



Cancer Record

Newsletter for Cancer Registries in Canada



Spring 2000 - Issue Number 19

Editor's Note

Many months have passed since the last issue of the *Cancer Record* in April 1998. There has been a flurry of activity since then which is documented in this issue.

As many of you know, I was off for four months this past summer on Parental leave, which put me quite behind in many of my tasks. But, I have been back at the office now for a few months and I can finally see my desk again! Our new addition to the family has been a great joy as well as a challenge. I want to thank all of you that sent me email and phone messages over the summer wishing us well. It meant a lot to have the thoughts. I also want to take this opportunity to thank the Planning Committee members from this past year's CCR Technical Workshop who made the workshop a grand success! Especially to Elaine Hamlyn who painstakingly took minutes at every conference call we held and to Carol Russell who did a lot of preparation in Edmonton for the workshop. Preparing for the workshops is no small feat and it really paid off!

Ghislaine has written an update on some of the Cancer activities over the last few months on page 5. Some of the activities which have taken place since the last issue of the *Cancer Record* are four NAACCR (North American Association of Central Cancer Registries) data submissions, the 18th and 19th CCR Technical Workshop, and three face to face Data Quality Committee meetings (February and September 1999 and February 2000). All of these activities are documented in this issue of the *Cancer Record*.

As always, a Readers Feedback form is included at the back of the *Cancer Record* for your convenience.

Your comments are welcome.

*Ingrid Friesen, Managing Editor
Statistics Canada*

Contents

Articles

- Coding and Reporting Issues 2-3
- Canadian Cancer Registry Update 5
- International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3) Update 6
- International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) 6
- Canadian Cancer Statistics 2000 7
- Reference Section 7-8
- SINQ 8
- Internet Web sites 9
- Canadian Coalition On Cancer Surveillance 10-11
- Journal of Registry Management- Call for Papers .. 12
- CCR Data Quality Committee report 13-14
- Québec Cancer Registry 19
- News From Coast to Coast- Staff changes 21
- Readers Feedback Form 23

Workshops/Conferences/Training

- National Cancer Registrars Association Annual Education Conference 4
- Canadian Council of Cancer Registries Annual Meeting 8
- Your Call for Data Toolkit Workshop 12
- Upcoming Training/Education Workshops 15-16
- Ottawa Regional Cancer Centre Staging Workshop 16
- Canadian Cancer Registry Technical Workshop Activities 17-18
- Canadian Health Record Association Annual Meeting 20-21



Statistics
Canada

Statistique
Canada

Canada

CODING/REPORTING ISSUES

QUERY NO. 1:

Update to Query No. 1 of Cancer Record #18

Subject: *High Grade Prostatic Intraepithelial Neoplasia (PIN III)*
ICD-O-2 morphology code 8148/2

The term "prostatic intraepithelial neoplasia" or PIN was selected at a conference in 1989 from a whole variety of other names for the same condition. This entity originally was subdivided into three groups; PIN I, PIN II and PIN III. These groups have now been renamed into only two groups, which are low grade and high grade. **The high grade type is the same as PIN II and PIN III and the low grade type is the same as PIN I.** The high grade type is the only PIN that is reportable to the CCR at this time. There is a strong association between PIN III and invasive prostate cancer, so it is important to record this entity. The pathologists do not usually report the low grade PIN, so this term is unlikely to appear on pathology reports. The correct morphology code for the high grade PIN III is 8148/2 and is now accepted in the Canadian Cancer Registry.

References:

The Pathologic Examination of Prostate Tissue, Oppenheimer, Jonathon R., Clinical Review 97/0005; September 30, 1997 (from The Prostate Cancer InfoLink Internet site).
The CCR Data Quality Committee (1998)

Cancer Record

The Cancer Record is a newsletter for Cancer Registries in Canada, published by Statistics Canada.

Correspondence and/or inquiries should be sent to:

Ingrid Friesen
Managing Editor
Cancer Record
Health Statistics Division
18th Floor R.H.Coats Building
Statistics Canada
Ottawa, ON
K1A 0T6

Email: ingrid.friesen@statcan.ca
Phone: 613 951-8384
Fax: 613 951-0792

Contributors

Dr. Fred Alexander, Tom Baker Cancer Centre
Darlene Dale, Cancer Care Ontario, Data Quality Committee Chair
Barbara Foster, Canadian Coalition on Cancer Surveillance
Joanne Hamm, Nova Scotia Cancer Centre
Coreen Hildebrand, Cancer Care Manitoba
Brigitte Morin, SSSS, Québec Cancer Registry
Karen Robb, Saskatchewan Cancer Agency
Ghislaine Villeneuve, Canadian Cancer Registry, Statistics Canada
Jo-Anne Walker, Cancer Care Manitoba

Production and Composition

Renée Bourbonnais, Robert Pellarin
Agnes Jones, Micheline Pilon

Editing

Murielle Campeau

The next issue will be published in the Fall 2000.

