Policy and Procedure Manual

Surveillance and Epidemiology Unit

Cancer Care Nova Scotia

2007

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Surveillance and Epidemiology Unit
Cancer Care Nova Scotia
1278 Tower Road, Room 555-C Bethune Building
Halifax, Nova Scotia B3H 2Y9
Phone: (902) 473-5172
Toll free: 1-866-599-2267
Fax: (902) 473-4425
Email: epi.unit@ccns.nshealth.ca
Web: www.cancercare.ns.ca

Staff Directory

Role	Name	Phone Number	Email
Director	Maureen MacIntyre	473-6084	maureen.macintyre@ccns.nshealth.ca
Administrative Assistant	Mary Gillis	473-5172	mary.gillis@ccns.nshealth.ca
Epidemiologist	Ron Dewar Grace Johnston Nathalie St-Jacques Gordon Walsh	473-6057 473-6014 473-3749 473-7258	ron.dewar@ccns.nshealth.ca grace.johnston@ccns.nshealth.ca nathalie.st-jacques@ccns.nshealth.ca
Research and Statistical Associate	Jun (Tony) Gao	473-2248	jun.gao@ccns.nshealth.ca
Registry Team Leader	Karen Starratt	473-6058	karen.starratt@ccns.nshealth.ca
Health Information Management Professional	Tamara Brownlee Joanne Hamm Rhonda Miller	473-6617 473-3478 473-7439	tamara.brownlee@ccns.nshealth.ca joanne.hamm@ccns.nshealth.ca rhonda.miller@ccns.nshealth.ca
Registry Assistant	Rosalee Walker	473-3494	rosalee.walker@ccns.nshealth.ca
Patient Enrollment Clerk	Debbie Hughes	473-7259	debbie.hughes@ccns.nshealth.ca

Mission

To operate a population-based cancer registry for the province of Nova Scotia in accordance with appropriate national and international standards and to promote the utilization of the registry for support of surveillance and research activities across the cancer control spectrum.

Goals

- Maintain a high quality database of cancer information for Nova Scotia.
- Continually monitor and improve the quality of the data.
- Make this data accessible for research, education, planning and public knowledge while maintaining confidentiality.
- Fulfill Nova Scotia's commitment to the Canadian Cancer Registry.
- Increase external awareness and understanding of the Nova Scotia Cancer Registry's data and activities.
- Participate in research studies.

History of the Nova Scotia Cancer Registry

The Nova Scotia Cancer Registry (NSCR) was established in 1964 to collect data, provide information for research purposes, study the epidemiology of cancer, and provide current data to benefit cancer control. Initially, the reporting was under the auspices of the Victoria General Hospital and operated as part of the cancer clinic where radiation treatment was delivered. The registry has data dating back as far as 1953. Legislation governing the reporting of cancer was enacted in 1964 and is contained in Section 101 of the Nova Scotia Health Act.

In 1981 the NSCR became part of a newly formed provincial cancer program under the authority of the Cancer Treatment and Research Foundation of Nova Scotia (CTRFNS), which was a stand alone healthcare organization created by Bill 80, An Act to Incorporate the Cancer Treatment and Research Foundation of Nova Scotia, 1980. The CTRFNS had the following objects:

(a) to establish multidisciplinary referral facilities for the diagnosis and treatment of cancer;
(b) the co-ordination of facilities for the diagnosis and treatment of cancer, including cancer clinics in community hospitals;
(c) the research into problems relating to cancer;
(d) the education of the public in the importance of early diagnosis and treatment of cancer in co-operation with the Nova Scotia Division of the Canadian Cancer Society;
(e) the providing of assistance for undergraduate and postgraduate study relating to cancer;
(f) the training of technical personnel to assist in the examination, diagnosis, treatment and study of cancer;
(g) the providing and awarding of funds for research and training fellowships in consultation with the Nova Scotia Division of the Canadian Cancer Society;

(h) *the provision of a central tumor registry for the analysis and retrieval of data on cancer patients*;

(i) to collaborate with the Canadian Cancer Society in assisting financially with the care of persons undergoing treatment for cancer.

In 1995, the CTRFNS became part of the Queen Elizabeth Health Sciences Centre (QEII HSC) as outlined in the Queen Elizabeth II Health Sciences Centre Act. The QEII HSC was responsible for carrying out the previous objects of the CTRFNS. The cancer registry was operated as part of the QEII Cancer Program.

Cancer Care Nova Scotia (CCNS) was established in 1998 to strengthen the cancer system in Nova Scotia and to function as the body responsible for overall cancer control. CCNS is a program of the Nova Scotia Department of Health. The NSCR was formally moved under the responsibility of CCNS in 2000 and is now part of the Surveillance and Epidemiology Unit. As a program of CCNS, the SEU is fully funded by the Department of Health.

Role as a Population Based Registry

The NSCR is a population based registry that collects and analyzes data on all diagnosed cases of cancer in the province of Nova Scotia. The main responsibility of a population based registry as stated by the *Canadian Council of Cancer Registries*, is to "record and consolidate information regarding all cases diagnosed within a specific geographic area and therefore provide data that can determine rates across regions of the country." Registry operations meet the consensus on cancer registration standards outlined by both the Canadian Cancer Registry (CCR) and the North American Association of Central Cancer Registries (NAACCR). The NSCR works collaboratively with Statistics Canada to ensure that Nova Scotia data is part of the national Canadian Cancer Registry.

Number of Records Processed Annually (New Cases)

	2003	**2004**	**2005**
Invasive	5276	5477	5534
In situ	845	889	902
Uncertain	161	150	124
Benign	63	56	59
Total	6345	6572	6619

Completeness

For the data submitted for 2004, the completeness percentage is 95.1% as assessed through the NAACCR certification process. To learn more about the methods used to make this estimate, refer to Appendix G in NAACCR Standards for Cancer Registries Volume III: Standards for Completeness, Quality, Analysis, and Management of Data.

Canadian Cancer Registry

The SEU submits data on an annual basis to the Canadian Cancer Registry (CCR). The CCR is an administrative survey that collects information on cancer incidence in Canada from each of the provincial and territorial cancer registries (PTCRs). CCR operations are the responsibility of Statistics Canada with oversight provided by the Canadian Council of Cancer Registries (CCCR). All PTCRs including Nova Scotia are represented on this council.

The CCR was previously known as the National Cancer Incidence Reporting System (NCIRS) from 1969 to 1991. The NCIRS was event-oriented meaning that it only captured incidence data without linking information on the same patient. The CCR is a stand alone data system distinct from the NCIRS and was created as a person-oriented data set that allows for the identification of patients with multiple disease records. CCR continues to evolve with updates to the database system as well as changes in data collection standards. For more information about the CCR please refer to the Statistics Canada web site.

North American Association of Central Cancer Registries

As stated on the association's web site (www.naaccr.org), "The North American Association of Central Cancer Registries, Inc. is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America."

Nova Scotia Certification History
Nova Scotia has been a member of the North American Association of Central Cancer Registries (NAACCR) since 1995. NAACCR offers an annual certification review of data quality for the registry data set based on established standards. This review serves as an external validation of the work conducted by the registry. It is done retrospectively and offers a pass (either at the gold or silver level) or a fail grade. The NAACCR certification status of the NSCR data from 1997 to present is displayed below.

Data Year	Submitted By	Certification Status
1997	Statistics Canada	None
1998	Statistics Canada	Gold
1999	Statistics Canada	Silver
2000	Statistics Canada	Silver
2001	Statistics Canada	Silver
2002	SEU	Silver
2003	SEU	None
2004	SEU	Gold

Report Requirements

District Cancer Reports
The SEU provides cancer reports to each of the nine District Health Authorities (DHAs) on an annual basis. The district cancer reports vary from year to year but always have a section of descriptive cancer statistics. The nine DHAs in Nova Scotia include the following:
- Annapolis Valley Health
- Cape Breton Health Authority
- Capital Health
- Colchester East Hants Health Authority
- Cumberland Health Authority
- Guysborough Antigonish Strait Health Authority
- Pictou County Health Authority
- South Shore Health
- SouthWest Health

Monographs
Every five years, the SEU publishes a monograph offering a detailed statistical analysis of the cancer profile in Nova Scotia. Recent monographs published by the SEU include:
- Understanding Cancer in Nova Scotia, 2000-2004 (Published December, 2006)
- Cancer Statistics in Nova Scotia: A Focus on 1995-1999 (Published in 2002)
- A Portrait of Gynaecological Cancer and Cervical Screening in Nova Scotia for the Period Ending 2001 (Published in 2003)

Canadian Cancer Statistics
The SEU also contributes to *Canadian Cancer Statistics,* an annual publication produced by the Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/ Territorial Cancer Registries and the Public Health Agency of Canada. *Canadian Cancer Statistics* is available on the Canadian Cancer Society's web site (http://www.cancer.ca).

Specific Responsibilities

The SEU participates in special studies when opportunities arise. In addition to the administrative and physical relationship with Capital District Health Authority and the sharing of the Oncology Patient Information System (OPIS), the SEU provides support for clinical data queries from cancer program staff.

Data Submission

Data is submitted to CCR by March 1 (14 months after calendar year end) and data is submitted to NAACCR by December 1 (23 months after calendar year end). CCR data is used by Statistics Canada for national and interprovincial cancer statistics. NAACCR data is used to produce the *Cancer in North America* publication. Every 5 years, data is submitted to the International Association of Cancer Registries (IACR) for the production of *Cancer in Five Continents.*

SEU Performance Measures

Number of Requests for Information
Since the SEU is responsible for collecting and analyzing data for all diagnoses cases of cancer for Nova Scotia, a number of inquiries and requests for data are received on an ad hoc basis. The SEU tracks the number of requests for information and the types of information required by the requestor. Requestors range from clinicians to members of the general public. A request for information database was created in 2006 to log and track such requests.

CCR and NAACCR Data Submission
As mentioned above, data is submitted to both the CCR and NAACCR on an annual basis. The SEU keeps track of dates the registry submitted data to ensure all data submission deadlines are achieved.

Completion of District Cancer Reports
As previously indicated, the SEU provides an annual report for each DHA with both district specific and provincial level data. The data contained in these reports assists each DHA with their cancer control efforts. The SEU tracks the progress of the district cancer reports to ensure they are completed on time. The SEU is in touch with representatives from each DHA to ensure the annual reports meet the information needs of the districts.

Completion of Quarterly Vital Statistics Linkage
The SEU completes a vital statistics linkage for the NSCR every quarter to keep death information on OPIS as up to date as possible. The currency of death information is monitored by registry staff.

Completion of Cancer Staging
The SEU plays a leadership role with respect to the collection of cancer staging variables for NS cancer cases. The SEU as well as staff at both the CBCC and NSCC enter staging variables on OPIS. Current sites include breast, colorectal, lung, prostate, lymphoma and head and neck. Lists of cases not staged are obtained from OPIS. The Registry Team leader tracks completeness of staging data by year for each site.

Timeliness of Case Ascertainment
The SEU strives to have high quality, current data in the NSCR. Cases are entered on an ongoing basis to keep data on OPIS as timely as possible. The SEU tracks the currency of case ascertainment to monitor progress.

SEU Team

- *Administrative Assistant*
  - Provides administrative support to SEU staff.

- *Analytical Staff* (Epidemiologists and Statistical Research Associate)
  - Provide analytical support for the production of key surveillance indicators (e.g. incidence and prevalence projections).
  - Provide input and advice into protocols for epidemiological and health services research involving registry data.
  - Create and maintain data sets for analysis.
  - May carry out analysis for specific projects.

- *Director*
  - Directs key surveillance components of the cancer control program in NS and provides leadership for the SEU.

- *Health Information Management (HIM) Professionals*
  - Abstract and code cancer information including disease classification, staging and prognostic variables obtained from source documents (e.g. pathology reports) and patient charts.
  - Carry out special studies as assigned.

- *Patient Enrollment Clerk*
  - Responsible for editing, updating and entry of registration data (e.g. patient demographics) in the NSCR database.
  - Processes all paperwork received for case registration and files reports in designated areas once case registration has been completed by a Health Information Professional.

- *Registry Assistant*
  - Responsible for coordinating and managing registry-based research initiatives
  - Prepares ethics submissions for registry projects and assists staff with research proposals, publications and presentations
  - Assists with data management activities in the registry

- *Registry Team Leader*
  - Responsible for data management operations at the SEU and advises the registry team on issues related to data collection, abstracting, processing and reporting.
  - Monitors data quality and adherence to defined standards (e.g. CCR and NAACCR).
  - Oversees data submission to CCR and serves as primary contact for data requests.

Job Descriptions

More detailed job descriptions are available on the *CCNS* shared drive for all SEU positions.

CCNS Organizational Chart

Cancer Care Nova Scotia

Commissioner, Cancer Care Nova Scotia
Vacant

Chief Operating Officer
Ms. Theresa Marie Underhill

Executive Assistant
Vacant

Administrative Assistant
Belva Mills

Systemic Therapy Manager
Larry Broadfield

- **Admin Assistant**
Kris Kennedy (0.5)
- **Pharmacist**
Marlene Sellon

Surgical Oncology Coordinator
Sandra Cook (0.5)

- **Admin Assistant**
Peggy Jones (0.3)

Quality Coordinator & Cancer Site Team (CST) Coordinator
Jill Petrella

- **Admin Assistant**
Kris Kennedy (0.5)
- **Admin Assistant for CST**
Heather MacKenzie

Prevention Coordinator
Judy Purcell

- **Admin Assistant**
Monika Drozdowska (0.5)

Surveillance & Epidemiology Director
Maureen MacIntyre

- **Admin Assistant**
Mary Gillis
- **Epidemiologists:**
Ron Dewar
Grace Johnston
Nathalie St-Jacques
Gordon Walsh
- **Registry Assistant**
Rosalee Walker
- **Health Record Analyst**
Karen Starratt
- **Health Record Technicians**
Joanne Hamm
Tamara Brownlee
Rhonda Miller
- **Data Processing Clerk**
Debbie Hughes (0.5)
- **Stats Research Assoc**
Jun Gao

Colorectal Cancer Screening Program Manager
Vacant

- **Admin Assistant**
Vacant
- **Data Management Supervisor**
Vacant
- **Data Management**
Vacant (4 FTE)

Cancer Outcomes Research Program Director
Dr. Eva Grunfeld (0.2)

- **Admin Assistant**
Caroline Lyons
- **CCNS Project Officer**
Pauline Hart
- ****Project Coordinator Analyst**
Lynn Lethbridge
- ****Project Coordinator**
Amy Lewis
- ****Research Associate**
Robin Gillingham

Patient Family Network Coordinator
Emmie Luther-Hiltz

- **Admin Assistant**
Peggy Jones (0.3)

Cervical Cancer Prevention Program Manager
Margery MacIsaac

- **Admin Assistant**
Tammy Plante
- **Data Management Supervisor**
Janice Rhodes
- **Data Management**
Kathy Miller
Tanya Richard
Vacant
- **Data Processing Clerk**
Debbie Hughes (0.5)

Palliative & Supportive Care Coordinator
Judy Simpson

- **Admin Assistant**
Monika Drozdowska (0.5)

Communications Coordinator
Christine Smith

- **Communications Assistant**
Kyle Turner

Director, Admin & Special Projects
Chris Collier

- **Admin Assistant**
Lisa Daye

Education & Patient Navigation (PN) Provincial Manager
Anne Murray

- **Project Manager PN**
Sandra Cook (0.5)
- **Community Liaison PN**
Donna Smith
- **Admin Assistant PN**
Peggy Jones (0.3)
- **Project Officer Education**
Margaret Jorgenson
- **Oncology Curriculum Coordinators**
Lisa Cicchelli (0.5)
Michelle Rogez (0.5)

Project Manager PICE
Andrea Hilchie-Pye

Admin Assistant PICE
Somer Bergman

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Staff and Line Relationship

All SEU staff report to the SEU Director. The SEU Director reports to the Chief Operating Officer (COO) of *CCNS*.

