

Cancer Care Ontario – Personal Information Bank

CCO as an institution under the *Freedom of Information and Protection of Privacy Act* is required to publish an index of all personal information banks. In addition to the personal information bank, CCO makes available a list of its CCO Data Holding List and HINP Services which is available [here](#).

Name: Trillium Gift of Life Network	
Location	Stored in secure location subject to CCO’s Internal Data Access Request process.
Authority	Trillium Gift of Life Network Act, R.S.O. 1990, c. H.20, s. 8.20.(1)
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Referral & Consultation Data; • Referral & consultation data; • Living donor; • Kidney waitlist ; and • Kidney transplant
Disclosure	Regional Renal Programs
Uses	For purposes that a Prescribed Entity may use and disclose PHI in accordance with subsection 45 of PHIPA and subsection 18 of PHIPA Regulation as it relates to tissue donations or transplants, including: <ul style="list-style-type: none"> i) increasing the rate of kidney transplants in Ontario; ii) support quality improvement initiatives relate to kidney transplants and living kidney donations.
Users	CCO Analytics and Ontario Renal Network
Individuals in Bank	Tissue donations or transplant data
Retention & Disposal	As per Data Sharing Agreement with TGLN, CCO may retain the TGLN Data indefinitely provided that CCO continues to require the TGLN Data for the CCO Purposes. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Patient and Family Advisor (Person Centered Care)	
Location	Stored in secure location subject to CCO’s Internal Data Access Request process.
Authority	Cancer Act, R.S.O. 1990, c. C.1, s. 5

Cancer Care Ontario – Personal Information Bank

Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Contact information including address; and • Personal opinions and experiences
Disclosure	<ul style="list-style-type: none"> • Regional Cancer Centres (RCCs)/Integrated Cancer Program Host Hospitals • Other Patient and Family Advisors and • Partner organizations including the Ministry of Health and Health Quality Ontario,
Uses	Drive system level quality improvement and fulfill CCO's mandate.
Users	Person Centered Care Patient and Family Advisor staff.
Individuals in Bank	Patient and Family Advisors with respect to cancer.
Retention & Disposal	<ul style="list-style-type: none"> • For individuals who are not selected as a Patient, Family Advisors (PFA), forms will be retained for 3 years. • As per the Participation Agreement with PFAs, the PFA's information will be retained for the period of time required to fulfill the purpose for which it was collected. • Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Patient and Family Advisor (Ontario Renal Network)	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Memorandum of Understanding and Accountability Agreement with Ministry of Health.
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Contact information including address; and • Personal opinions and experiences
Disclosure	<ul style="list-style-type: none"> • Regional Renal Program (RRP) staff and RRP/Host Hospitals; • Other Patient and Family Advisors (i.e. RRP Advisors, Regional Renal Advisors or RRP Host Hospital Advisors; frequently referred to as non-CCO Advisors); and • Partner organizations including the Ministry of Health and Health Quality Ontario
Uses	Drive system level quality improvement and fulfill CCO's mandate

Cancer Care Ontario – Personal Information Bank

Users	Ontario Renal Network Patient and Family Advisor staff
Individuals in Bank	Patient and Family Advisors with respect to renal
Retention & Disposal	<ul style="list-style-type: none"> • For individuals who are not selected as a PFA, forms will be retained for 3 years. • As per the Participation Agreement with PFAs, the PFA’s information will be retained for the period of time required to fulfill the purpose for which it was collected. • Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: City of Toronto	
Location	Stored in secure location subject to CCO’s Internal Data Access Request process.
Authority	Memorandum of Understanding and Accountability Agreement between CCO and the Ministry of Health.
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient information including their contact information; • Date of enrollment; • Date of cancellation; and • Other administrative data
Disclosure	Regional Renal Programs
Uses	<ul style="list-style-type: none"> • To determine eligibility for the water rebate portion under the Home Hemodialysis Utility Grant; and • The Ontario Renal Network uses this information to calculate grant amount which will be shared with the Regional Renal Program
Users	ORN Analytics and ORN Funding Policy and Operations
Individuals in Bank	Applicants to Home Dialysis Water Rebate Program
Retention & Disposal	<p>As per Data Sharing Agreement with City of Toronto, CCO may retain the data indefinitely provided that CCO continues to require the data for the CCO Purposes.</p> <p>Data is destroyed in accordance with the Digital Media Disposal Standard.</p>