QUERY NO. 2

Subject: High Grade Squamous Intraepithelial Lesions of the Cervix (HGSIL)

Cervical lesions are becoming more complex to resolve. Now, there is a way of reporting the results of pap tests by using the *Bethesda System*. This is a system for cytology. This system uses descriptive diagnostic terms rather than class numbers when reporting the results. Squamous intraepithelial lesion (SIL) is a term used to describe abnormal cells in cytology specimens from the epithelium of the cervix (Bethesda System). There are two new classification terms for the Bethesda System (developed by the National Cancer Institute), as follows:

1. Low-grade squamous intraepithelial lesion (LGSIL) =Mild dysplasia or CIN I

The term Low –grade SIL refers to early changes in the size, shape, and number of cells (epithelial cells on the surface of the cervix). Some LGSILs go away on their own, while others may grow larger or become more abnormal, forming an HGSIL.

2. High-grade squamous intraepithelial lesion (HGSIL)

- =Moderate dysplasia/CIN II
- =Severe dysplasia/CIN III
- =Carcinoma in situ/CIN III

The term High-grade SIL means there are a significant number of cells that look abnormal (dysplastic). These are shed from the epithelium on the surface of the cervix. Some cytologists/pathologists may still call HGSIL by the previous terms of moderate or severe dysplasia; CIN II or CIN III; or carcinoma in situ. These terms are used for reporting cervical biopsies.

Dysplasia of the cervix is a term used to describe histologic abnormalities in biopsies from the epithelium on the surface of the cervix. Dysplasia has been described as mild, moderate or severe, depending on how abnormal the cells appear at what level in the epithelium and how abnormal their relationship is to each other.

Carcinoma in situ (CIS) of the cervix has been used to describe the most severe degree of dysplasia in the absence of invasion into the underlying tissue. The inability to distinguish severe dysplasia consistently

from carcinoma in situ has led to new terminology-cervical intraepithelial neoplasia.

Cervical intraepithelial neoplasia (CIN) is more recent terminology that is used to describe the same changes as dysplasia and is divided into CIN I, II and III; where CIN III includes the previous categories of severe dysplasia and carcinoma in situ.

We only have a way to report the CIN III cases at this time. The ICD-O-2 coding book does not contain a morphology code for CIN I (low grade or mild dysplasia) or CIN II (moderate dysplasia). The only ICD-O-2 morphology codes available are (8077/2) CIN III (with or without severe dysplasia) and/or squamous cell carcinoma in situ (8070/2) of the cervix.

Of note, the NAACCR, NPCR (National Program of Cancer Registries), SEER and COC (Commission on Cancer) adopted a recommendation that “population-based registries discontinue routine collection of data on pre-invasive cervical neoplasia unless there is strong local need and interest and sufficient resources are available to collect all high-grade squamous intraepithelial lesions and its equivalent terms, effective January 1, 1996 data.”

The CCCR Data Quality Committee is reviewing this issue and will make a recommendation in the coming year.

References:

- Dr. Fred Alexander, Director of Pathology, Tom Baker Cancer Centre
- SINQ (SEER Inquiry System) Query #141 of the SEER section
- ICD-O-2 Introductory page xxix **Carcinoma in situ and CIN III**
- Histological Typing of Female Genital Tract Tumours (WHO Blue book) page 40-41
- Internet:
 - www.yourhealth.com
 - www.lib-sh.lsumc.edu
 - www.pathlabsofark.com/bethesdasys.htm
 - www.ncc-online.org
- American Family Physician 1995 February 1; 51(2): 434-440 **Preventing cervical cancer: the role of the Bethesda system**. Shepherd JC; Fried RA

NATIONAL CANCER REGISTRARS ASSOCIATION CONFERENCE 1999

Howdy Y'all!

