Data Warehouse (EDW)-OCSR. Both alone, and as source records for incident cases, OOP data support management decision-making, planning, disease surveillance and research.</li> <li>2. PHI is collected to ensure accuracy in linking records in EDW. PHI is used by internal and external researchers at the source record level.</li> </ol>	<p>This dataset will contain:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data</li> <li>- demographic data</li> </ul>	<ul style="list-style-type: none"> <li>-Out of Province</li> <li>-Notifications from other provinces/territories of Ontario residents diagnosed or treated for cancer in the notifying P/T</li> </ul>	<b>Mary Jane King,</b> Manager, Data Management and the Ontario Cancer Registry, Cancer Informatics
<b>Pathology Datamart</b>	<ol style="list-style-type: none"> <li>1. This data holding is derived from the PIMS data holding and uploaded into the EDW for planning and management purposes.</li> <li>2. PHI is used to support management decision-making, planning, disease surveillance and research, as well to contribute to resolving incidence case data in the OCSR.</li> </ol>	<p>This dataset contains</p> <ul style="list-style-type: none"> <li>-administrative data</li> <li>-clinical data</li> <li>-demographic data</li> <li>-facility data</li> </ul>	-PIMS	<b>Mary Jane King,</b> Manager, Data Management and the Ontario Cancer Registry
<b>RPDB Datamart</b>	The RPDB is a listing of all persons insured under OHIP. This data is used to ensure that individuals in other data sources are identified correctly and to support analysis by demographic groups and geography.	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- Ontario Health Insurance Number</li> <li>- administrative data</li> <li>- demographic data</li> </ul>	-Ministry of Health and Long-Term Care	<b>Mary Jane King,</b> Manager, Data Management and the Ontario Cancer Registry

<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>Interim Annotated Tumour Project (ATP) Database</b>	<ol style="list-style-type: none"> <li>1. The Interim ATP Database provides an integrated set of data, combining tumour information from the Ontario Institute for Cancer Research's Tumour Bank with CCO's OCSR, for the purpose of increasing the accuracy and utility of the information for both researchers and CCO planners.</li> <li>2. PHI is used by researchers to study the association between genetics and response to cancer drugs. CCO also uses the PHI in this data holding to create clinical guidelines for the care and treatment of cancer patients in Ontario.</li> </ol>	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data</li> <li>- demographic data</li> </ul>	<ul style="list-style-type: none"> <li>-OICR</li> <li>-CCO's Cancer Registry</li> </ul>	<b>Mary Jane King,</b> Manager, Data Management and the Ontario Cancer Registry
<b>Ontario Renal Network (ORN)</b>	<ol style="list-style-type: none"> <li>1. The purposes of the ORN data holding are <ul style="list-style-type: none"> <li>• Performance measurement and management;</li> <li>• Monitoring of system quality;</li> <li>• System planning; and</li> <li>• CKD funding model development.</li> </ul> </li> <li>2. PHI is used to support management decision-making, planning, disease surveillance and research activities.</li> </ol>	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>-Clinical data</li> <li>-Demographic data</li> </ul>	-Hospitals	<b>Cathy Cattaruzza,</b> Director, Access to Care & Ontario Renal Network Information Program, Acting Director, Analytics

Data Holding	Purpose	Data	Source	Data Steward
<b>Wait Times Information System (WTIS)</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to enable the monitoring of wait times, the Ontario Wait Time Strategy implemented the web-based Wait Time Information System (WTIS) to facilitate wait time management and to provide the public with wait time information on surgical and diagnostic procedures.</li> <li>2. PHI is collected from hospitals and the Enterprise Master Patient Index (EMPI) (which interfaces with the WTIS in order to organize patient information) and is used for the planning and management of the health care system.</li> </ol>	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- clinical data</li> <li>- demographic data</li> </ul>	<ul style="list-style-type: none"> <li>-Hospitals</li> <li>-EMPI</li> </ul>	<p><b>Cathy Cattaruzza</b>,  Director,  Access to Care &amp; Ontario Renal Network Information Program,  Acting Director,  Analytics</p>
<b>Emergency Room National Ambulatory Reporting System Initiative (ERNI)</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to evaluate ER wait times for provincial ER/ALC Strategy, including but not limited to return on investment, performance improvement, Ministry LHIN Performance Agreements and data quality assessment.</li> <li>2. PHI is collected to determine and remove duplicate data entry errors from the analysis as well as to calculate percentage of patients returning to an ER within a specified time period as a measure of quality of care and potential negative impact of ER focus.</li> </ol>	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- clinical data</li> <li>- demographic data</li> </ul>	<p>Hospital sites submit to CIHI-NACRS. Extract of file is transferred securely from CIHI to ATC Informatics within CCO using Tumbleweed</p>	<p><b>Cathy Cattaruzza</b>,  Director,  Access to Care &amp; Ontario Renal Network Information Program,  Acting Director,  Analytics</p>