Cancer Care Ontario – Personal Information Bank

Name: Case-by-Case Review Program (CBCRP)	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	<ul style="list-style-type: none"> • Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5), s.39(1)(a) and s. 49(6) • Cancer Act, R.S.O. 1990, c. C.1, s.5
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient demographic information; and • Patient clinical data
Disclosure	Ministry of Health
Uses	For health system planning; and To determine or verify eligibility for reimbursement
Users	CBCRP program staff
Individuals in Bank	Ontario cancer patients
Retention & Disposal	50 years from the last date of access in accordance with Records series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Evidence Building Program (EBP)	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5), s.39(1)(a) and s. 49(6).
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient demographic information; and • Patient clinical data
Disclosure	N/A
Uses	For health system planning; and To determine or verify eligibility for reimbursement
Users	Provincial Drug Reimbursement Program staff.

Cancer Care Ontario – Personal Information Bank

Individuals in Bank	Ontario cancer patients seeking coverage for Trastuzumab (Herceptin) and Oxaliplatin cancer drugs.
Retention & Disposal	50 years from the last date of access in accordance with Records Series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Brachytherapy	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5), s.39(1)(a) and s. 49(6)
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient demographic information; and • Patient clinical data
Disclosure	N/A
Uses	For health system planning; and To determine or verify eligibility for reimbursement
Users	Radiation Treatment Program Staff
Individuals in Bank	Ontario cancer patients who have received brachytherapy treatment for prostate cancer patients.
Retention & Disposal	50 years from the last date of access in accordance with Records series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Complex Malignant Hematology (CMH) – Fellowship and Nurse Practitioner Mentorship Programs	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Cancer Act, R.S.O. 1990, c. C.1, s.5

Cancer Care Ontario – Personal Information Bank

Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • First name; • Last name; • Employment start date; and • Mentorship start/end date
Disclosure	N/A
Uses	<ul style="list-style-type: none"> • Drive system level quality improvement and fulfill CCO's mandate; and • The CCO Models of Care uses this information to calculate honorarium for Mentorship Host Sites and a stipend to the Regional Cancer Centres to support mentees
Users	CCO New Ambulatory Models of Care, Ministry of Health
Individuals in Bank	<ul style="list-style-type: none"> • CMH Nurse Practitioner Mentor and Mentees; and • Acute Leukemia (AL) and Hematopoietic Cell Transplantation (HCT) fellows
Retention & Disposal	<p>50 years from the last date of access in accordance with Records Series 900.</p> <p>Data is destroyed in accordance with the Digital Media Disposal Standard.</p>

Name: Anti-Thymocyte Globulin (ATG) for Aplastic Anemia	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Cancer Act, R.S.O. 1990, c. C.1, s.5
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Health card number; • Postal code; and • Dosage amounts
Disclosure	N/A
Uses	To conduct reimbursements of ATG drugs for Aplastic Anemia patients and to fulfill CCO's mandate.
Users	CCO Internal Program Teams, Acute Leukemia Service Sites, CMH Advisory Committees and Steering Committees, and CMH Executive Sponsors.
Individuals in Bank	Anti-Thymocyte Globulin (ATG) for Aplastic Anemia Patients

Cancer Care Ontario – Personal Information Bank

Retention & Disposal	50 years from the last date of access in accordance with Records Series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.
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Name: Chimeric Antigen Receptor (CAR) T-Cell Therapy	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	<ul style="list-style-type: none"> • Cancer Act, R.S.O. 1990, c. C.1, s.5 • Memorandum of Understanding and Accountability Agreement between CCO and the Ministry of Health
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient demographic information; • Health Card Number; and • Treatment information;
Disclosure	Ministry of Health and Health Information Custodians
Uses	To conduct reimbursements of CAR T-cell Therapy and to fulfill CCO's mandate.
Users	CCO Internal Program Teams, Ministry of Health
Individuals in Bank	Chimeric Antigen Receptor (CAR) T-Cell Therapy Patients.
Retention & Disposal	50 years from the last date of access in accordance with Records Series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Carfilzomib	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Cancer Act, R.S.O. 1990, c. C.1, s.5
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient ID Number; • Patient Name; • Patient Province; • Date of Birth;