The National Cancer Registrars Association Silver Anniversary Conference was held May 25-28, 1999 in Dallas, Texas at the Adam's Marks Hotel. Pre-Conference workshops were held May 25th, 1999. These included a pre-certification workshop, a workshop on Meeting the Commission on Cancer Program Standards, a Cyberday, and a Goal-Setting Workshop. The Pre-certification workshop was a review for the National Board for Certification of Registrars' CTR credentialing examination. The Survey Savvy workshop was a seminar which helps hospital-based registrars prepare for a Cancer Programs Survey based on the Standards of the Commission on Cancer. The Cyberday included an introduction to the Internet, a session on advanced Internet usage, a session on how to access and use on-line cancer data, and a practicum on using NCI's "SEER Stat" application. The focus of the Goal-Setting Workshop was to identify and acquire skills needed for the future.

Opening day sessions began with concurrent Special Interest Group (SIG) Meetings and breakfast, followed by Opening Ceremonies and a Spotlight Speaker. The President, Steven Roffers announced that approximately 780 of the 2800 members of the NCRA were in attendance. Dr. John Young, President of the International Association of Cancer Registries, who brought congratulations from IACR on the 25th Anniversary of the NCRA, gave the opening address. Dr. D. Miller spoke on the *Evolution of the Cancer Registrar*. He began his presentation by asking everyone to write down the first names of family and friends who had been diagnosed with cancer. These names were then mounted on a banner, which was revealed later in the presentation. The audience was told that there were over 8000 pieces of paper distributed. The banner, which stretched across the large ballroom, emphasized the way that cancer touches everyone. Dr. Miller stressed that as the baby boomers age, the workload of the cancer registrar will increase by 30 to 40%, and he stressed the need for Certified Tumour Registrars. From the intensity of Dr. Miller's presentation, we moved to an uplifting presentation on *Positive Assertiveness-Humor in the Workplace*, given by Nancy Etzold. The focus of this presentation was on using humour and having a positive attitude in the workplace. During the Business Meeting and Luncheon, members voted on amendments to the bylaws and committee reports were presented. After lunch, Dr. Thomas Tucker and Michelle Hoskins'

presentation discussed the positive aspects of communication between hospital and central cancer registries. *Managed Care and The Registry* was presented by Jacquie Hill and she discussed how registry data are utilized to assess quality outcomes of cancer care.

The second day began with the Certified Tumour Registrars Recognition Breakfast, which acknowledged recently certified registrars. Concurrent sessions consisted of: The Central Registries Track, Data Usage Track, Pediatric Track, Advanced Track, and Registry Operation-Principles and Practice Track. These were held during the remainder of the day, with five topics discussed in each track. The first session we attended was on *Sentinel Lymph Node Mapping* and was presented by Karen Malnar. This session gave an overview of sentinel node mapping, what it is, why it is being used and how it is performed. This session also included a video of a sentinel node excision. The second session we attended was presented by April Fritz, and covered the topic of *Visual Presentation of Registry Information*. This session reviewed guidelines for using graphics in Presentations. A session on *Developing Policies and Procedures, A Road Map to the Registry*, outlined the development and maintenance of a Policy and Procedure manual. We attended a session on *Stem Cell Transplantation*, presented by Dr. Carl Lenarsky. He described the indications, procedures, risks and outcomes as well as an overview of the basic anatomy and physiology of bone marrow. The final presentation we attended was entitled *Let's Hear from the Registrar* and was a very lively and informative presentation on how to give presentations.

The regional meetings were held on the final day of the conference, and discussed areas of concern for each of the three regions (Eastern, Midwestern, and Western). Following the regional meetings, four oral abstract presentations were given. These included: *AJCC Collaborative Staging Task Force, Surveillance of Primary Intracranial and CNS Tumours, Mortality from Multiple Myeloma and Non-Hodgkin's Lymphoma in Jefferson, Orange, and Hardin Counties*, and finally, *The National Programs of Cancer Registries: Progress from 45 States and the District of Columbia*. Dr. Bridget McCarthy gave a presentation on the Central Brain Tumour Registry of the United States (CBTRUS). The purpose of this presentation was to inform participants of the role of the CBTRUS.

CANADIAN CANCER REGISTRY UPDATE

Mrs. Constance Percy presented the new ICD-O-3 lymphoma and leukemia terms in her presentation entitled *ICD-O-3: Did You Know?* The afternoon session began with a presentation by Rosemarie Clive on the history of cancer registration and the major milestones of the NCRA during her 25-year career as a registry secretary/registrar. The final presentation, *The War Against Cancer*, was presented by Katie Clark. She discussed the development of a state Cancer Registry from legislation to implementation.