Time and Attendance

The Administrative Assistant is responsible for submitting and approving all time information through the electronic CDHA human resources system. All staff must get authorization for time off (e.g. vacation) in writing and must provide notification of unplanned time off (e.g. sick time) by phone or email.

Staff Performance Evaluations

All employees receive performance appraisals during their probationary period. Following the probationary period, all employees receive a performance appraisal every 1-2 years. Performance Management is outlined in CDHA Policy # 40-040. Information on Performance Management is available on the Intranet or the Human Resource Department.

Job Vacancies

When hiring new staff, the SEU follows the Capital District Health Authority (CDHA) Recruitment and Selection Policy and Procedure (CH 40-020) available on the CDHA Intranet. The hiring process for SEU positions is coordinated by the *CCNS* Director of Administration and CDHA Human Resources.

Continuing Education and Career Development

SEU staff routinely participate in continuing education and career development activities. Current examples as of 2007 include:
- Canadian Cancer Registry Professionals Workshop – sponsored by Statistics Canada and the Public Health Agency of Canada (PHAC)
- Canadian Council of Cancer Registries (CCCR) – meet annually face-to-face and communicate throughout the year via teleconferencing
- NAACCR
  - At least one member of SEU attends annual conference
  - SEU staff receive survival analysis training and registry staff attend Webinars
- Canadian Society for Epidemiology and Biostatistics – attend conference every 1-2 years
- CCCR/PHAC – national staging training
- Special workshops (e.g. Geographic Information Systems and record linkage)
- Local SAS user group in Halifax
- Oncology rounds
- Graduate level courses – SEU staff may audit graduate courses offered at Dalhousie
- National Cancer Registrar's Association (USA) – occasionally attend annual conference

OPIS Training

All OPIS training is provided in-house through Capital Health Information Technology Services. When any major updates are made to the fields on OPIS, the Registry Team Leader provides training to the HIM Professionals working for the registry and those who work for the cancer centres in Halifax and Sydney.

Travel

All travel requests must be submitted to the Director for approval. The Director must have their travel approved by the COO. All travel requests must be placed in writing. (See Travel Request Form from Financial Services available on the CDHA Intranet).

Budget Oversight

The SEU Director is responsible for the program's operational budget. Items not included in the operational budget are the responsibility of the COO of *CCNS*. Funding opportunities through external awards (e.g. Health Canada) may require signatures/approval by the Nova Scotia Department of Health.

The SEU Director is responsible for submitting variance analysis reports on a quarterly basis to the *CCNS* Director of Administration for the first three quarters of the fiscal year. During the last quarter of the fiscal year, monthly budget reports are required. The SEU Director receives monthly electronic budget statements through the Capital Health finance system. Budget preparation for the next fiscal year occurs in November/December.

Signature Authority

Signature authority resides with the SEU Director for items such as SEU staff travel approval and the costs within the approved operating budget. Expenditures or contracts outside of the approved budget must be reviewed with the COO or designate.

Grant / Contract Responsibility

All grants and contracts need to go through the SEU Director. The responsibility for a grant or contract is dependent on the project and issuing authority. The Registry Assistant is responsible for monitoring all studies and handles all ethics submissions. The Registry Assistant may need to be involved with invoicing for grants when required.

OFFICE MANAGEMENT

Administrative Files (Hard Copy)

Personnel Files
Some personnel information is kept in files stored in the registry director's office. Full personnel files are stored in the CDHA human resources department.

Budget Files
The Administrative Assistant is responsible for maintaining budget files. Budget files for the current and previous fiscal years are kept in the Administrative Assistant's office. The older budget files are stored off-site (Iron Mountain).

All Other Administrative and Research Files
Some files are retained on-site and others are stored off-site. Current files (within approximately the last 2 years) are stored in a cabinet in the Administrative Assistant's office. Current research/project files (within approximately the last 7 years) are stored in the Registry Team Leader's office and older files are stored in room 565. All inactive files are stored in an off-site location (Iron Mountain).

Registry Cancer Case Source Information Files (Hard Copy)

Recent source documents are stored on-site at the registry and older documents are kept in another location off-site (Iron Mountain). Please refer to the Filing Procedure for Paper Reports for more information.

Correspondence

Incoming
All media calls are handled by the *CCNS* Communications Coordinator. General registry inquiries by phone are received by the SEU Administrative Assistant and forwarded to the appropriate staff person. Most requests/inquiries are handled by the SEU Director. Requests for published materials are the responsibility of the SEU Administrative Assistant. Reporting facility questions are directed to the Registry Team Leader. Mail is received by the Administrative Assistant on a daily basis and distributed to SEU staff members. The SEU also has a general email address, epi.unit@ccns.nshealth.ca, and messages to this address are received by the Administrative Assistant.

Each staff member has their own phone lines and should answer the phone beginning with "Surveillance and Epidemiology Unit" or "Cancer Registry." If a staff member is unavailable they should update their voice mail message or have their calls forwarded to another line. Vacation messages should also set up on email by staff members to inform senders, through an automatic reply, that they will be absent for a certain period of time and/or who to contact until they return.

Outgoing
The Administrative Assistant is responsible for maintaining the SEU mailing list and handles all outgoing correspondence. *CCNS* has a contact database for tracking contact information and to aid with the creation of mailing lists.

Registry Resources

Scheduling Conference Rooms
CCNS has its own audiovisual equipment (e.g. TV, laptops, projectors) for meetings and presentations. The *CCNS* meeting room is 548 and can be booked by the Administrative Assistant. All other rooms need to be booked through Central Room Booking. Please refer to CDHA Central Room Booking Policy and Procedure (CH 60-050). Booking instructions are located at http://chdintra/departmentservices/audiovisual/avCrbRooms/avCrbRoomListing.html

Videoconferencing
Cancer Care Nova Scotia (CCNS), in partnership with the Capital Health Department of Medicine (DoM), purchased videoconferencing equipment in support of continuing educational activities and regular provincial meetings. *CCNS* and DoM have also partnered with the Nova Scotia Telehealth Network in this endeavour. Please refer to the CCNS Videoconferencing Policy available on the *CCNS* shared drive at S:\CCNS New\Quality\Policy Manual Development\draft policies\Videoconferencing Equipment.

Purchasing Supplies and Equipment

Office supplies are purchased by the Administrative Assistant. There is a standing purchase order with an office supply company through CDHA which allows the Administrative Assistant to order directly from this company. A purchase order may need to be requested to buy items for which the standing purchase order does not apply (e.g. any computer equipment).

INFORMATION TECHNOLOGY

Hardware

Computer hardware and operating system software
Each employee is equipped with his or her own PC, using Windows XP Professional. All desktop hardware used by the SEU is leased from CDHA Information Technology Services (ITS) and each PC is replaced according to the CDHA evergreen program cycle. The SEU is responsible for purchasing peripheral items such as computer monitors and printers.

All desktop PCs have password-protection and are physically secured with a computer lock kit. Offices are locked when staff members are not present. Users are asked to log-off their computer when leaving their workstation for an extended period of time. Please refer to policy number CH 50-020 for information regarding Computer End-User Acceptable Use.

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Internet and Email
The SEU Internet service is provided through ITS. Acceptable Internet Access/Use is defined in CDHA Policy Number CH 50-005. Each staff member is also provided with an electronic mail account through ITS. Refer to policy number CH 50-045.

Software

Data Management Program
The data management program used for the NSCR is the Oncology Patient Information System (OPIS). It is a custom designed and developed, relational database. In addition to its registry based functions, it also serves as the patient information system for the Nova Scotia Cancer Centre (NSCC) located in Halifax as part of the CDHA and the Cape Breton Cancer Center (CBCC) in Sydney, which is managed by the Cape Breton District Health Authority (CBDHA).

OPIS has the following modules:
- *Patient Registration* – Demographics including age, gender and address are collected.
- *Disease Registration* – Information relating to the cancer site and morphology, date of diagnosis and diagnosis methods are entered into OPIS. Disease staging information is also captured.
- *Scheduling* – Visits to the NSCC and CBCC for consultations and treatment are scheduled through OPIS.
- *Encounters* – Outpatient clinic and treatment visits are confirmed on OPIS for diagnosis, physician and service workload statistics.
- *Chart tracking* – NSCC charts are tracked using this module on OPIS.
- *Reports* – Workload reports for physicians and other staff can be generated on OPIS.
- *Special Studies* – Some studies are done where information is captured using OPIS.

For more information about OPIS, including system specifications, please refer to the Personal Information Data Holding Description for OPIS on the CCNS shared drive.

Data Analysis Software
1. Statistical analysis software:
    - SAS
    - R
    - Joinpoint
    - SEER*Stat
    - SEER*Prep
    - Microsoft Access
    - Microsoft Excel
2. Geographic information system (GIS) program:
    The SEU uses the ESRI ArcGIS as its GIS software package. GIS software provides epidemiologists with a way to conduct geographic analyses of cancer incidence, mortality, and treatment.

Record Linkage Program
The SEU currently uses LinkageWiz for record linkage. This program uses probabilistic matching routines.

Data Edits
The SEU uses custom, in-house edits to meet the requirements of CCR and NAACCR.

Office Management
All staff are provided with the Microsoft Office Suite which includes Word, Excel and PowerPoint. Other Microsoft software programs are purchased when required. SigmaPlot a graphics program by Systat Software Inc. is used to create professional graphs for reports, publications and posters.

Technical Support

All technical support is provided by ITS. When users experience problems or need assistance, they can contact the ITS Help Desk at 3399 or HELPDESK@cdha.nshealth.ca. Questions regarding the OPIS database should be directed to one of the OPIS database coordinators.

Data Security

Each staff member is only provided with access to data systems and files that they need to carry out their assigned role. Data systems including OPIS, STAR, HPF and Web1000, are all password protected. Different levels of access are assigned to different user groups. The network used by the SEU is protected by the CDHA Internet firewall. When data is submitted to Statistics Canada, Entrust software is used to encrypt the data.

Data Items

All data items collected by the SEU, NSCC and CBCC and their definitions can be found in the OPIS Data Dictionary available on the NSCC shared drive.

Reporting Sources

For reporting sources, please refer to the Case Ascertainment Policy and Procedure.

Reportable List

The following list outlines all diagnoses and types of cancer that are reported by the NSCR. It is provided to pathology laboratories and health record departments located around the province. The reportable tumors are typically those listed in the *International Classification of Diseases for Oncology, Third Edition* (ICD-O-3) which have a behaviour defined as in situ (behaviour code = /2) or invasive (behaviour code =/3).

Sites	ICD-9 Codes	ICD-10 Codes
Malignant neoplasms of lip, oral cavity and pharynx	140-149	C00-C14
Malignant neoplasms of digestive organs	150-157	C15-C26
Malignant neoplasms of respiratory and intrathoracic organs	160-165	C30-C39
Malignant neoplasms of bone and articular cartilage	170	C40-C41
Melanoma and other malignant neoplasms of skin	172-173	C43-C44
Malignant neoplams of mesothelial and soft tissue	158, 171	C45-C49
Malignant neoplasm of breast	174-175	C50
Malignant neoplasms of female genital organs	179-184	C51-C58
Malignant neoplasms of male genital organs	185-187	C60-C63
Malignant neoplasms of urinary tract	188-189	C64-C68
Malignant neoplasms of eye, brain and other parts of central nervous system	190-192	C69-C72
Malignant neoplasms of thyroid and other endocrine glands	193-194	C73-C75
Malignant neoplasms of ill-defined, secondary and unspecified sites	195-199	C76-C80
Malignant neoplasms of lymphoid, haematopoietic and related tissue	200-208	C81-C96
Insitu neoplasms Includes intraepithelieal neoplasia, grade III	230-234	D00-D09
Benign neoplasm of meninges, brain and other parts of central nervous system	225	D32-D33
Neoplasms of uncertain behaviour	235-239	D37-D48

Terms changing from benign to uncertain/borderline that are now reportable
- Transitional cell papilloma, NOS
- Glucagonoma, NOS
- Thymoma, NOS
- Sertoli cell tumor, NOS
- Pick tubular adenoma
- Sertoli cell adenoma
- Tubular androblastoma, NOS
- Testicular adenoma
- Neurocytoma
- Refractory Anemias

Last updated: January 1, 2001

Ambiguous Terms List

Consider as diagnostic of cancer
- apparent(ly)
- appears to
- comparable with
- compatible with
- consistent with
- favor(s)
- malignant appearing
- most likely
- presumed
- probable
- suspect(ed)
- suspicious (for)
- typical of

Exception: If cytology is reported as "suspicious," do not interpret this as a diagnosis of cancer. Abstract the case only if a positive biopsy or a physician's clinical impression of cancer supports the cytology findings.

NOT considered diagnostic of cancer*
Do not include patients who have a diagnosis consisting only of these terms.

- cannot be ruled out
- equivocal
- possible
- potentially malignant
- questionable
- rule out
- suggests
- worrisome

*without additional information

Required Data Set

Reporting hospitals submitting registry forms to the SEU are asked to provide the data items listed below.

Demographic information
- Full name
- Gender
- Date of birth
- Address
- Previous surnames
- Nova Scotia health card number

Diagnosis
- Diagnosis method
- Date of diagnosis
- Exact primary site
- Histology (behaviour)
- Extent of disease
- Previous malignancies

Treatment information
- Type of treatment (radiotherapy, chemotherapy, etc.)
- Date of treatment

Physician/Hospital information
- Physician name
- Family and/or referring physician
- Hospital name
- Patient unit number

Vital Status
- Alive or deceased
- Date of death
- Cause of death

Minimal Requirements for Registering a Case on OPIS

Demographic information
- Surname
- First Name
- Gender

Disease information
- Disease type (e.g. registry, admitted) - defaults to pending
- Diagnosis method
- Registration date
- Initial and definitive diagnosis date – only required to enter year
- Site
- Extent
- Histology

Reporting Facilities

Health record departments from the following hospitals report cases of cancer to the NSCR. Hospitals with an asterisk have laboratory facilities that send pathology reports to the registry. Cytology reports from the QEII lab are sent directly to the registry printer. The physician office code is used when a biopsy is conducted in a physician's office outside a hospital.