Cancer Care Ontario – Personal Information Bank

	<ul style="list-style-type: none"> • Current Physician Name; and • Dosage Data
Disclosure	N/A
Uses	To enroll patients into the New Drug Funding Program and process reimbursement claims.
Users	New Drug Funding Program
Individuals in Bank	Chemotherapy patients who were receiving the drug Carfilzomib funded by Amgen’s Victory Program.
Retention & Disposal	<p>50 years from the last date of access in accordance with Records Series 900.</p> <p>Data is destroyed in accordance with the Digital Media Disposal Standard.</p>

Name: Quality Management Partnership	
Location	Stored in secure location subject to CCO’s Internal Data Access Request process.
Authority	Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5)
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Physician Name; • CPSO Number; and • Individual performance indicators
Disclosure	Quality indicators are disclosed to the individual physician to whom they relate as part of a quality management report.
Uses	<ul style="list-style-type: none"> • Reporting of quality indicators for mammography and colonoscopy services at the facility, regional and provincial levels; • Reporting of quality indicators at the individual physician level; and • Supporting peer discussions and facilitated feedback discussion to improve healthcare quality
Users	CCO’s Quality Reporting and Improvement Team
Individuals in Bank	<ul style="list-style-type: none"> • All physicians in Ontario who read mammograms; and

Cancer Care Ontario – Personal Information Bank

	<ul style="list-style-type: none"> All physicians in Ontario who perform endoscopies and colonoscopies
Retention & Disposal	<p>50 years from the last date of access in accordance with Records Series 900.</p> <p>Data is destroyed in accordance with the Digital Media Disposal Standard.</p>

Name: Asbestos Workers Registry	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Cancer Act, R.S.O. 1990, c. C.1, s.5
Personal Information Maintained (Data Elements)	<p>Information on workers working within particular types of operations involving asbestos:</p> <ul style="list-style-type: none"> Demographic data; Contact information; Employer information; and Employment information
Disclosure	N/A
Uses	Research Project: <i>Mortality and Cancer Incidence among Workers in the Ontario Asbestos Worker Registry</i>
Users	Researchers within the Occupational Cancer Research Centre (OCRC) at CCO.
Individuals in Bank	Workers working within particular types of operations involving asbestos pursuant to Ontario Regulation 278/05 of the <i>Occupational Health and Safety Act</i> .
Retention & Disposal	Data will be destroyed 7 years after the Research Project completion and no copies of the data will be retained.

Name: Complex Malignant Hematology Fellowship	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.

Cancer Care Ontario – Personal Information Bank

Authority	Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5)
Personal Information Maintained (Data Elements)	Information on the individuals who enroll in the Fellowship program, including: <ul style="list-style-type: none"> • Training start and end dates; • Interruptions during their training; and • Location of their post-fellowship position
Disclosure	N/A
Uses	CCO is providing funding to 3 CMH Fellowship training sites (Juravinski Cancer Centre, The Ottawa Hospital Cancer Centre, Princess Margaret Cancer Centre) as salary support for new Acute Leukemia (AL) and hematopoietic cell transplantation (HCT) fellows. The data that we are asking these training sites to provide will help us track the number of fellows who have completed the program and the location of their practice post-fellowship.
Users	New Ambulatory Models of Care (NAMoC) (CPQI – System Improvement and Integration). Ministry of Health
Individuals in Bank	Individuals enrolled in the Fellowship program
Retention & Disposal	50 years from the last date of access in accordance with Records Series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Death (Mortality) Data	
Location	Stored in secure location subject to CCO’s Internal Data Access Request process.
Authority	Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5)
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Administrative data; and • Demographic data
Disclosure	Statistics Canada (for Canadian Cancer Registry) and NAACCR (de-identified)
Uses	For planning and management purposes and to measure cancer survival.