The conference included an exhibition hall, which included displays from software companies, various state registries, NCRA, NAACCR, ACSCC, CDC, and the SEER Program from NCI. Ample opportunity was given to visit these displays and network with colleagues.

Social events included a Welcome Reception, Texas Style BBQ luncheon, and the Silver Anniversary Installation and Awards Banquet. The Welcome Reception was a Texas style ho-down complete with Tex-Mex hors d'oeuvres and beverages, a country band, and line dancing. The ballroom for the Award's Banquet was festively decorated in blue and silver stars and balloons. Following the Texas Steak dinner, new executive members were installed and the Outstanding New Professional Award, Distinguished Member Award, and Literary Award were presented. The winner of the Poster presentation for NCRA Week 2000 was also announced. The banquet provided an opportunity to make new friends and visit with colleagues.

The next NCRA conference will be held in Albuquerque, New Mexico, May 9-12, 2000.

We would like to thank Jeri Kostyra, CTR and Dr. Erich Kliewer for giving us the opportunity to attend this conference. It was a very enriching and educational experience we won't soon forget.

Jo-Anne Walker, HRT, CTR
Coreen Hildebrand, HRT, CTR
Manitoba Cancer Registry

The Canadian Cancer Registry (CCR) has grown rapidly over the past two years. At the time of release of the last issue of the Cancer Record in the Spring of 1998, the CCR had approximately 352,947 patient records on its base, compared with 644,849 patient records in March 2000. Also, timeliness has improved markedly. The Provincial Territorial Cancer Registries (PTCRs) are expected to submit their 1998 data to the CCR before the end of June 2000. All data received by then will be used in the preparation of projections for *Canadian Cancer Statistics 2001*.

The third internal CCR Record Linkage cycle has recently been completed. The linkage allowed for the identification of duplicate tumours within and across eleven provincial/territorial registries. All groupings of potential duplicates have been resolved by PTCRs and as a result, more than 1,000 patient and tumour records have been deleted from the CCR base. The database has since been «unfrozen» and can now receive updates, corrections and data submissions for any year starting with 1992.

The second cycle of the CCR Death Clearance Module will be run in production in early April 2000 and will use death registration records from 1992 to 1997. Feedback reports generated during this process will be sent to the PTCRs for review.

Data from the CCR were sent for eight of the provincial and territorial registries participating in the *2000 NAACCR Call for Data*. All deadlines were met and Statistics Canada will be happy to assist the registries once again next year.

The International Agency for Research on Cancer (IARC) Call for Data for the *Cancer Incidence in Five Continents (Volume VIII)* publication has been received. The Provincial/Territorial Cancer Registries will soon be contacted by Statistics Canada about their intention to participate. The deadline for all submissions to IARC is July 31, 2000.

Ghislaine Villeneuve
Chief
Vital and Cancer Statistics

INTERNATIONAL CLASSIFICATION OF DISEASES FOR ONCOLOGY, THIRD EDITION (ICD-O-3) UPDATE

In June 1998, a meeting was held in Lyon, France by the International Association of Cancer Registries to begin the review of the ICD-O-3. The ICD-O-3 is a collaborative effort with the US National Cancer Institute (NCI), the World Health Organization (WHO), the International Association of Cancer Registries (IACR) and the International Agency for Research on Cancer (IARC). The editors of the ICD-O-3 Field Trial are April Fritz and Constance Percy of the NCI. A request for new morphology terms and supporting documentation was sent out prior to this meeting. The material was reviewed and a Field Trial edition of the ICD-O-3 was created. This past summer, a Field Trial was run from June 15 through August 31, 1999 to evaluate the new morphology codes. The results of the Trial are being evaluated and a new ICD-O-3 is planned for early 2000 with implementation of the ICD-O-3 for **January 1, 2001**. The Uniform Data Standards Committee of the NAACCR is working on the programs and is planning to have them available in early 2000. The conversion programs will be prepared at SEER for distribution. The next CCR Technical Workshop will have a block of time devoted to the ICD-O-3 for training and information. In addition, there also will be some satellite conferencing and web-based training programs run through SEER to supplement individual training which hopefully will be ready in July of 2000. The training will focus on the new morphology terms, as well as how to code pathology reports based on the final diagnosis or microscopic diagnosis.

The ICD-O-3 committee is also reviewing the proposed new terminology from the World Health Organization for **bladder** tumours to see how it fits into the new ICD-O.