In the early 1990's there were a number of hospital closures and mergers in Nova Scotia. At this time, new hospital codes were created on OPIS. All hospital codes were retained for historical purposes and to allow old cases to be registered if necessary.

Hospitals with an *active* status are those which are still currently being used. An *inactive* status means that the hospital has either closed or merged with another facility.

Code	Hospital Name	Location	Status
10	PHYSICIAN OFFICE	NOVA SCOTIA	Active
11*	ABERDEEN HOSPITAL	NEW GLASGOW	Active
12	ALL SAINTS HOSPITAL	SPRINGHILL	Active
13	ANNAPOLIS COMMUNITY HLTH CENTRE	ANNAPOLIS ROYAL	Active
14	HEALTH SVR ASSOCIATION OF SOUTH SHORE	BRIDGEWATER	Active
15	BUCHANAN MEMORIAL HOSPITAL	NEILS HARBOUR	Active
16	CAMP HILL HOSPITAL (OLD)	HALIFAX	Inactive
17	ISAAC WALTON KILLAM HOSP. (OLD)	HALIFAX	Inactive
18*	COLCHESTER REGIONAL HOSPITAL	TRURO	Active
19*	SOUTH SHORE REGIONAL HOSPITAL	BRIDGEWATER	Active
20	DIGBY GENERAL HOSPITAL	DIGBY	Active
21	EASTERN KINGS MEMORIAL HOSPITAL	WOLFVILLE	Active
22	EASTERN MEMORIAL HOSPITAL	CANSO	Active
23	EASTERN SHORE MEMORIAL HOSPITAL	SHEET HARBOUR	Active
24	FISHERMEN'S MEMORIAL HOSPITAL	LUNENBURG	Active
25	GLACE BAY GENERAL HOSPITAL (OLD)	GLACE BAY	Inactive
26	GRACE MATERNITY HOSPITAL (OLD)	HALIFAX	Inactive
27	GUYSBOROUGH MEMORIAL HOSPITAL	GUYSBOROUGH	Active
28	HALIFAX INFIRMARY HOSPITAL (OLD)	HALIFAX	Inactive
29	HARBOUR VIEW HOSPITAL (OLD)	SYDNEY MINES	Inactive
30*	CUMBERLAND REG.HOSP.(OLD HIGHLAND VIEW)	AMHERST	Active
32	LILLIAN FRASER MEMORIAL HOSPITAL	TATAMAGOUCHE	Active
33	MUSQUODOBOIT VALLEY MEMORIAL HOSPITAL	MIDDLE MUSQUODOBOIT	Active
34	INVERNESS CONSOLIDATED MEMORIAL HOSPITAL	INVERNESS	Active
35	NORTH CUMBERLAND MEMORIAL HLTH CARE CTR	PUGWASH	Active
36	NOVA SCOTIA REHABILITATION CENTER (OLD)	HALIFAX	Inactive
37	HANTS COMMUNITY HOSPITAL	WINDSOR	Active
38	QUEENS GENERAL HOSPITAL	LIVERPOOL	Active
39	ROSEWAY HOSPITAL	SHELBURNE	Active
40	ST. ANNE COMMUNITY CENTER (OLD)	ARICHAT	Inactive

Code	Hospital Name	Location	Status
41	NORTHSIDE HARBOURVIEW HOSPITAL	NORTH SYDNEY	Active
42	GLACE BAY COMMUNITY HOSPITAL (OLD)	GLACE BAY	Inactive
43*	ST. MARTHA'S REGIONAL HOSPITAL	ANTIGONISH	Active
45	ST. MARY'S MEMORIAL HOSPITAL	SHERBROOKE	Active
46	SYDNEY COMMUNITY HEALTH CENTRE (OLD)	SYDNEY	Inactive
47	SACRED HEART HOSPITAL	CHETICAMP	Active
48	SOLDIERS MEMORIAL HOSPITAL	MIDDLETON	Active
49	SOUTH CUMBERLAND COMMUNITY CARE CENTRE	PARRSBORO	Active
50	SUTHERLAND-HARRIS MEMORIAL HOSPITAL	PICTOU	Active
51	SYDNEY CITY HOSPITAL (OLD)	SYDNEY	Inactive
52	TWIN OAKS WAR MEMORIAL HOSPITAL	MUSQUODOBOIT HARBOUR	Active
53	VICTORIA COUNTY MEMORIAL HOSPITAL	BADDECK	Inactive
54	VICTORIA GENERAL HOSPITAL (OLD)	HALIFAX	Inactive
55	WESTERN KINGS MEMORIAL HEALTH CENTRE (OLD)	BERWICK	Inactive
56*	YARMOUTH REGIONAL HOSPITAL	YARMOUTH	Active
57	HALIFAX CIVIC HOSPITAL (OLD)	HALIFAX	Inactive
58	BAYVIEW MEMORIAL HOSPITAL	ADVOCATE HARBOUR	Active
59	CANADIAN FORCES HOSPITAL	HALIFAX	Active
61	COBEQUID COMMUNITY HEALTH CENTRE	SACKVILLE	Active
63	NEW WATERFORD CONSOLIDATED HOSPITAL	NEW WATERFORD	Active
64	POINT PLEASANT LODGE	HALIFAX	Active
65*	DARTMOUTH GENERAL HOSP & COMMUN. HEALTH	DARTMOUTH	Active
67*	VALLEY REGIONAL HOSPITAL	KENTVILLE	Active
68	STRAIT-RICHMOND HOSPITAL	RICHMOND CO	Active
69	NOVA SCOTIA HEARING & SPEECH	HALIFAX	Active
72	CAPE BRETON HOSP (OLD HOSPITAL)	SYDNEY RIVER	Inactive
73*	CAPE BRETON DISTRICT HEALTH AUTHORITY	SYDNEY	Active
75	GLACE BAY HEALTH CARE COMPLEX	GLACE BAY	Active
77	NOVA SCOTIA HOSPITAL	DARTMOUTH	Active
78	NOVA SCOTIA CANCER CENTRE	HALIFAX	Active
79	COBEQUID HEALTH CENTER (OLD/DUPLICATE)	SACKVILLE	Inactive
81	ATLANTIC CHILD GUIDANCE	HALIFAX	Active
85*	QEII-HSC(QEII HEALTH SCIENCE CENTRE)	HALIFAX	Active
86	IWK HEALTH CENTRE	HALIFAX	Active
87	VALLEY REGIONAL HOSPITAL (OLD)	KENTVILLE	Inactive

* Facility with a laboratory that sends pathology and/or cytology reports to the registry.

Data Received From Other Canadian Registries

The following codes are used when information is supplied through reciprocal reporting by the twelve other provincial and territorial registries across Canada. The New Brunswick Cancer Registry often sends pathology reports for NS residents to the NSCR from the Moncton Hospital, Georges-L. Dumont Hospital and Saint John Regional Hospital and the codes for these hospitals would be entered on OPIS.

Code	Registry Name
800	PRINCE EDWARD ISLAND CANCER REGISTRY
801	NEW BRUNSWICK CANCER REGISTRY
802	NEWFOUNDLAND CANCER REGISTRY
803	ONTARIO CANCER REGISTRY
804	QUEBEC CANCER REGISTRY
805	MANITOBA CANCER REGISTRY
806	SASKATCHEWAN CANCER REGISTRY
807	ALBERTA CANCER REGISTRY
808	BRITISH COLUMBIA CANCER REGISTRY
809	YUKON CANCER REGISTRY
810	NORTH WEST TERRITORY CANCER REGISTRY
811	NUNAVUT CANCER REGISTRY

Registry Data Collection and Coding Manuals

International Classification of Diseases for Oncology
Site and histology on the disease registration (DR) screen are currently coded using the *International Classification of Diseases for Oncology, Third Edition* (ICD-O-3). The following table shows the revisions of ICD-O that have been used since the NSCR was created in 1964. The revision used is dependent on the year of diagnosis. Please refer to the site and histology sections of the data dictionary.

Year of Diagnosis	ICD-O Manual
1964 – 1978	ICD-8
1979 – 1991	ICD-O Revision 0
1992 – 2000	ICD-O Revision 2
2001 – present	ICD-O Revision 3

SEER Summary Stage Manual 2000
This manual provides the codes and coding instructions for the summary stage field for cases diagnosed January 1, 2004 and forward. This field is called the extent field on OPIS on the DR screen. Summary staging is a way to code how far a cancer has spread from its point of origin. The manual is divided into chapters based on body system and provides anatomical drawings for staging. The manual can be downloaded at http://seer.cancer.gov/tools/ssm/

American Joint Committee on Cancer (AJCC) Cancer Staging Manual (6th edition)

This manual is used by oncologists, pathologists, surgeons, cancer registrars, and medical professionals as a reference tool for cancer staging. The manual is organized by disease site and broken into 48 chapters. It describes the TNM cancer staging system which stands for tumor size or extent (T), spread to regional lymph nodes (N) and metastases (M).

Collaborative Staging Manual and Coding Instructions

As of January 1, 2004, the NSCR began to capture staging information using the Collaborative Staging System. The Collaborative Staging System combines the American Joint Committee on Cancer (AJCC) Tumour, Nodes, Metastases (TNM) staging system and the SEER Summary Staging system. The stage indicates how far the cancer has spread and can be determined by the extent of disease, depth of tumour invasion, as well as the presence lymph node involvement or metastases. HIM professionals capture staging by reviewing the hospital chart and/or the NSCC or CBCC chart. Sites currently being staged are shown in the table below. The Collaborative Staging Manual can be downloaded from http://www.cancerstaging.org/cstage/manuals.html

Site	Diagnosis Years
Breast	2003 - present
Colon	2001 - present
Head and neck	2005 - present
Lung	2004 - present
Lymphoma	2003 - present
Prostate	2004 - present

2007 Multiple Primary and Histology (MP/H) Coding Rules Manual

This manual contains site-specific rules for multiple primaries and histology coding. These rules came into effect on January 1, 2007. The multiple primary rules provide a standardized method that can be used by cancer registrars to determine the number of primaries. The histology coding rules contain detailed histology coding instructions. The MP/H rules can be downloaded from http://seer.cancer.gov/tools/mphrules/download.html

Residency Guidelines for the Provincial/Territorial Cancer Registries in Canada

These guidelines were provided by the Canadian Cancer Registry (CCR) to help cancer registrars across Canada determine residency at time of diagnosis. The residence at diagnosis is considered to be the usual residence as stated by the patient or, as stated in the Census definition, "the dwelling in Canada where a person lives most of the time." The CCR residency guidelines assist with capturing the address information for those "categories of persons whose residence is not immediately apparent." See Appendix A for this document.

Nova Scotia Health Act, **CHAPTER 195 of the Revised Statutes, 1989: Section 101, Part VII**
Legislation governing the collection of data is found in this act and reads as follows:

Report

101 (1) Every medical practitioner who attends or treats a person who has cancer or who makes a diagnosis of cancer, the superintendent of every hospital or institution in which patients are being diagnosed or treated and any other person or agency required by the Minister in writing shall, within ten days after a diagnosis of cancer in any form has been established, report the case on a form prescribed by the Minister to the Executive Director of the Cancer Treatment and Research Foundation of Nova Scotia or such other person as may be designated by the Minister.

(2) Every report made under this Part is confidential and no person engaged in the administration of this Part shall disclose any such report or any part of its contents to any person except in the performance of his duties. *R.S., c. 195, s. 101.*

Designation – Health Act, Section 101
In 1999, after the creation of *Cancer Care Nova Scotia,* the following authorization was established for reporting purposes:

Pursuant to Section 101 of the *Health Act,* I, the Honourable James A. Smith, Minister of Health, hereby designate Dr. Andrew Padmos, Commissioner, *Cancer Care Nova Scotia*, as a person to whom a report on a diagnosis of cancer shall be made for the Province of Nova Scotia: Dated June 16, 1999.

Freedom of Information and Protection of Privacy (FOIPOP) Act (1993)
The *FOIPOP Act* establishes fundamental rules respecting protection of privacy and the basic framework for disclosure of personal information held by the Nova Scotia government.

Authorization Health Services and Insurance Act (2000)
An authorization is in place under the Nova Scotia Health Services and Insurance Act – Section 34 (c) to permit the SEU access to Health Card Information data held by the Insured Programs Management and Clinical Rationalization Branch of the Department of Health. This is dated November 4, 1996.

Hospitals Act – Release to Cancer Registries (1984)
This notification provides permission to all NS facilities under the Hospital's Act to release information to any provincial/territorial cancer registry regarding a patient from their jurisdiction.

DATA COLLECTION / SHARING AGREEMENTS

1. A signed agreement exists between the Government of Nova Scotia and Statistics Canada to support the flow of cancer registry data between the Canadian Cancer Registry (CCR) and the NSCR now operated by *CCNS*. The agreement also permits the flow of cancer registry information between provincial and territorial registries within Canada.
2. The SEU also routinely receives mortality data from Nova Scotia Vital Statistics under an agreement established in 1994. This data is received electronically. In addition, the SEU has an agreement signed in 2002 that permits the exchange and/or submission of mortality data with Quebec.

PRIVACY

The SEU follows the *CCNS* privacy policy which can be accessed from the *CCNS* shared drive at S:\CCNS New\Quality\Privacy\final documents\CCNS privacy statement. New staff members are required to sign a privacy pledge which can found at S:\CCNS New\Quality\Privacy\working documents\CCNS Privacy Pledge.

The Director, Administration & Special Projects for *CCNS* has been designated as the Chief Privacy Officer (CPO) for *CCNS*. The accountabilities of the *CCNS* Privacy Officer are described in S:\CCNS New\Quality\Privacy\working documents\CPO Accountabilities. Other *CCNS* privacy policies that apply to the SEU include the following:

Breaches
Explains how to deal with occasions when staff members become aware of or suspect a privacy breach. Examples include sending a fax or email to the wrong person or unauthorized viewing of sensitive information.
S:\CCNS New\Quality\Privacy\working documents\Breaches

Data Access
This policy defines the principles and procedures that are used by CCNS to guide decisions about granting access to the data for which CCNS is responsible. The following sections are included in this policy:
1. Legislative Requirements
2. Definitions of Data Types
3. Principles for the Release of CCNS Data
4. Access to Aggregate Data
5. Non-aggregate (i.e. identifiable) Data
6. CCNS Data Request Review Criteria
7. Cost Recovery
8. Publication of Information Using CCNS Data
9. Procedures for Accessing CCNS Data for Research Purposes
10. Procedures for Accessing CCNS Data for Planning or Quality Management Purposes
S:\CCNS New\Quality\Privacy\working documents\Data Access Policy

Handling and Access of Confidential Information
This document outlines procedures for the handling and access of confidential material both hard copy and electronic formats for staff members, students and volunteers. Access to confidential information is provided on a need-to-know basis.
S:\CCNS New\Quality\Privacy\working documents\Handling & Access Confidential Info Policy

Disclosure of Identifiable Personal Information
This policy applies to individuals requesting their own information or health professionals requesting information about patients under their care.
S:\CCNS New\Quality\Privacy\working documents\Disclosure Policy

Record Linkage
Record linkage involves the use of various manual or electronic methods to identify the same individual in two or more distinct data sets. Individual level, identifiable data must be used to conduct record linkage. This document lists the guiding principles that must be followed when carrying out a record linkage.
S:\CCNS New\Quality\Privacy\working documents\Record Linkage

Complaint Procedure
A procedure explaining how to deal with any privacy complaints received in person, by telephone or in writing.
S:\CCNS New\Quality\Privacy\working documents\Complaint Procedure

Complaint Form
This is a form that individuals can use to file a complaint regarding the handling of personal information by CCNS.
S:\CCNS New\Quality\Privacy\working documents\Complaint Form

CCNS Data Access Review Committee

Reporting to the Commissioner (or delegate), the CCNS Data Access Review Committee (DARC) is responsible for overseeing activities related to managing access to data stored in designated CCNS data holdings. The DARC has the following responsibilities:
1. Review and determine a status on all requests for data access according to CCNS Privacy Policy, Data Access Policies and Procedure and any additional direction that from time to time, may be provided by CCNS administration.
2. Quality Assurance: Perform an annual review of data requests to ensure consistency in the process for data access and advise on any changes to existing policies and procedures.