<b>Data Holding</b>	<b>Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>Ontario Laboratory Reporting System (OLIS)</b>	<ol style="list-style-type: none"> <li>1. To support CCO's ORN and DAP-EPS Programs in accordance with CCO's Data Privacy Agreement with the MOHLTC as a PE, as amended.</li> <li>2. PHI is required to enable CCO to link OLIS data with its patient records within other PE data holdings – such linkage is required to carry out health analytics.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>-Laboratory test result information from patients across Ontario</li> </ul>	MOHLTC (via eHealth Ontario)	<b>Daniela Sabatini</b> (Acting), Senior Manager, Data Management
<b>eOutcomes-H&amp;N</b>	<ol style="list-style-type: none"> <li>1. The purpose of the data holding is to capture and monitor outcomes data for patients with head and neck cancer treated with radiotherapy in a provincial, systematic way.</li> <li>2. PHI is collected to ensure accurate capture of patients' outcomes post-radiotherapy, and to facilitate the identification of inadvertent duplicate cases.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>-Clinical data (e.g. outcomes, diagnosis, radiotherapy details)</li> <li>-Demographic data (patient name, MRN)</li> </ul>	<ul style="list-style-type: none"> <li>-Physicians / Data Managers (outcomes)</li> <li>-ALR data (diagnosis, radiotherapy details)</li> </ul>	<b>Eric Gutierrez</b> , Program Manager, Radiation Treatment Program, Clinical Programs

## APPENDIX C

### CCO PRIMARY DATA HOLDINGS FOR THE PRESCRIBED REGISTRY as at JUNE 2014

<b>Data Holding</b>	<b>Statement of Purpose</b>	<b>Data</b>	<b>Source</b>	<b>Data Steward</b>
<b>CCC Interim Solution</b>	<p>System no longer used, required for Data migration, Archive and Audit only</p> <ol style="list-style-type: none"> <li>The purpose of the data holding is to securely store data (including PHI) to support Colon Cancer Check Screening Operations.</li> <li>PHI is collected for CCC client management and operations including, clinical results, direct client interactions and correspondence.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>Clinical data</li> <li>Demographic and address data</li> <li>Call centre operational activities data</li> </ul>	<ul style="list-style-type: none"> <li>MOHLTC</li> <li>Laboratories</li> <li>Fulfillment House</li> <li>Call Centre direct data entry.</li> </ul>	<b>Cathy Cattaruzza</b> , Director, Access to Care & Ontario Renal Network Information Program, Acting Director, Analytics
<b>CCC LMS</b>	<ol style="list-style-type: none"> <li>The purpose is to support Colon Cancer Check Screening Operations.</li> <li>PHI is collected for data exchange to and from Health Service Providers via secure web portal (OMD) as well as for validation of patient lists and electronic distribution of Provider Reports.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>Clinical data</li> <li>Client Demographic data</li> <li>Provider Demographic and Address data</li> </ul>	<ul style="list-style-type: none"> <li>CCC - Siebel</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>CCC - Siebel</b>	<ol style="list-style-type: none"> <li>The purpose of this data holding is to support Integrated Screening Operations, Planning and Performance.</li> <li>Integrated Screening Siebel CRM system. It is a front end system for InScreen client management and operations including, Clinical Results, direct client interaction and Correspondence.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>Clinical data</li> <li>Demographic and address data</li> <li>Call centre operational activities data</li> </ul>	<ul style="list-style-type: none"> <li>MOHLTC (RPDB, HNS, CHDB, CPDB, CAPE)</li> <li>Laboratory (LIRT)</li> <li>Hospital (CIRT)</li> <li>Fulfillment House</li> <li>Statistics Canada (PC to LHIN)</li> <li>Call Center direct data entry</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>Screening Hub Integration</b>	<ol style="list-style-type: none"> <li>The purpose of this data holding is to support Integrated Screening Operations, Planning and</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>Clinical data</li> <li>Demographic and address</li> </ul>	<ul style="list-style-type: none"> <li>MOHLTC (RPDB, HNS, CHDB, CPDB, CAPE)</li> <li>Laboratory</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of