Cancer Care Ontario – Personal Information Bank

Users	CCO analytics staff
Individuals in Bank	All deaths in Ontario
Retention & Disposal	50 years from the last date of access in accordance with Records Series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Ontario Health Study (Cancer Cohort)	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Cancer Act, R.S.O. 1990, c. C.1, s.5
Personal Information Maintained (Data Elements)	Information on workers working within particular types of operations involving asbestos: <ul style="list-style-type: none"> • Demographic data; • Contact information including address; • Employer information; and • Employment information.
Disclosure	Approved researchers who have an approved Research Ethics Board Application and approval from CCO's Data Disclosure Subcommittee for cancer registry data of Ontario Health Study participants with a diagnosis of cancer.
Uses	For research related purposes.
Users	CCO's Data Analysts
Individuals in Bank	Individuals who have consented to participate in the Ontario Institute of Cancer Research's Ontario Health Study.
Retention & Disposal	Data will be destroyed within 5 days of termination of the data sharing agreement between CCO and the Ontario Institute of Cancer Research.

Name: Employee Personal Information
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Cancer Care Ontario – Personal Information Bank

Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Cancer Act, R.S.O. 1990, c. C.1, s. 8
Personal Information Maintained (Data Elements)	Information on employees includes names; date of birth; home address and contact information; employment, promotion and termination letters; banking information; benefits and beneficiaries; performance assessments.
Disclosure	N/A
Uses	CCO uses the personal information of its employees to deliver human resources services and manage employment relationships.
Users	CCO's Human Resources staff and individual CCO employees.
Individuals in Bank	CCO employees, contractors and consultants.
Retention & Disposal	Individual Employee Files: period of 10 years after end of employment as per Records Series 074.001. Individual Employee Pay Records: Retention period of 6 years as per Records Series 074.002. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: CCO Out-of-Country (OOC) Cancer Applications	
Location	Stored in secure location subject to CCO's Internal Data Access Request process.
Authority	Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5), s.39(1)(a) and s. 49(6).
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient's First and Last Name; • Health Card Number; and • Medical History
Disclosure	Ministry of Health
Uses	<ul style="list-style-type: none"> • For health system planning; and • To determine or verify eligibility for reimbursement

Cancer Care Ontario – Personal Information Bank

Users	CCO OOC program staff
Individuals in Bank	Applicants to Ministry of Health’s Out-of-Country Program related to specific cancer requests
Retention & Disposal	50 years from the last date of access in accordance with Records Series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: CCO Positron Emission Tomography (PET) Scan	
Location	Stored in secure location subject to CCO’s Internal Data Access Request process.
Authority	<ul style="list-style-type: none"> • Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5), s.39(1)(a) and s. 49(6); and • Cancer Act, R.S.O. 1990, c. C.1, s.5
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none"> • Patient demographic information; • Health Card Number; and • Treatment information;
Disclosure	N/A
Uses	<ul style="list-style-type: none"> • For health system planning; and • To determine or verify eligibility for reimbursement
Users	CCO Cancer Imaging and Drug Reimbursement program staff
Individuals in Bank	Ontario patients requiring PET Scans
Retention & Disposal	50 years from the last date of access in accordance with Records Series 900. Data is destroyed in accordance with the Digital Media Disposal Standard.

Name: Out-of-Country Hemodialysis Reimbursement Program	
Location	Stored in secure location subject to CCO’s Internal Data Access Request process.

Cancer Care Ontario – Personal Information Bank

Authority	<ul style="list-style-type: none">• Direct collection from individuals is necessary for the proper administration of a lawfully authorized activity Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F.31, s. 38(2)• Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A , s.45(5), s.39(1)(a) and s. 49(6).
Personal Information Maintained (Data Elements)	<ul style="list-style-type: none">• First Name and Last Name• Health Card Number• Date of Birth• Sex• Mailing address• Residence address• Telephone number• Facility and Treatment Information• Banking information
Disclosure	<ul style="list-style-type: none">• Ministry of Health• Kidney Foundation of Canada
Uses	<ul style="list-style-type: none">• Process claims• For health system planning; and• To determine or verify eligibility for reimbursement
Users	<ul style="list-style-type: none">• ORN Funding Policy and Operations Team• Information Program Team• Finance
Individuals in Bank	Claimants for Out-of-Country Hemodialysis Reimbursement Program
Retention & Disposal	Seven (7) years from the date of collection