The DARC Terms of Reference are available at S:\CCNS New\Quality\Privacy\working documents\DARC-Terms of Reference Final July 19_06. Procedures and responsibilities for the DARC are outlined in S:\CCNS New\Quality\Privacy\working documents\DARC-Procedures & Responsibilities July 19_06.

**Surveillance and Epidemiology Unit
Policy and Procedure**

Title: Policy and Procedure Maintenance

Number:

Category: Cancer Registry Operations	Approval Date:
	Revision Date(s):
	Target Review Date:
Source: Surveillance and Epidemiology Unit	Approval: SEU Director

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POLICY

The SEU maintains a policy and procedure manual which is stored electronically on the *Cancer Care Nova Scotia* (*CCNS*) shared drive. A hard copy is available from the Registry Team Leader. All policies and procedures are reviewed at a minimum of once every three years or more frequently if circumstances warrant. The Registry Team Leader is responsible for coordinating the development of new policies and procedures as well as reviewing any updates. The SEU Director is responsible for reviewing and authorizing all new and updated policies and procedures.

PROCEDURE

1. Format

All policies and procedures are available in Microsoft Word read-only format on the *CCNS* shared drive. Go to S:\CCNS New\Surveillance & Epidemiology Unit\Policy and Procedures. One paper copy is available from the Registry Team Leader.

2. Coordination and Review of Updates

The Registry Team Leader is responsible for maintaining the schedule of review to ensure that procedures are reviewed and updated on the agreed schedule. When changes need to be made they are forwarded to the Registry Team Leader for review. The proposed change is then discussed with the SEU Director and all staff members that would be affected by this change. Policies and procedures can only be edited by the Registry Team Leader or the SEU Director. All changes must be approved by the SEU Director before being implemented.

3. Review Schedule

All policies and procedures will be reviewed and updated as necessary, but not less than once every three years. New policies and procedures will be written when required. For example, policies and procedures may need to be updated due to staffing changes or information system upgrades.

4. Signing Authority

The SEU Director is responsible for authorizing all updates and new policies and procedures.

5. Documentation of Changes

On all policies and procedures, record the approval date as well as the revision date. The SEU Policies and Procedures folder on the *CCNS* shared drive has three separate folders for drafts, final versions and previous versions. Any significant changes will be noted at the bottom of each policy and procedure.

6. Method of Distribution

All new employees will be told where the electronic files are stored and where the paper copy is stored. When any updates or new policies and procedures are introduced, all staff members are informed of these changes through e-mail and staff meetings.

Surveillance and Epidemiology Unit
Policy and Procedure

Title: Case Ascertainment

Number:

Category: Cancer Registry Operations		Approval Date:
		Revision Date(s):
		Target Review Date:
Source: Surveillance and Epidemiology Unit		Approval: SEU Director

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POLICY

The Surveillance and Epidemiology Unit (SEU) collects and analyzes data on all diagnosed cases of cancer in NS. In order to ensure a high degree of case completeness, a variety of methods are used to identify newly diagnosed cases. Case ascertainment methods must be routinely reviewed since new options may be available or possible with advances in information technology or other system changes.

PROCEDURE

The procedure section provides an outline of the current methods used to identify cases. The majority of cases are obtained from pathology reports and registry forms. Since a number of methods are used to ascertain cases, it is possible to have multiple sources for the same case.

1. **Pathology and Cytology Reports (Hard Copy)**

    All pathology departments across the province (except for the Izaak Walton Killam Health Centre) send reports with a cancer diagnosis to the SEU. This method has been in place since 1983. The Queen Elizabeth II Health Science Centre (QEII HSC) laboratory began sending cytology reports directly to the SEU printer effective, October 2006 for the diagnosis period February 1, 2006 to present.

2. **Registry/Neoplasm Report Forms (Hard Copy)**

    These are submitted primarily by hospital health record departments by facsimile or mail, when a new cancer diagnosis is noted on a routinely abstracted record (e.g. inpatient or day surgery). Occasionally, these forms are completed directly by a physician. The SEU

sometimes receives additional documents attached to the registry forms such as diagnostic imaging reports or operative reports. This method has been used since 1964.

3. **Cancer Centre Referred Cases**

The Halifax Cancer Centre, the Sydney Cancer Centre and the SEU share the Oncology Patient Information System (OPIS). This database has been the Nova Scotia Cancer Registry (NSCR) and Halifax Cancer Centre system since 1991 and has been used by the Sydney Cancer Centre since 1997. The predecessor information system to OPIS was called Cycare. It was used by both the Halifax Cancer Centre and the NSCR from 1983 until the transition to OPIS.

Sometimes cases not received by the SEU are obtained when patients visit the Halifax or Sydney Cancer Centre and are enrolled on OPIS. Since the HIM professionals working at the cancer centres have access to patient charts, they are often able to update or add to the information already entered on OPIS by the SEU staff.

4. **Hematology Linkage**

Since hematological cases are usually not referred to the NSCC and are often diagnosed on laboratory tests alone, a linkage is conducted to ascertain cases seen at the QEII HSC that were not reported to the SEU through regular reporting mechanisms. Approximately once every three months, the SEU obtains an Excel file from Capital Health Information Technology Services (ITS) of all patients seen at the QEII HSC for hematological oncology or bone marrow transplant. Capital Health ITS generates this Excel file using a script from STAR for the requested time period with visit codes HMONC (hematological oncology) or HMB (bone marrow transplant).

Before the Excel file generated from STAR can be electronically linked with OPIS, multiple visits for the same patient are removed. The Excel file is then imported into SAS (analytical software package) to format the QEII chart number and the health card numbers. Data from OPIS is also imported into SAS and formatted so that the chart numbers are in a more standardized format. The data from STAR and the data from OPIS are imported as two tables in an Access database. This Access file is imported into LinkageWiz, a record linkage software package. The data from STAR and OPIS are then linked using a number of data fields including medical record number, name, sex, date of birth, postal code and occasionally OPIS number generated from STAR.

All potential cases not on OPIS are reviewed by a HIM professional. For patients found on OPIS, it is determined whether they already are registered with hematological malignancies. Any cases that do not have hematological histologies (9590/3 through 9989/3) are reviewed.

5. **Vital Statistics – Death Clearance**

The SEU periodically receives electronic files from Vital Statistics containing death information where the cause of death is cancer. These electronic files are linked with OPIS to

determine if any cancer cases are missing. All cases in the Vital Statistics file that are not found on OPIS need to be reviewed. For more information please refer to the Death Clearance Procedure.

6. Reciprocal Notification

The SEU receives pathology and cytology reports from other provincial or territorial cancer registries for NS residents in either hard copy (paper) or electronic formats. Information for cancer cases on OPIS that are not NS residents is sent by the SEU to the appropriate provincial or territorial registry. Out-of-province patients are identified on OPIS using the county codes from the patient's address at diagnosis.

7. Special Studies

On occasion, a researcher completing a study may identify cases from other data sets that are not found on OPIS.

Surveillance and Epidemiology Unit
Policy and Procedure

Title: Mail Procedure

Number:

Category: Cancer Registry Operations   Approval Date:
                                                         Revision Date(s):
                                                         Target Review Date:
Source: Surveillance and Epidemiology Unit   Approval: SEU Director

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POLICY

The Surveillance and Epidemiology Unit (SEU) is responsible for collecting and analyzing data on all diagnosed cases of cancer in NS. Legislation governing the mandatory reporting of cancer is outlined in Section 101 of the Nova Scotia Health Act.

Mail is received by the SEU on a daily basis consisting of pathology reports from laboratories and registry forms from health record departments, physician offices or other hospital departments. The SEU obtains operative reports from some hospitals. Out-of-province death notices are also received from other cancer registries for NS residents where the cause of death is cancer. Cytology reports from the Queen Elizabeth II Health Sciences Centre (QEII HSC) lab are sent directly to the SEU printer. The Patient Enrollment Clerk is responsible for retrieving and sorting the mail each day.

Each report received by the SEU is carefully reviewed to see if the case meets the reporting criteria. If a case does not meet these criteria, the report is discarded in confidential shredding. One exception is basal cell and squamous cell carcinoma of the skin for which reports are retained but the cases are not entered into the registry database. Reports containing ambiguous terminology not diagnostic of cancer are forwarded to the Quality Management Technician.

PROCEDURE

All reports received by the SEU are collected by the Patient Enrollment Clerk and date stamped. This is so the HIM professionals can enter the date received on the disease registration screen on the Oncology Patient Information System (OPIS). Loose report pages are stapled together. The Patient Enrollment Clerk checks the final diagnosis and clinical history sections on the reports for a diagnosis of cancer. For cases diagnosed January 1, 2007 and onward, the microscopic

description is no longer being used to code histology. Please refer to the 2007 Multiple Primary and Histology Coding Rules. Cases not found on the reportable list are discarded in confidential shredding. Some exceptions are discussed below.

1. Basal Cell and Squamous Cell Carcinoma of the Skin

Presently, the SEU does not capture basal cell carcinoma (BCC) or squamous cell carcinoma (SCC) of the skin but these reports are retained. As the mail is being reviewed, reports for BCC and SCC of the skin are pulled. The reports are then filed by year of diagnosis and within each year, the reports are organized alphabetically by the first letter of patients' surname.

2. Ambiguous Terminology Not Diagnostic of Cancer

Reports containing final diagnoses with ambiguous terms not diagnostic of cancer (refer to ambiguous terms list) are also pulled as the mail is being processed. The Patient Enrollment Clerk searches for these patients on OPIS using the strategies outlined in the Patient Enrollment Procedure. If the patient is found on OPIS, the OPIS number is written on the top right-hand corner of the report. All reports with ambiguous terminology not meeting the reporting criteria are forwarded to the Quality Management Technician who reviews the cases at a later date.

3. Non-Reportable Conditions of the Cervix

For non-reportable conditions of the cervix including cervical intraepithelial neoplasia (CIN) grade I or II, dysplasia (not stated to be CIN III) or high grade squamous intraepithelial lesion (HSIL) (not stated to be CIN III), the Patient Enrollment Clerk checks to see if the patient is registered on OPIS. When the diagnosis is high grade squamous intraepithelial lesion (HSIL), the report is reviewed carefully to ensure there is no mention of grade 3 because HSIL includes grade 2, grade 3 as well as carcinoma in situ. If the patient has a non-reportable condition of the cervix and is not found on OPIS, the report is pulled and discarded in confidential shredding.

Reports are retained for patients found on OPIS with a previous cancer of the cervix. Sometimes a patient will have an initial biopsy showing CIN III and will then go on to have a cone biopsy or loop electrosurgical excision procedure (LEEP) for treatment which only shows CIN I or CIN II. Although CIN I or II is not reportable, the second pathology report is retained since it is from a treatment procedure and the information needs to be captured on OPIS by an HIM professional.

4. Sorting Reports for Case Enrollment

All cases determined to be reportable are retained for case enrollment / updates. Reports are sometimes set aside for the following activities:
   a) *Rapid case ascertainment* – Special studies may require cases for certain sites to be entered on OPIS immediately so that the information is as current as possible.
   b) *Training requirements* – Trainee(s) may only be working on specific sites.
The remaining reports are placed on the shelf for case enrollment / updates. If the SEU is experiencing a backlog, the reports are sorted according to the month of diagnosis provided on the report to ensure that the oldest reports are completed first.

Mail Procedure

Collect mail and retrieve cytology reports from printer

↓

Date stamp all reports and staple any report pages if necessary

↓

Check diagnosis to ensure case meets reporting criteria

↓

BCC or SCC of the skin case? — Yes → File reports by year of diagnosis. Within each year, file alphabetically by first letter of patients' surname.

No ↓

Non-diagnostic ambiguous terms used? — Yes → Search for patient on OPIS using search strategies described in Patient Enrollment Procedure. Label report with OPIS number if patient found. → Forward report to Quality Management Technician who reviews case at a later date.

No ↓

Non-reportable condition involving cervix? — Yes → **Patient on OPIS with previous cervical cancer?** — No → Discard in confidential shredding.

Yes (from Patient on OPIS) → Place reports on shelf

No ↓

Other diagnosis not meeting reporting criteria? — Yes → Discard in confidential shredding.

No ↓

Required for trainee or special study? — Yes → Pull report and give to HIM professional or trainee involved with the study for case registration.

No ↓

Place reports on shelf for case enrollment / updates. If currently experiencing a backlog, sort reports according to month of diagnosis.

→ To CPI Search

Cancer Care
Nova Scotia

Surveillance and Epidemiology Unit
Policy and Procedure

Title: Patient Enrollment Procedure

Number:

Category: Cancer Registry Operations	Approval Date:
	Revision Date(s):
	Target Review Date:
Source: Surveillance and Epidemiology Unit	Approval: SEU Director

POLICY

The objective of the Patient Enrollment Procedure is to compile a patient profile complete with all of the necessary details which may be used in statistical analyses of the cancer burden in the province. The SEU compiles pertinent demographic data about each Nova Scotia resident who is diagnosed with cancer. This procedure is the main responsibility of the Patient Enrollment Clerk.

To ensure data integrity, in particular to prevent duplicate patient registrations, a thorough search of the Central Patient Index (CPI) must be completed before registering a new patient. When a patient is found on the Oncology Patient Information System (OPIS) their information is checked and updated to ensure the data is as current as possible. When a patient is not found on OPIS, a new enrollment is started. Information is entered from the source document(s) as well as from the Capital Health STAR system and the Nova Scotia health card database.

PROCEDURE

1. Searching the Central Patient Index (CPI) on OPIS

There are three methods by which the CPI can be queried to identify a patient that is already enrolled or to establish that a patient is not enrolled on OPIS.

1.1 Patient Search by Insurer (PIS)

This search utilizes the health insurance number of the patient. It is the preferred search method since Nova Scotia has adopted the use of a unique identifier as its health insurance number, known as the Health Card Number (HCN). All other types of health

insurance numbers can be searched using this screen (MSI, Blue Cross, Government of Canada and all out of province insurers).