	<p>Performance.</p> <p>2. InScreen Integration Hub (Customer Data Integration) to support downstream InScreen information and data requirements. E.g. Siebel InScreen and Datamart reporting. Various sources from MOHLTC, Siebel InScreen, StatsCan and CCO are standardized, cleansed and integrated for downstream operations.</p>	<p>data</p> <ul style="list-style-type: none"> <li>• Call centre operational activities data</li> </ul>	<p>(LIRT)</p> <ul style="list-style-type: none"> <li>• Hospital (CIRT)</li> <li>• Fulfillment House (Correspondence)</li> <li>• Statistics Canada (PC to LHIN)</li> <li>• Siebel Call Center</li> </ul>	<p>Excellence</p>
<p><b>Screening Hub Stage – CAPE</b></p>	<p>1. The CAPE data set will be used to identify physicians in Ontario who have rostered patients.</p> <p>2. This information will be used to compile a list of eligible rostered patients who will be invited to participate in the ColonCancerCheck (“CCC”) program.</p>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>• Administrative Physician Data</li> <li>• HIN</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC</li> </ul>	<p><b>Cathy Cattaruzza</b>, Director, Access to Care &amp; Ontario Renal Network Information Program, Acting Director, Analytics</p>
<p><b>Screening Hub Stage – CHDB</b></p>	<p>1. The claims data received will be used to determine volumes of non-program FOBT kits processed and validating performance of facilities and physicians who have conducted Colonoscopies.</p> <p>2. It will also be used as criteria for identifying the candidate population for the invitation pilot.</p>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>• Administrative Care</li> <li>• Clinical Data</li> <li>• PHI</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC</li> </ul>	<p><b>Cathy Cattaruzza</b>, Director, Access to Care &amp; Ontario Renal Network Information Program, Acting Director, Analytics</p>
<p><b>Screening Hub Stage – CIRT</b></p>	<p>1. The purpose of this data holding is to understand colonoscopy activity conducted within participating facilities.</p> <p>2. The data collected through CIRT will be used to understand colonoscopy activity conducted within participating facilities</p>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>• Administrative Care</li> <li>• Clinical Data</li> <li>• PHI</li> </ul>	<ul style="list-style-type: none"> <li>• Hospitals</li> </ul>	<p><b>Rebecca Comrie</b>, Director, Informatics – Centre of Excellence</p>

	from volume, wait time and quality perspectives. It is also used to determine funding and volume allocations across participating facilities.			
<b>Screening Hub Stage – LIRT</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to gather information from laboratories on FOBT results.</li> <li>2. The data collected through the LIRT are FOBT results that is used for (a) generate participant communications; and (b) monitoring and reporting on FOBT volumes, geographic differences, test quality, variations between participating laboratories and highlighting the need for further awareness or education programs.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>• Administrative Care</li> <li>• Clinical Data</li> <li>• PHI</li> </ul>	<ul style="list-style-type: none"> <li>• Laboratories</li> </ul>	<p><b>Cathy Cattaruzza</b>, Director, Access to Care &amp; Ontario Renal Network Information Program, Acting Director, Analytics</p>
<b>Screening Hub Stage - OPDB (Pharmacy Claims)</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to gather information of FOBT dispensed by pharmacies.</li> <li>2. This data will be used to evaluate the level of dispensing of FOBT kits at the pharmacies.</li> </ol>	<p>This dataset contains</p> <ul style="list-style-type: none"> <li>• Administrative Pharma Data</li> <li>• PHI</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC</li> </ul>	<p><b>Cathy Cattaruzza</b>, Director, Access to Care &amp; Ontario Renal Network Information Program, Acting Director, Analytics</p>
<b>Screening Hub Stage - OCSR</b>	<ol style="list-style-type: none"> <li>1. The OCSR is a computerized database of information on all Ontario residents who have been diagnosed with cancer ("incidence") and/or who have died of cancer ("mortality"). All new cases of cancer are registered, except non-melanoma skin cancer.</li> <li>2. This information is used to support OCSR by identifying individuals who are ineligible for colorectal and cervical screening.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>• Administrative Care</li> <li>• Clinical Data</li> <li>• PHI</li> </ul>	<ul style="list-style-type: none"> <li>• CCO as PE</li> </ul>	<p><b>Mary Jane King</b>, Manager, Data Management and the Ontario Screening Registry</p>
<b>Screening Hub</b>	1. This data holding	The dataset	<ul style="list-style-type: none"> <li>• MOHLTC</li> </ul>	<b>Rebecca</b>