A search is performed by entering the health insurance number. Once executed, the search finds any and all patients with the insurance number that was entered. If the patient is not found, the Patient Enrollment Clerk goes to another search method.

1.2 Patient Search by Name (PNS)

This search locates a patient by their name. Information can be entered in as many or as few fields as desired as long as there is information in the Surname field. Name search uses Soundex so names that sound like the one that has been entered will be identified. When conducting a search, it is important to try several possibilities including:
-   Preferred or nicknames
-   Reversing the first and last names
-   Other common spellings i.e. Eisnor, Isner or Eisenor
-   Part of a hyphenated surname
-   Name variations i.e. Saudi Arabian names sometimes use "Al" as part of their name, so search for Fayed, Emad and Alfayed, Emad

It is good practice to enter the least amount of criteria for a search (in this case, just surname and common name) as this will identify the largest number of possible matches.

1.2.1   Performing a Name Search with Date of Birth

When performing a name search with the date of birth, first try the exact date of birth. Also, try January 1 of the year of birth as well as with one year before and one year after the correct year of birth. This is because in the distant past, many patients were registered when only their age in years was known – not their exact day, month and year of birth. For example, for Angela Smith born December 25, 1925 the following searches should be conducted:

A) Smith   Angela   1925 – December – 25
B) Smith   Angela   1925 – January – 01
C) Smith   Angela   1924 – January – 01
D) Smith   Angela   1926 – January – 01

1.2.2   Female Patients

For adult female patients that cannot be found using the methods described above it is important to check for previous MSI numbers or previous surnames on the health card database. Previous surnames can also be found under MPI Review on STAR. Select the patient emulator (PT EMUL) icon to find previous surnames.

Another PIS search is performed if an MSI number is found. The four searches shown above in 1.3.1 are conducted for any previous surnames found on the

health card or STAR databases. If a patient Angie Smith with date of birth January 1, 1926 were located during this search, the reports on file for this patient would be accessed and compared with the current documentation to determine if they are the same person. A HIM professional is consulted by the Patient Enrollment Clerk for assistance in making this decision.

1.3 Patient Search by Hospital (PHS)

If the patient is not found with either an insurance or name search, the Patient Enrollment Clerk will then try a search using the patient's hospital unit number. Caution must be used when doing a hospital search because there are no guidelines in place for hospital unit number entry. Hospital unit numbers can be entered in a variety of ways (with or without leading zeros, using leading alpha characters and with or without hyphens).

A search is performed by entering the hospital chart number. If the patient is still not found on OPIS, the Patient Enrollment Clerk will begin a new enrollment.

2. Finding a Duplicate Record or Old OPIS Numbers

It is possible for the Patient Enrollment Clerk to find a patient that has been registered more than once with different OPIS numbers. In addition, some patients may be found on OPIS with a unit number beginning with 40. These were assigned in the past to individuals receiving radiotherapy for benign conditions such as warts. When either of these situations occurs, the reports should be forwarded to a HIM professional to be rectified. Please refer to either the Duplicate Record Resolution Procedure or the OPIS Number Reassignment Procedure.

3. Out-of-Province Cases

Out-of-province cases are pulled by the Patient Enrollment Clerk. The address at diagnosis is confirmed by searching for the patient on OPIS, the Nova Scotia health card database and/or the Capital Health STAR system.

All out-of-province reports are sorted by province/territory and forwarded to the Administrative Assistant at the end of each month. The Administrative Assistant is responsible for sending the out-of-province reports to the appropriate provincial or territorial cancer registry. An Excel spreadsheet is used to track the number of reports that are sent to each province/territory.

4. Patient Updates and New Enrollments

If a patient is already on OPIS, the information is reviewed by the Patient Enrollment Clerk and updated if required. If a patient is not found, a new enrollment is started. Information is entered from the source document(s) as well as from STAR and/or the Nova Scotia health card database.

When working with a registry form that has complete information, the Patient Enrollment Clerk can begin entering information without having to check STAR or the health card database. For

all other reports or incomplete registry forms, additional information needs to be gathered from other sources. If the patient has been seen within Capital Health, the Patient Enrollment Clerk checks STAR for information. From MPI Review on STAR, it is possible obtain address information and the patient's family physician. Previous surnames can be found by clicking on the PT EMUL icon within MPI Review. For patients not seen at Capital Health, address information and previous surnames are gathered from the health card database.

4.1 Demographic information (PM)

On this screen, the patient's name, date of birth and current address are entered. It is very important to the SEU that address information be correct and entered in a systematic manner. All addresses are formatted using guidelines and abbreviations issued by Canada Post. For every address entered on OPIS, the Canada Post website (www.canadapost.ca) is checked to ensure proper formatting is used and to ensure the postal code entered on OPIS is the valid postal code for the address entered. Refer to the addressing information available from SEU staff.

4.2 Health insurance information (PI)

On this screen, the health card number is added or updated.

4.3 Physician information (PP)

The PP screen is where the family physician and any referring physicians are entered. The family physician can be obtained on STAR within MPI Review.

Physicians from the following specialties are not entered on OPIS:
- Anatomical pathology
- Anesthesiology (note that anesthetists may practice as family physicians and would be entered on PP)
- Diagnostic and therapeutic radiology
- Emergency medicine
- General pathology
- Psychiatry

4.4 Hospital information (PNH)

All hospitals where a patient has received care for their cancer are entered on this screen along with the hospital unit number.

4.5 Previous surnames (PPN)
Any previous surnames for adult female patients found on either the STAR system or the provincial health card database are entered on this screen.

4.6 Vital status and death information (PD)

If death information is provided, the Patient Enrollment Clerk updates the vital status on the PD screen. Information entered on the PD screen includes the source, death date, province of death, hospital of death and autopsy status (y/n).

5. Completion of Patient Enrollment

When patient enrollment has been completed, the report is placed in the designated area for the HIM professionals to continue with disease registration.

Cancer Care Nova Scotia
Surveillance and Epidemiology Unit

Searching the Central Patient Index

From Mail → Obtain pathology reports, cytology reports and registry forms from shelf

Out-of-province patient? — Yes → Check OPIS / STAR and/or health card database to verify patient's address → Set aside all out-of-province reports. Sort according to province / territory. → Forward to Admin Asst who mails out-of-province reports to appropriate provincial / territorial cancer registry. Record number of reports sent in an Excel spreadsheet.

Out-of-province patient? — No → Begin searching for patient on OPIS

Confirmed as out-of-province? — No → Begin searching for patient on OPIS
Confirmed as out-of-province? — Yes → (up to Set aside all out-of-province reports)

Duplicate or OPIS # starting with 40? — Yes → Forward to a HIM professional to be rectified
Duplicate or OPIS # starting with 40? — No → Update patient information on OPIS → To Patient Enrollment

Begin searching for patient on OPIS → Patient found using PIS?
Patient found using PIS? — Yes → Check for possible duplicate registration or OPIS # starting with 40
Patient found using PIS? — No → Patient found using PNS?

Patient found using PNS? — Yes → Check for possible duplicate registration or OPIS # starting with 40
Patient found using PNS? — No → Is this an adult female patient?

Is this an adult female patient? — Yes → Search for previous surnames on STAR and health card database. Check for previous MSI # on health card database. → Search OPIS using previous name(s) / MSI # → Found with previous surname or old MSI #?
Is this an adult female patient? — No → Patient found using PHS?

Found with previous surname or old MSI #? — Yes → Check for possible duplicate registration or OPIS # starting with 40
Found with previous surname or old MSI #? — No → Add new patient to OPIS

Patient found using PHS? — Yes → Check for possible duplicate registration or OPIS # starting with 40
Patient found using PHS? — No → Add new patient to OPIS

Add new patient to OPIS → To Patient Enrollment

40

Cancer Care Nova Scotia
Surveillance and Epidemiology Unit

Patient Enrollment Procedure

From CPI Search

When patient is found on OPIS, update existing information. When patient is NOT found, begin new enrollment.

Registry form with complete info?

→ No → **Capital Health patient?**

→ No → Obtain address, and any previous names from health card database

Capital Health patient? → Yes → Obtain address, physician names and any previous names from STAR

Registry form with complete info? → Yes →

Add / update patient demographic information on the PM screen. Verify address information using the Canada Post website. Refer to Canadian addressing guide for proper formatting.

Add / update health card number on the PI screen.

Add / update family and referring physician(s) on the PP screen.

Add / update hospital name(s) and hospital unit number(s) on the PNH screeen.

Add / update any previous surnames for adult females on the PPN screen.

Update vital status and add death information to PD screen if necessary.

Label report with OPIS number in upper right-hand corner and place in designated area for HIM professionals to continue with case registration.

To Disease Registration & Staging

Surveillance and Epidemiology Unit
Policy and Procedure

Title:	Duplicate Record Resolution Procedure

Number:

Category: Cancer Registry Operations	Approval Date:
	Revision Date(s):
	Target Review Date:
Source: Surveillance and Epidemiology Unit	Approval: SEU Director

POLICY

To ensure data integrity of the Oncology Patient Information System (OPIS), the Surveillance and Epidemiology Unit (SEU) identifies possible duplicate records as part of preparations for the Death Clearance Procedure which is conducted on a quarterly basis. The Patient Enrollment Clerk or one of the HIM professionals may also come across possible duplicates through daily patient registrations and updates. By examining them on an individual basis, the duplicates are confirmed and resolved by retaining one record and deleting the additional enrollment(s). If two or more records are confirmed to be distinct individuals, they are left on OPIS however, any additional identifying information found during the resolution process is updated to the system.

PROCEDURE

1. A list of possible duplicates identified with record linkage software during death clearance procedure preparations is generated and forwarded to the Quality Management Technician. Any possible duplicates found through daily patient registrations by the Patient Enrollment Clerk are given to a HIM professional to be rectified.

2. After possible duplicates have been identified, the records are reviewed on OPIS to see if each case is registry-only or admitted to either the Nova Scotia Cancer Centre (NSCC) or the Cape Breton Cancer Centre (CBCC). This is necessary to determine whether the duplicate resolution is to be handled by the SEU or HIM professionals working at the NSCC or CBCC. This can be achieved by checking disease type (DR), scheduling (SPAD), patient referral (PREF) or chart tracking (CSHQ) screens on OPIS. When both records are admitted, they need to be forwarded to staff at the NSCC or CBCC. All other possible duplicates are handled by SEU staff.

3. When resolving duplicates for death clearance purposes, the Quality Management Technician emails the OPIS chart numbers of all possible cancer centre duplicates to a HIM professional at either the NSCC or CBCC. Possible duplicates identified through daily patient registrations that need to be handled by NSCC or CBCC staff are forwarded as they arise. Once the duplicates are resolved, the NSCC or CBCC HIM professionals contact the SEU to let staff know which number was retained or if the records were determined to be two distinct records.

4. All source documents are assembled including off-site charts (refer to the Procedure for Requesting Charts from Off-Site), pathology reports and registry forms. External databases are used such as STAR and MSI, to obtain previous names or old MSI numbers, confirm birth dates etc. For two distinct records not found to be duplicates, the records are updated with any new or additional information obtained during the resolution process.

5. For each pair of duplicates found, it needs to be determined which records should be deleted. The following are the possible scenarios:

Record 1	Record 2	Record to be deleted
Registry	Admitted	SEU staff delete the registry record as no scheduling exists. If the admitted record is more recent and does not have any scheduling information, then the registry record would be retained and the admitted record would be deleted.
Admitted	Admitted	The NSCC or CBCC clinic staff review the records to determine which one should be deleted and combine the two patient charts.
Registry	Registry	SEU staff delete the record with the higher number (the second one registered)

6. Once the record being retained has all of its data plus that from the deletion record, the contents of each screen of the to-be-deleted record need to be deleted. The DDEL screen is used to delete any disease records. After all the screens are cleared, the record is deleted by entering F6 on the PDEL screen. If any data items remain on any screen, a message will appear directing the user to the appropriate screen.

7. After a record is deleted, it is important to make sure all documents have the correct number and forward the documents to the Patient Enrollment Clerk for filing.

Cancer Care Nova Scotia
Surveillance and Epidemiology Unit

Duplicate Record Resolution Procedure

Possible duplicates identified with record linkage software for death clearance preparations or through daily patient enrollments / updates.

Determine if each case is registry-only or admitted to NSCC or CBCC by checking either SPAD, PREF or CSHQ on OPIS.

Are both records admitted?

No → Duplicate resolution handled by SEU staff

Yes → Duplicate record resolution handled by staff at NSCC or CBCC

Assemble all source documents including off-site charts, any pathology reports or registry forms on file.

Check STAR and the health card database for any previous names, old MSI #'s, confirm DOB, etc.

Confirmed to be a duplicate?

No → Update two distinct records with any new or additional information obtained during the resolution process.

Yes → Both records registry-only?

Yes → SEU staff delete record with higher OPIS number (second one registered).

No →

Delete registry record as no scheduling exists. If the admitted record is more recent and does not have any scheduling information, then the registry record would be retained and the admitted record deleted.

Print face sheet of the to-be-deleted record.

Add all pertinent information from the to-be-deleted record to the record being retained. Also, include any new or additional information found on STAR or health card database.

Delete the contents on each screen of the to-be-deleted record. Use DDEL to delete the disease(s). Delete the patient record by entering F6 on PDEL.

Review documents to make sure they all have the correct OPIS number.

Forward documents to Patient Enrollment Clerk for filing.

To Filing

Surveillance and Epidemiology Unit
Policy and Procedure

Title: OPIS Number Reassignment Procedure

Number:

Category: Cancer Registry Operations   Approval Date:
                                                     Revision Date(s):
                                                     Target Review Date:
Source: Surveillance and Epidemiology Unit   Approval: SEU Director

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POLICY

The predecessor to the Oncology Patient Information System (OPIS) was called Cycare. In the past individuals with benign conditions (e.g. warts) came to the Nova Scotia Cancer Centre (NSCC) to be treated with radiotherapy. All individuals who came to the NSCC for a benign condition were registered on Cycare with a unit number beginning with a 40. These old records are now part of OPIS.

When a patient is found on OPIS with a unit number beginning with a 40, they need to be reassigned a new number. All information found on the old record is added to the new record. The record with the old unit number is deleted. This procedure is completed by HIM professionals at the SEU and the NSCC.

PROCEDURE

1. When the Patient Enrollment Clerk encounters a patient with a unit number beginning with a 40 while conducting case registrations, the report(s) for this patient are forwarded to a HIM professional. The unit number is attached to the reports on a Post-It note.

2. The HIM professional enters the unit number beginning with a 40 to bring up the record on OPIS.

3. The PM screen is checked to see if a chart is available off-site. Please refer to the Procedure for Requesting Charts from Off-Site.

4. A Face Sheet is printed which provides all key information recorded on OPIS for that record.

5. All information from the PI screen is deleted. This is because it is not possible to have two records with the same health insurance number (provincial health card number).

6. A new enrollment is created and the disease is registered. Any pertinent information from the off-site chart and any new information available on STAR or the health card database is entered on the newly created record.

7. The off-site chart and Face Sheet are provided to a HIM professional at the NSCC with the new number clearly marked.

8. The HIM professional at the NSCC creates a new chart.

Cancer Care Nova Scotia
Surveillance and Epidemiology Unit

Patient Enrollment Clerk encounters a patient with an OPIS # beginning with a 40. Unit number is attached to the report on a Post-It note and forwarded to a HIM professional.

HIM professional brings up record on OPIS and checks PM screen to see if a chart is available off-site.

Request off-site chart if available. Refer to Procedure for Requesting Charts from Off-Site.

Print a face sheet to view all key information for that record.

Delete information from Patient Insurance (PI) screen. (Not possible to have two records with same health care number).

Create new enrollment and register disease. Refer to Patient Enrollment and Disease Registration procedures. Enter any pertinent information from the off-site chart, STAR or the health card database on newly created record.

Attach face sheet to off-site chart and give the chart to a HIM professional at the NSCC in Halifax.

HIM professional at NSCC creates new chart with new number.

**Surveillance and Epidemiology Unit
Policy and Procedure**

Title: Procedure for Requesting Charts from Off-Site (Iron Mountain)

Number:

Category: Cancer Registry Operations   Approval Date:
                                               Revision Date(s):
                                               Target Review Date:
Source: Surveillance and Epidemiology Unit Approval: SEU Director

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POLICY

SEU staff may require access to historical/inactive cancer charts stored off-site by Iron Mountain. Information found on off-site charts may be needed to assist with Duplicate Record Resolution or the OPIS Number Reassignment Procedure (old 40 numbers). Off-site charts are requested from Iron Mountain by a HIM professional on an as needed basis.

PROCEDURE

1. Complete Iron Mountain Chart Request Form (see next page). The box number can be found on the PM screen on OPIS.

2. Fax form to Iron Mountain.

3. Chart is received from Iron Mountain. The recipient makes sure they have the correct chart. If the chart was not found, call Iron Mountain to ask them to look again.

4. If the correct chart has been received, the chart's location is updated to "Reg" using CGT.

5. Complete Duplicate Record Resolution or OPIS Number Reassignment using information available on the off-site chart.

6. Remove contents of chart and send to health records. Ensure that all documents contain the correct OPIS number and sign the chart out to health records using CGT.

IRON MOUNTAIN Chart Request

Customer ID 10670 – Cancer Registry

Address Code: CANREG (QEII Health Science Centre – VG Site – 1278 Tower Road, Bethune Building, 5th Floor, Room #553

Date: ___ / ___ / ___   Time: ___ : ___   Requested by: _____ (FIRST & LAST NAME)   PHONE: 473 - _____

Order Type (Circle one): **DELIVERY   FAX   FAX & DELIVER   - FAX #** _____ (IF APPLICABLE)

Priority: (Circle one)   **HALF DAY   RUSH**   Department Code: _____ (IF APPLICABLE)

	Box Number	Chart	Year	Last Name	First Name	Additional Info.
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						

SPECIAL INSTRUCTIONS: QEII NOTES _____

WE HAVE # _____   CHARTS TO BE RETURNED FOR REFILE (IF LEFT BLANK WE HAVE NO CHARTS AT THIS TIME).

Procedure for Requesting Charts from Off-Site (Iron Mountain)

Complete Iron Mountain Chart Request Form. Obtain the box number from the PM screen on OPIS.

Fax form to Iron Mountain

Chart obtained from Iron Mountain and ensure correct chart(s) have been received. If chart was not found, call Iron Mountain and ask them to take a second look.

Update chart location to "Reg" using the CGT screen.

Complete Duplicate Record Resolution or OPIS Number Reassignment using information available on the off-site chart.

Remove contents of chart and send to health records. Ensure all documents contain the correct OPIS number and sign the chart out to health records using CGT.

Surveillance and Epidemiology Unit
Policy and Procedure

Title: Disease Registration and Staging

Number:

Category: Cancer Registry Operations	Approval Date:
	Revision Date(s):
	Target Review Date:
Source: Surveillance and Epidemiology Unit	Approval: SEU Director

POLICY

The SEU is responsible for coding and abstracting disease information into the NSCR for all cases of cancer in Nova Scotia. Disease registration (DR screen) and staging (DSCS and DSTN screens) are the responsibility of Health Information Management (HIM) professionals certified by the Canadian Health Information Management Association (CHIMA).

Disease registration and staging are completed by HIM professionals at the SEU as well as those employed by the NSCC and the CBCC. SEU staff enter disease information for all NS cases whereas staff at the NSCC and CBCC, only enter information for those cases seen at one of the two cancer centers. Disease information has been collected since the NSCR began in 1964. Stage data collection began in 2004. Sites currently being staged by the SEU and CBCC include colon, breast, lymphoma, prostate, lung, and head and neck. Staff at the NSCC only enter staging information for colon and prostate diagnosed from 2006 to present.

Data is standardized on OPIS to meet the data submission requirements of the Canadian Cancer Registry (CCR) and the North American Association of Central Cancer Registries (NAACCR) as well as locally identified needs. According to the CCR, only information gathered through completion of surgery(ies) in the first course of treatment or all information available within four months of the date of diagnosis (in the absence of disease progression), whichever is longer, is to be used for disease registration.

SEU staff code disease registration information according to the International Classification of Diseases for Oncology, Third Edition (ICD-O-3), the Surveillance Epidemiology and End Results (SEER) Summary Stage Manual (2000) and the 2007 Multiple Primary and Histology (MP/H) Coding Rules. A useful resource for coding hematological conditions is the Abstracting and Coding Guide for the Hematopoietic Diseases (SEER, 2002). Staging resources include the American Joint Committee on Cancer (AJCC) Cancer Staging Manual (6th edition) and the

Collaborative Staging Manual and Coding Instructions. The patient's address at diagnosis is entered and/or verified using the online Canadian Addressing Guide available at http://www.canadapost.ca/business/offerings/address_management/pdf/addressing_guide-e.pdf. The CCR has provided Residency Guidelines to be used when an individual's usual place of residence cannot be easily determined (see Appendix A).

Current data systems that may be used to obtain additional information for disease registration and staging include Web1000 (Provincial radiology system), CDHA Laboratory Information System (LIS), Horizon Patient Folder (HPF - Imaged historical record in electronic format), STAR (Enterprise Registration and Patient Accounting for CDHA) and Canada Post (address information). New applications may be added from time to time.

This policy and procedure provides a general overview of disease registration and disease staging. More detailed explanations of each field on the DR, DSCS and DSTN screens are located in the Data Dictionary available on the NSCC shared drive.

PROCEDURE

1. Obtain reports that have been completed by the Patient Enrollment Clerk.

2. Bring up record on OPIS by entering the number recorded on the top right-hand corner of the source document.

3. **Disease Registration (DR)**
   Check the DQ screen to see if there are any diseases registered. If the disease is already registered or shown as pending, select the disease and go to the DR screen. When the disease has not already been entered, a new disease record needs to be added.

   Add/update the disease record using the information provided on the source document (e.g. registry form or pathology report). Site and histology are coded using ICD-O-3. Extent is coded using the SEER Summary Staging Manual. Any metastases present at diagnosis are captured at the bottom of the DR screen. Refer to the 2007 MP/H Rules for determining whether to code a single primary or multiple primaries and for coding histology. When additional information is needed to code the case, refer to Web1000, LIS, HPF or STAR.

   3.1. **Hematology Coding**
   Please refer to the Hematology Review Policy and Procedure for information regarding case registration for hematologic malignancies seen in the QEII Hematology Clinic which were not reported to the SEU through regular case reporting mechanisms.

   3.2. **Treatment Information**
   Treatment information may be provided on the registry form or obtained through patient chart reviews. The first treatment date is captured when available and primary treatment information is included in the initial treatment section. Any treatment given

after the primary treatment period is captured in the treatment summary section. For more information about these fields refer to the OPIS Data Dictionary.

3.3. Behaviour change

Prior to 2007, the SEU was able to register two cases for the same anatomical site and histological grouping but different behaviours (e.g. insitu case became invasive) and link them on OPIS. With the introduction of the 2007 MP/H coding rules, progression cases are no longer linked on OPIS. Refer to the Behaviour Change Procedure for cases registered before 2007.

3.4. Metastases, relapses and recurrences (DMRR)

Any metastases, relapses or recurrences are to be entered on the DMRR screen. Guidelines for data entry are contained in the OPIS Data Dictionary.

3.5. Multiple skins (DMS)

This screen is used to enter new basal and/or squamous cell carcinoma skin primaries which have been previously registered on the Disease Registration screen (DR). This screen is limited to site codes C440 to C449 from the International Classification of Diseases for Oncology (ICD-O) with histology 805-808, 809-871, 914 and 970.

4. Disease Staging

Once disease registration has been completed, enter staging variables. Staging can only be entered for those disease sites where the DSCS and DSTN screens have been activated on OPIS. Staging information is captured by reviewing the hospital chart and/or the NSCC or CBCC chart.

The HIM professionals at the NSCC and CBCC enter staging information from the cancer center charts. Staff at the SEU will try to locate patients on HPF and enter as much staging information as possible. If necessary, the SEU staff will request the NSCC chart to obtain more information. If additional documentation is required, the staging screens are left as incomplete by one of the HIM professionals. Once all staging fields have been completed after reviewing the available documentation, the staging screens are shown as verified.

When completing the DSCS screen, the rules and guidelines outlined in the Collaborative Staging and Coding Manual (available at http://www.cancerstaging.org/cstage/manuals.html) need to be strictly followed. The DSTN screen is completed using the AJCC Cancer Staging Manual (6th edition).

5. After completion of disease registration and staging, provide the source document to the Patient Enrollment Clerk for filing.

Disease Registration and Staging

From Patient Enrollment

Obtain reports that have been completed by the PE Clerk.

Bring up record on OPIS by entering number recorded on the top right-hand corner of the source document.

Check DQ screen to see if any diseases are registered

Disease entered or pending? — Yes → Select disease record and go to DR screen

No

Add new disease record on DR screen

Metastasis, relapse or recurrence? — Yes → Enter information on DMRR screen

No

Multiple skins? — Yes → Enter information on DMS screen

No

Add/update disease record using information provided on source document. Enter site and histology using ICD-O-3. Use SEER Summary Staging Manual for extent field. Any metastases at diagnosis are entered at the bottom of the DR screen. Refer to 2007 M/PH Rules when required. Obtain additional information from Web1000, LIS, HPF or STAR.

Staging screens activated on OPIS for site? — No

Yes

Search HPF for patient

Enough information on HPF for staging? — Yes

No

Obtain NSCC chart

Complete staging fields and verify case. Use Collaborative Staging Manual for DSCS and AJCC Manual for DSTN.

Provide source document to Patient Enrollment Clerk for filing

To Filing

Surveillance and Epidemiology Unit
Policy and Procedure

Title: Hematology Review

Number:

Category: Cancer Registry Operations   Approval Date:
                                                Revision Date(s):
                                                Target Review Date:
Source: Surveillance and Epidemiology Unit   Approval: SEU Director

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POLICY

A linkage is conducted approximately every three months to ascertain hematological cases seen at the Queen Elizabeth Health Sciences Center (QEII HSC) that may not have been reported to the SEU. Many hematological cancers are diagnosed through laboratory tests alone and these reports are not received through regular reporting mechanisms. In addition, individuals with hematological cancers are usually not referred to the NSCC but are seen at the QEII HSC. The hematology linkage process is outlined in the Case Ascertainment Policy and Procedure.

The hematologists at the QEII HSC have asked the SEU to register all patients (including those from out-of-province) seen at the hematology clinic for reportable conditions. All potential cases not registered on the Oncology Patient Information System (OPIS) are reviewed by a HIM professional. For patients found on OPIS, it is determined if a hematological condition has already been registered. Any cases that do not have hematological histologies (9590/3 through 9989/3) are reviewed.

PROCEDURE

1. Obtain hematology list from epidemiologist responsible for linkage.

2. Eliminate any cases already registered on OPIS with a hematological condition.

3. Search for a patient on Horizon Patient Folder (HPF) by entering the QEII HSC medical record number.

4. Review documents on HPF to determine the reason why the patient was seen at the hematology clinic. For inpatient encounters, review the Discharge Summary. For outpatient

encounters go to the folder titled Ambulatory Care Reports to review the hematology clinic notes. Check the laboratory reports for diagnostic information. If a patient was diagnosed with a particular condition at an earlier date and then referred to the QEII HSC for a recurrence or relapse, review the documents that were faxed from the referring hospital.

5. After a diagnosis has been found, determine whether or not the disease/condition is reportable by checking the International Classification of Diseases for Oncology, Third Edition (ICD-O-3) code book. Another excellent reference is the *Abstracting and Coding Guide for the Hematopoietic Diseases* published by Surveillance Epidemiology and End Results (SEER), 2002.

6. If a reportable hematological condition is found, complete a registry form. Information that needs to be collected includes the following:
   - Address at diagnosis and the patient's current address
   - QEII unit number and the diagnosing hospital unit number if they were diagnosed at another hospital and then referred to the QEII
   - Family physician and the hematologist at the QEII
   - Site, histology and diagnosis date. If you do not find an exact diagnosis date, you can enter a partial date (year and month or year only).
   - Information pertaining to any metastases, relapses or recurrences.
   - Date of first treatment (chemotherapy or radiotherapy) and if any treatment was provided for a recurrence or relapse captured on the metastases, relapses and recurrences (DMRR) screen.

7. Enter information obtained from HPF on OPIS. In the third field at the top of the Disease Registration (DR) screen, enter a C within the brackets for non-cancer centre clinic. For diagnosis method, usually histology is entered. All chronic lymphocytic leukemia cases should have a diagnosis method of H - histology even if they were diagnosed on peripheral blood with a cell surface marker test. The diagnosis method of T - Lab Test/Marker Study is used for other conditions diagnosed on blood from the year 2004 onward such as monoclonal gammopathy of undetermined significance (MGUS) or polycythemia rubra vera. Radiology is used for cases diagnosed on blood tests prior to 2004.

8. For lymphoma cases, enter the collaborative staging variables on the DSCS and enter the Ann Arbor stage on the DSTN.

9. Once all information has been entered on OPIS, write the OPIS number on the top right hand corner of the registry form. Also write "hematology review" to indicate the case was ascertained by reviewing the QEII chart.