<b>Stage - RPDB</b>	<p>contains information from Registered Person Database. This data is used in operationalization of colorectal and cervical screening.</p> <p>2. This data will be used to identify Ontarians who are eligible and could be invited to participate in the CCC program. It will also be used for identity validation and data linking for client cancer journey assessment.</p>	<p>contains:</p> <ul style="list-style-type: none"> <li>Administrative Care</li> <li>Clinical Data</li> <li>PHI</li> </ul>		<b>Comrie</b> , Director, Informatics – Centre of Excellence
<b>Screening Hub Stage - Siebel</b>	<p>1. The purpose of this data holding is to integrate information for InScreen.</p> <p>2. Recent Client, Address and Screening related activity within Siebel InScreen, required in the Screening Hub for integration purposes.</p>	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>Client demographics and address information</li> <li>PHI</li> </ul>	<ul style="list-style-type: none"> <li>Integration Hub</li> <li>Call Centre direct entry</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>Primary Care Provider Reporting</b>	<p>1. This data holding contains information on primary care providers.</p> <p>2. This is used to store primary care provider screening activity reports. The reports summarize client level information for providers.</p>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>Clinical data</li> <li>PHI</li> </ul>	<ul style="list-style-type: none"> <li>Integration Hub</li> <li>Siebel</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>Ontario Cervical Screening Program (OCSP)</b>	<p>1. The purpose of this data holding is to gather information on pap tests for Ontario women from 1997 onwards.</p> <p>2. PHI is collected to implement, plan, manage, evaluate, allocate resources to, and report on performance of, the program. PHI is also collected for OCSP client management and operations including, clinical results, direct client interactions and correspondence</p>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>Administrative data</li> <li>Clinical data</li> <li>Demographic data</li> </ul>	<ul style="list-style-type: none"> <li>-CytoBase</li> <li>-RPDB</li> <li>-OCSR</li> </ul>	<b>Cathy Cattaruzza</b> , Director, Access to Care & Ontario Renal Network Information Program, Acting Director, Analytics
<b>Cytobase</b>	<p>1. The purpose of this data holding is:</p> <ul style="list-style-type: none"> <li>-to carry out the mandate of the CSP</li> </ul>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>-Demographic data about the</li> </ul>	<ul style="list-style-type: none"> <li>-CytoBase</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics –



	<p>-to facilitate the provision of health care related to cervical cancer screening to allow CCO to notify participants of their results</p> <p>-to maintain the OCSR</p> <p>-to conduct cancer planning and management as well as to perform quality and program management functions.</p>	<p>patient, the requesting physician and the laboratory that assessed the test</p> <p>-Health information number</p> <p>-cervical test result</p>		Centre of Excellence
<b>OCSP - Siebel</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to support Integrated Screening Operations, Planning and Performance.</li> <li>2. Integrated Screening Siebel CRM system. It is a front end system for InScreen client management and operations including, Clinical Results, direct client interaction and Correspondence.</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>• Clinical data</li> <li>• Demographic and address data</li> <li>• Call centre operational activities data</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC (RPDB, HNS, CHDB, CPDB, CAPE)</li> <li>• Cytobase</li> <li>• Fulfillment House</li> <li>• Statistics Canada (PC to LHIN)</li> <li>• Call Center direct data entry</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>Oracle Business Intelligence Enterprise Edition (OBIEE)</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to provide segmentation of data which enables Siebel CRM, via Campaign Management, to generate invitation, reminder, recall and test result notification correspondence for each of the three Cancer Screening modules (CCC, OCSP and OBSP).</li> </ol>	<p>This dataset contains:</p> <ul style="list-style-type: none"> <li>• Clinical data</li> <li>• Demographic and address data</li> <li>• Call centre operational activities data</li> </ul>	<ul style="list-style-type: none"> <li>• This dataset is populated with data from Siebel CRM and the Integration Hub.</li> </ul>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence
<b>Ontario Breast Screening Program (OBSP)</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is to screen and assess clients in order to operate the program.</li> <li>2. PHI is collected to implement, plan, manage, evaluate, allocate resources to, and report on performance of, the OBSP. PHI is also collected for OBSP client management and operations, including</li> </ol>	<p>This dataset contains:</p> <p>-Clinical data (test(s) and results, clinical history, performance data for OBSP radiologists, nurse examiners, screening sites, and assessment sites; program outcomes data)</p> <p>-Demographic</p>	<p>-Data entry by OBSP sites</p> <p>-OCSR data linkage</p> <p>-Death registry linkage</p>	<b>Rebecca Comrie</b> , Director, Informatics – Centre of Excellence

	clinical results, direct client interactions and correspondence.	data (appointment scheduling, physician contact data, correspondence data)		
<b>Mortality Data</b>	<ol style="list-style-type: none"> <li>1. The purpose of this data holding is for CCO to receive mortality data which contains the date of death and cause of death for Ontario residents who have died in Ontario for planning and management purposes.</li> <li>2. PHI is collected to identify cases for the Ontario Cancer Screening Registry and for measuring cancer survival.</li> </ol>	<p>The dataset contains:</p> <ul style="list-style-type: none"> <li>- administrative data</li> <li>- demographic data</li> </ul>	<ul style="list-style-type: none"> <li>-Ministry of Government Services</li> <li>-Office of the Registrar General</li> </ul>	<p><b>Mary Jane King,</b>  Manager, Data Management and the Ontario Cancer Registry</p>