10. Forward all registry forms from the hematology review to the Patient Enrollment Clerk for filing.
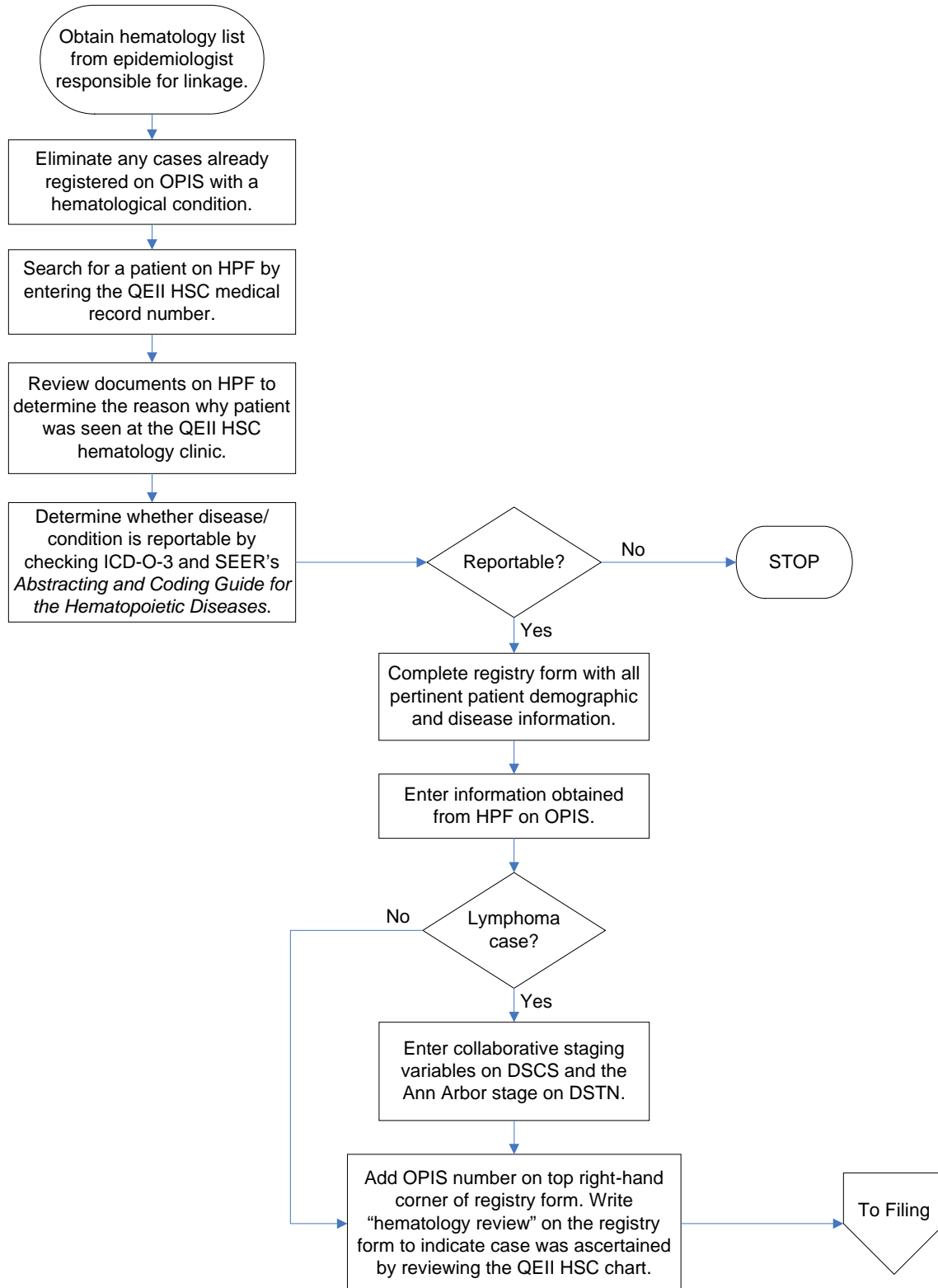
Hematology Review

Obtain hematology list from epidemiologist responsible for linkage.

↓

Eliminate any cases already registered on OPIS with a hematological condition.

↓

Search for a patient on HPF by entering the QEII HSC medical record number.

↓

Review documents on HPF to determine the reason why patient was seen at the QEII HSC hematology clinic.

↓

Determine whether disease/ condition is reportable by checking ICD-O-3 and SEER's *Abstracting and Coding Guide for the Hematopoietic Diseases.*

→ **Reportable?** — No → **STOP**

↓ Yes

Complete registry form with all pertinent patient demographic and disease information.

↓

Enter information obtained from HPF on OPIS.

↓

No ← **Lymphoma case?**

↓ Yes

Enter collaborative staging variables on DSCS and the Ann Arbor stage on DSTN.

↓

Add OPIS number on top right-hand corner of registry form. Write "hematology review" on the registry form to indicate case was ascertained by reviewing the QEII HSC chart.

→ **To Filing**

Surveillance and Epidemiology Unit
Policy and Procedure

Title: Filing Procedure for Paper Reports

Number:

Category: Cancer Registry Operations	Approval Date:
	Revision Date(s):
	Target Review Date:
Source: Surveillance and Epidemiology Unit	Approval: SEU Director

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BACKGROUND

From 1964 to 1995 the Nova Scotia Cancer Registry (NSCR) operated in partnership with the Nova Scotia Cancer Centre. When cancer patients were seen in the cancer centre the registry form became part of their chart. All other registry forms were stored in separate filing cabinets. The Surveillance and Epidemiology Unit (SEU) still has access to old cancer centre charts stored off-site by Iron Mountain.

In 1995 the Nova Scotia Cancer Centre became part of the Queen Elizabeth II Health Sciences Centre. At this time, a decision was made to discard registry forms once the information was entered on the Oncology Patient Information System (OPIS). In the past, a chart had been created for both cancer centre and registry-only patients. When the merger took place, all charts were reviewed. If the only document on the chart was the registry form, the chart was destroyed.

Following an audit by the Department of Health and the Auditor General of Nova Scotia in 1999, registry forms were once again retained. It was recommended that the SEU keep all original source documents regardless of document type.

POLICY

All paper reports received by the SEU that meet the reporting criteria are permanently stored in filing cabinets on-site once disease registration has been completed by the HIM professionals. Filing is the responsibility of the Patient Enrollment Clerk and is completed on a daily basis. Reports are filed in numerical order using the OPIS chart number.
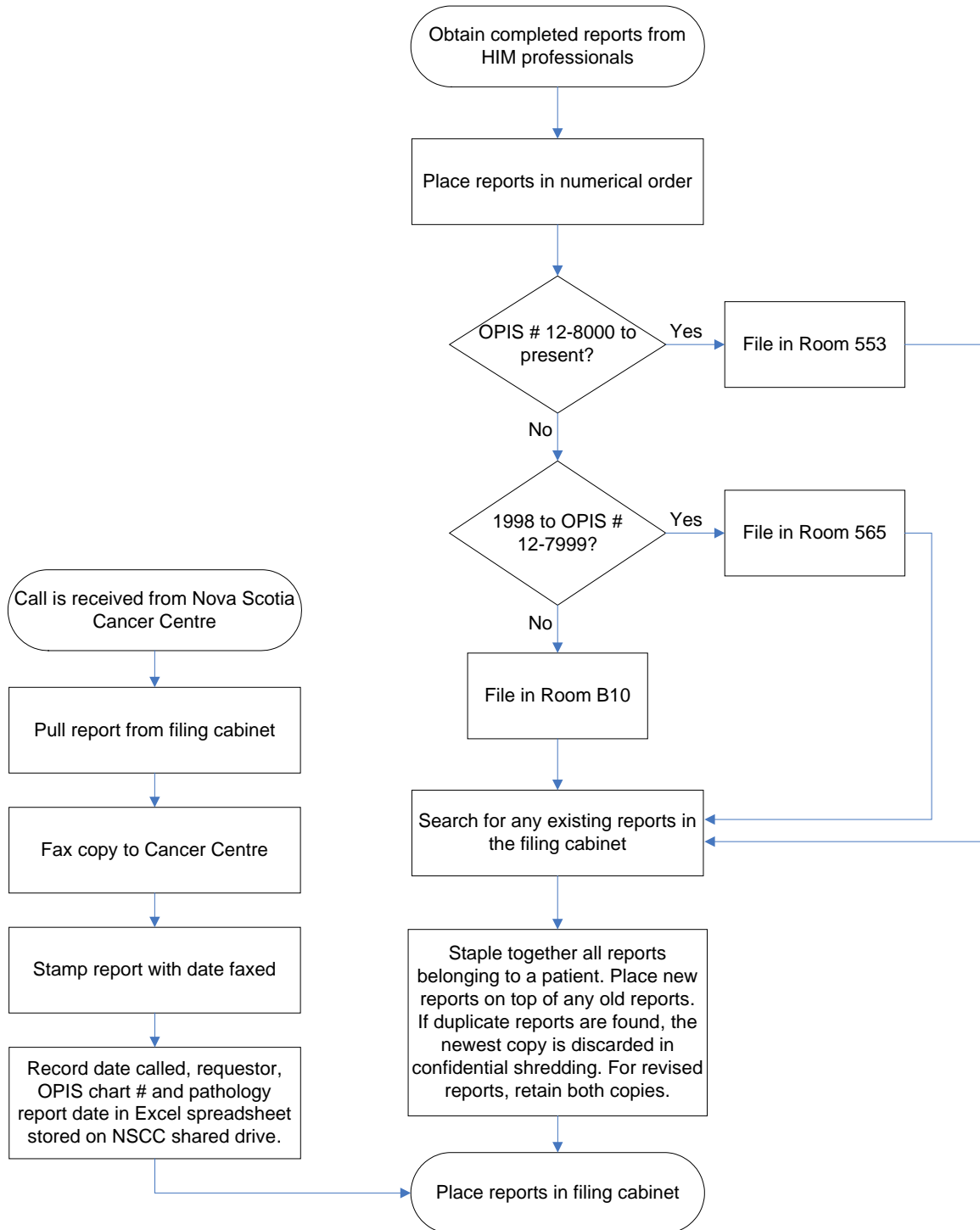
PROCEDURE

Each day the Patient Enrollment Clerk gathers completed reports from the HIM professionals. The reports are then placed in numerical order to save time when filing.

The Patient Enrollment Clerk files the reports in one of three locations. Reports with OPIS number 12-8000 to present are filed in room 553 and reports from 1998 through to 12-7999 are filed in room 565. The oldest reports for 1997 and earlier are kept in storage room B10 in the basement of the Bethune Building. (See exceptions in background section).

When filing, the Patient Enrollment Clerk searches for any existing reports on a patient. All reports belonging to a patient are stapled together. The new reports are placed on top of any old reports. If duplicate reports are found, the newest copy is discarded in confidential shredding. When reports have been revised, both copies are retained. Once everything is stapled together the reports are placed in the filing cabinet.

Occasionally, the Nova Scotia Cancer Centre Referral Office calls the SEU to obtain old reports that cannot be accessed on the Capital Health Laboratory Information System (LIS). The Patient Enrollment Clerk pulls the report requested, faxes a copy to the cancer centre, stamps the report to show the date faxed and then returns the report to the filing cabinet. The Patient Enrollment Clerk also maintains an Excel spreadsheet stored on the NSCC shared drive that tracks pathology report requests. Information captured on the spreadsheet includes date called, requestor, OPIS chart number and the report date.

Filing Procedure

Obtain completed reports from HIM professionals

↓

Place reports in numerical order

↓

OPIS # 12-8000 to present? —— Yes → File in Room 553

↓ No

1998 to OPIS # 12-7999? —— Yes → File in Room 565

↓ No

File in Room B10

↓

Search for any existing reports in the filing cabinet

↓

Staple together all reports belonging to a patient. Place new reports on top of any old reports. If duplicate reports are found, the newest copy is discarded in confidential shredding. For revised reports, retain both copies.

↓

Place reports in filing cabinet

Call is received from Nova Scotia Cancer Centre

↓

Pull report from filing cabinet

↓

Fax copy to Cancer Centre

↓

Stamp report with date faxed

↓

Record date called, requestor, OPIS chart # and pathology report date in Excel spreadsheet stored on NSCC shared drive.

↓

Place reports in filing cabinet

Surveillance and Epidemiology Unit
Policy and Procedure

Title:	Death Clearance		
Number:			
Category:	Cancer Registry Operations	Approval Date:	
		Revision Date(s):	
		Target Review Date:	
Source:	Surveillance and Epidemiology Unit	Approval: SEU Director	

POLICY

The NSCR database will be subject to a death clearance on a quarterly basis to support the acquisition of death information on registered cases and to identify potential unreported cases.

DEFINITIONS

Death Clearance – An electronic linkage of all existing registry cases (not already defined as deceased) with the Nova Scotia Vital Statistics Death File.

DCO (Death Certificate Only Case) – Person with a cancer diagnosis on the VS file that did not link to any person on OPIS.

DCD (Death Certificate Disease) – Person that links to OPIS but the cancer cause of death does not match with the cancer disease registered on OPIS.

Follow-back – An active search conducted by SEU staff to confirm whether a person has been previously diagnosed with cancer prior to death.

PROCEDURE

1. The Nova Scotia Vital Statistics Department (VS) sends a death file on a quarterly basis to the Surveillance and Epidemiology Unit (SEU) of all deaths that occurred in Nova Scotia for a specified time period. The SEU only has authorization to receive cause of death data where cancer was mentioned on the death certificate. Identifiers in this file include health card number, full name, birth date, death date, sex, postal code of residence at time of death, standard geographic code (SGC) of residence (county and municipality) and town name. The file also contains place of death and physician who signed the death. Cause of death and

contributing causes of death, if reported, are coded to the ICD-10 standard. The file is received and processed by an epidemiologist at the SEU.

2. An internal record linkage on the OPIS database is conducted using record linkage software. This is currently the responsibility of the epidemiology staff and the Registry Team Leader.

   2.1 Identify internal duplicates by linking all cases on OPIS enrolled after the first date on the death file to the entire database. This will identify potential duplicates within recent and historical registration. Duplicate resolution is carried out by HIM professionals at the SEU, NSCC and CBCC. Refer to the Duplication Resolution Procedure for more information.

3. Record linkage of death and NSCR files, under the direction of epidemiology staff and the Registry Team Leader.

   3.1. The VS death file is linked to the entire database, excluding those registrants already confirmed deceased by Vital Statistics and those diagnosed after the cutoff date of the VS file. The HIM professionals at the SEU examine questionable links (grey area resolution). Three files are generated from this process.
      - **Direct Match File**: All patient records where only death information needs to be updated on OPIS.
      - **DCO**: Individuals with a cancer diagnosis on the VS files that do not link to any patient on OPIS.
      - **DCD**: The VS record links to an OPIS patient but cause of death or contributing cause of death do not agree with the diseases on OPIS.

   3.2. The list of all possible DCD's is given to the Registry Team Leader who compares the OPIS data to the VS data to determine if a new disease record should be entered. The following are not considered to be a new DCO:
      - Unknown primary recently diagnosed and entered on OPIS with a different diagnosis on VS.
      - Patient is currently being followed in the NSCC or CBCC.
      - Data on DMRR screen matches VS cause of death
      - Sites in close anatomical proximity (e.g. stomach and esophagus)
      - Hematopoietic conditions with differences in classification systems (ICD-O-3 vs. ICD-10)
      - Diagnosis date is close to the death date
      - Pending cases where the patient has been registered on OPIS but no disease has been entered.
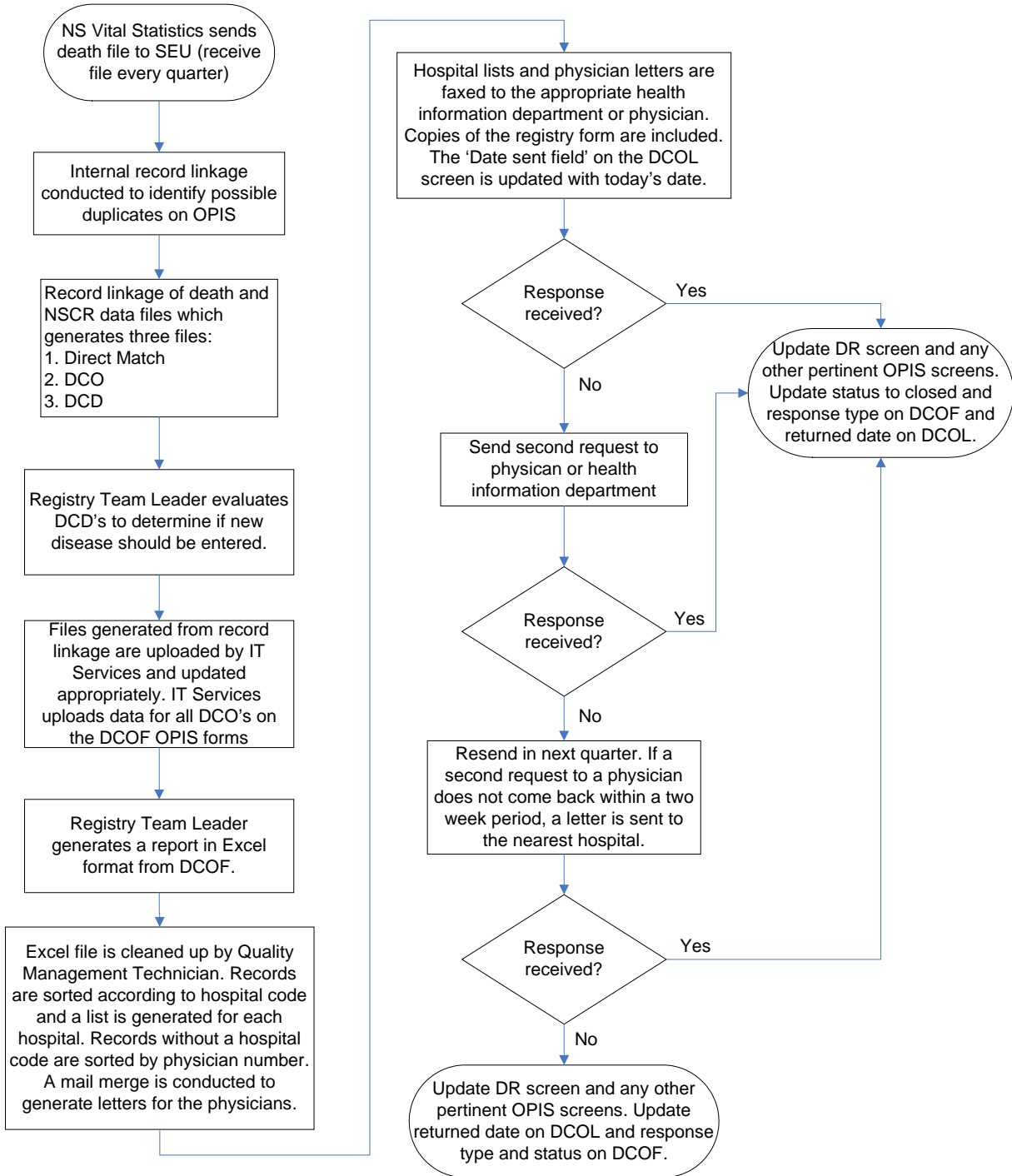
4. The three files are uploaded to OPIS by IT services:

    4.1 **Direct Match File** – Death data is added to the Central Patient Index (CPI) death table. The source of the death information is updated to 'S' for Statistics Canada, Provincial Death Clearance. If the date of birth, health card number and/or name is null, they are updated with information contained in the VS file.

    4.2 **DCO** – Patient identifiers, death data and disease records are added to OPIS using a program developed by IT Services. The initial and definitive diagnosis methods are entered as 'D' for death certificate only and the registry type is entered as 'F' for follow-back.

    4.3 **DCD –** Death information is added and a disease record is created from the VS data using a program developed by IT Services. The method of diagnosis is 'D' and registry type is 'F.' Null fields can be updated as indicated in section 4.1.

5. IT Services uploads data for all DCO's on the DCOF (followback) OPIS forms.

6. Follow-back is done for all DCO's to determine whether a person was previously diagnosed with cancer prior to death. Two management screens are available on OPIS to track the follow-back process:
    - DCO Follow-back (DCOF)
    - DCO Letters (DCOL)

    6.1 The field items downloaded to the DCOF, abstracted from the Vital Statistics death registration form, should be reviewed before commencement of the follow-back procedure.

    6.2 The Registry Team Leader generates a report in Excel format from DCOF with the following information:
    - OPIS #
    - Hospital #
    - Patient's Name
    - Individual's usual residence at time of death
    - Birth date
    - Health Card Number
    - Death date
    - Cancer cause of death
    - Underlying cancer cause of death
    - Physician who signed the death registration
    - Physician's address

    6.3 After the report is generated, the Quality Management Technician cleans up the Excel file. The records are sorted according to hospital code and a list is generated for each

hospital. Records that do not have a hospital code are sorted by physician number. A mail merge is done to generate letters for the physicians. The hospital lists and the physician letters are faxed to the appropriate health information department or physician. Copies of the registry form are provided.

6.4   The 'Date sent field' on DCOL screen of OPIS is entered with the date that the letters were sent.

6.5   As replies are received, the 'returned date' on the DCOL screen is entered with the date the reply was received and the 'response' on the DCOF screen is entered to reflect the appropriate response (0-None, 1-Info received, 2-Negative response, 3-Duplicate, 4-Non-malignant, 5-Out of province, 6-Mets) and the 'status' is updated to 'closed'.

6.6   Update the DR screen with appropriate disease information and update any other pertinent screens as information is received.

6.7   If no information is received from the physicians in the predetermined length of time (approx. one month) then a second request is sent. If information is not received after two requests, leave the status on the DCOF screen as 'active.' These active DCO's will be sent out again in the next quarter. If a second request to a physician does not come back within a two week period, a letter is sent to the nearest hospital. When no response is received after two requests in the second round, then the status on the DCOF screen is updated to 'closed' and today's date is entered as the returned date on the DCOL screen.

Death Clearance

NS Vital Statistics sends death file to SEU (receive file every quarter)

Internal record linkage conducted to identify possible duplicates on OPIS

Record linkage of death and NSCR data files which generates three files:
1. Direct Match
2. DCO
3. DCD

Registry Team Leader evaluates DCD's to determine if new disease should be entered.

Files generated from record linkage are uploaded by IT Services and updated appropriately. IT Services uploads data for all DCO's on the DCOF OPIS forms

Registry Team Leader generates a report in Excel format from DCOF.

Excel file is cleaned up by Quality Management Technician. Records are sorted according to hospital code and a list is generated for each hospital. Records without a hospital code are sorted by physician number. A mail merge is conducted to generate letters for the physicians.

Hospital lists and physician letters are faxed to the appropriate health information department or physician. Copies of the registry form are included. The 'Date sent field' on the DCOL screen is updated with today's date.

Response received?

Yes → Update DR screen and any other pertinent OPIS screens. Update status to closed and response type on DCOF and returned date on DCOL.

No → Send second request to physican or health information department

Response received?

Yes →

No → Resend in next quarter. If a second request to a physician does not come back within a two week period, a letter is sent to the nearest hospital.

Response received?

Yes →

No → Update DR screen and any other pertinent OPIS screens. Update returned date on DCOL and response type and status on DCOF.

REFERENCES

Association Websites

- Canadian Cancer Registry (CCR) – Statistics Canada
  www.statcan.ca/english/sdds/3207.htm

- Canadian Cancer Society
  http://www.cancer.ca/

- International Association of Cancer Registries (IACR)
  http://www.iacr.com.fr/

- North American Association of Central Cancer Registries (NAACCR)
  http://www.naaccr.org/

- Surveillance, Epidemiology and End Results (SEER)
  http://seer.cancer.gov/

Coding References and Manuals

- Abstracting and Coding Guide for the Hematopoietic Diseases – SEER, 2002

- AJCC Cancer Staging Manual 6th Edition – American Joint Committee on Cancer, 2002

- Collaborative Staging Manual and Coding Instructions – Version 01.03.00
  Available at: http://www.cancerstaging.org/cstage/manuals.html

- International Classification of Diseases for Oncology, Third Edition (ICD-O-3) – World Health Organization (WHO), 2001

- Multiple Primary and Histology Coding Rules – SEER, 2007
  Available at: http://seer.cancer.gov/tools/mphrules/download.html

- SEER Summary Staging Manual – Revision 2000
  Available at: http://seer.cancer.gov/tools/ssm/

Legislation

Historical

- Cancer Treatment and Research Foundation of Nova Scotia Act (Paper copy available at SEU)

- Queen Elizabeth II Health Sciences Centre Act
  Available at http://www.gov.ns.ca/legislature/legc/statutes/queen.htm

Current

- Freedom of Information and Protection of Privacy Act
  Available at: http://www.gov.ns.ca/legislature/legc/statutes/freedom.htm

- Health Services and Insurance Act
  Available at: http://www.gov.ns.ca/legislature/legc/statutes/healthsi.htm

- Health Act
  Available at: http://www.gov.ns.ca/legislature/legc/statutes/health.htm

- Hospitals Act
  Available at: http://www.gov.ns.ca/legislature/legc/statutes/hosptls.htm

- Vital Statistics Act
  Available at: http://www.gov.ns.ca/legislature/legc/statutes/vitalsta.htm

APPENDIX A: RESIDENCY GUIDELINES FOR THE PROVINCIAL/TERRITORIAL CANCER REGISTRIES IN CANADA

To ensure comparability of definitions of cases and the population at risk (numerator and denominator), the Canadian Cancer Registry (CCR) rules for determining **residency at time of diagnosis** are to be identical or comparable to rules used by the Canadian Census whenever possible.

The residence at diagnosis is generally the place of usual residence as stated by the patient or, as stated in the Census definition, "the dwelling in Canada where a person lives most of the time". Residency is their usual place of residence, regardless of where they are when diagnosed. For patients with multiple tumours, the address may be different for each primary tumour.

There are a number of situations where the process of determining residency is not intuitive and special guidelines have been created in order to define an individual's usual place of residence. The Data Quality Committee (DQC) for the Canadian Council of Cancer Registries (CCCR) recognizes that some Provincial/Territorial Cancer Registries (PTCRs) are removed from the direct patient contact relationship and may not have access to the patient or the information to confirm residency. Using the provincial health insurance number (HIN), as a determining factor of residency during initial case abstraction is appropriate. When permanently relocating, the HIN from previous province of residence is valid for three months. However, if the case is identified as a potential duplicate during a record linkage cycle additional information should be obtained before confirming residency as it may not be appropriate to default to using province of HIN as the primary residence.

PTCRs are encouraged to use these guidelines to determine residency for those categories of persons whose residence is not immediately apparent.

1. **Residence (one residence)**
   The dwelling in Canada where a person lives most of the time.

2. **Persons with more than one residence**
   Usual residence rule applies, however if the time spent at each residence is equal or the abstractor is not sure which one to choose, the residence where they were staying on the day cancer was diagnosed should be considered his or her usual place of residence. (See examples below)
   Exception: consider the residence they share with their family as their usual place of residence, even if they spend most of the year elsewhere.

   a) Commuter workers living away part of the week while working: Consider the residence they share with their family as their usual place of residence, even if they spend most of the year elsewhere. (I.e., parents, husbands, wives or common-law partners)

   b) Snowbirds: People who live at another residence (city, province or country) with a warmer climate. Residence should be documented as where they live most of the time.

   c) Children in joint custody: Residence should be documented as where they live most of the time. If time is equally divided, their residence is documented as where they were staying on the day cancer was diagnosed.

3. **Patients with rural addresses**
If the information provides a rural address only, which may be the post office box, record the address as stated but make every attempt within your resources to identify his/her actual physical place of residence at time of diagnosis.

4. **Patients with no usual place of residence (I.e. homeless, transient people)**
Residents who do not have a usual place of residence should be documented as where they were staying on the day cancer was diagnosed.

5. **Institutional collective dwellings (Collective dwellings that provide care or assistance services). Persons in institutions** with no other usual place of residence elsewhere in Canada or persons who have been in one or more institutions for a continuous period of six months or longer are to be considered as usual residents of the institution**.**

Institutional collective dwellings include:
i. Residents of a long-term care facility, hospital, or a home for the aged.
ii. In homes, schools, hospitals, or wards for the physically handicapped, mentally challenged, or mentally ill or in drug/alcohol recovery facilities.
iii. Inmates of correctional institutions, including prisons, jails, detention centers, or halfway houses.
iv. Children in juvenile institutions such as residential care facilities for neglected or abused children or orphanages.

For abused women, or for runaway or neglected youth please see section 6. Non-institutional collective dwellings.

6. **Non-institutional collective dwellings (Collective dwellings that do not provide care or assistance services).** Residence should be documented as their usual residence if they report one (the place where they live most of the time) or otherwise at the inn, hotel, etc.

Non-institutional collective dwellings include:
i. Inns, hotels, motels, and hostels.
ii. YMCAs/YWCAs, or public or commercial campgrounds.
iii. Military bases
iv. Migrant workers (lumber / mining camps & farms)
v. Members of religious orders in monasteries or convents

a) **Shelters with sleeping facilities for people without housing, for abused women, or for runaway or neglected youth.**
Residence should be documented as the shelter.

7. **Students**
Students who live away from home while attending school, but who return to live with their parents part of the year should consider their place of residence as their parents home, even if they spend most of the year elsewhere.

8. **Live-ins**

a) **Live-in nannies**
Residence should be documented as where they live most of the week.

b) **Foster children, boarders, or housemates**
Residence should be documented as where they are living at time of diagnosis.

9. **Merchant and Coast Guard Vessels**
Merchant vessels, coast guard vessels and oil rigs at sea should be documented as their usual onshore residence if they report one (the place where they live most of the time when they are onshore) or otherwise at their vessel's homeport.

Naval Vessels
Canadian Forces Naval Vessel residence should be documented as their usual onshore residence if they report one (the place where they live most of the time when they are onshore) or otherwise at their vessel's homeport.

Armed Forces
Canadian Armed Forces residence should be documented as their usual place of residence if they report one or otherwise where they are stationed at time of diagnosis.

10. **Non-permanent residents (Foreign Citizens)**
Persons who hold a student or employment authorization, Minister's permit or who were refugee claimants at time of diagnosis for a continuous period of six months or more.

a) **Citizens of foreign countries who have established a household or are part of an established household in Canada while working or studying, including family members with them.**
Residence should be documented as their household in Canada.

b) **Citizens of foreign countries who are living in Canadian embassies, ministries, legations or consulates.**
Residence should be documented as the embassy.

c) **Citizens of foreign countries temporarily travelling or visiting Canada.**
These cases are not reportable to the Canadian Cancer Registry.