More details will follow as they arise.

INTERNATIONAL STATISTICAL CLASSIFICATION OF DISEASES AND RELATED HEALTH PROBLEMS, TENTH REVISION (ICD-10)

The 10th revision of the ICD was approved by the World Health Organization in 1990 and has been available for implementation since 1993.

CIHI is responsible for the implementation of the ICD-10 in Canada for Morbidity. The planned implementation date is April 1, 2001 with the exception of: Alberta - 2002, Québec - not before 2002, Manitoba - 2002 and Ontario - 2001 or 2002. CIHI will be distributing a "Canadianized" version of the ICD-10 for morbidity. For more information on the ICD-10-CA implementation for morbidity contact CIHI Toronto at ccicd-10@cihi.ca, 416-481-2002. Also see the CIHI Web site www.cihi.ca.

The ICD-10 as published by the World Health Organization (WHO) is available from:

Canadian Public Health Association (CPHA)
Health Resources Centre
400-1565 Carling Ave.
Ottawa, Ontario
K1Z 8R1
Tel: 613-725-3769
Fax: 613-725-9826

All Canadian Vital Statistics Registries have implemented the ICD-10 as of **January 1, 2000** data. For more information contact **Patricia Wood, Mortality Classification Specialist at 613-951-1648 or woodpat@statcan.ca**.

REFERENCE SECTION

1. Canadian Cancer Statistics 1999

Canadian Cancer Statistics 1999 was released on April 8, 1999. This monograph was developed by a Steering Committee reporting to the Advisory Committee on Cancer Control of the National Cancer Institute of Canada. The Committee includes representatives of the National Cancer Institute of Canada, the Canadian Cancer Society, Health Canada, Statistics Canada, the Canadian Council of Cancer Registries and university-based cancer researchers.

The production and distribution of the monograph is the result of collaboration among all these groups.

This 76-page monograph contains actual rates and frequencies up to the most recent year for which complete data are available (1994 for incidence; 1996 for mortality), and in addition, estimated values for years up to 1999. The special topics this year are (1) an analysis of the relative impact of population growth and aging on cancer incidence in Canada, and (2) a review of current directions in cancer surveillance in Canada. This publication, now widely used by health professionals, media and the general public, has been successful in promoting the use of Canadian cancer data in Canada.

Canadian Cancer Statistics 1999 is available from Divisions of the Canadian Cancer Society, Statistics Canada or the Cancer Bureau at Health Canada. It is also available on the Internet at <http://www.cancer.ca> and <http://www.ncic.cancer.ca>.

The **Year 2000** issue will be released on **April 13, 2000**.

National Cancer Institute of Canada: *Canadian Cancer Statistics 1999*, Toronto, Canada, 1999.

2. TNM Atlas, Illustrated Guide to the TNM/pTNM Classification of Malignant Tumours, 4th edition, 1997

This fourth edition of the TNM Atlas is compatible with the AJCC Cancer Staging Manual, 5th Edition.

This edition of the TNM Atlas is available by calling 1-800-SPRINGER or from the Internet at <http://www.springer-ny.com/>.

3. TNM Interactive: An Illustrated Resource for the Classification and Staging of Malignant Tumours

The *TNM-interactive*, (*TNM-i*) is a product of the UICC (International Union Against Cancer). This CD-ROM allows the user to click on icons in the *TNM Classification of Malignant Tumours, Fifth Edition* book and view the related information in two other books. 479 illustrations from the *TNM Atlas: Illustrated Guide to the TNM/pTNM Classification of Malignant Tumours, Fourth Edition 1997* are included and 150 explanatory notes from the *TNM Supplement*. This software is more than a convenient electronic reference book; the software allows users to both print and save staging form data for individual cases.

TNM-interactive includes the existing TNM terminology and new nomenclature featured in the *TNM Classification of Malignant Tumour, Fifth Edition* that was ratified by a joint meeting of the UICC and the American Joint Committee for Cancer (AJCC) in November 1996.

The printed staging forms include illustrations of the primary site and information about the case (name, hospital number, dates, histology and so forth) as well as the text of the T, N, M and Stage Group. Each case may be saved electronically on your hard drive in ASCII format, but could also be loaded into a database created in another application such as *MICROSOFT ACCESS*.

System requirements are Windows 3.1/Windows 95/WindowsNT with a minimum of 486/66, 16 MB RAM, 2xCD-ROM drive (Also compatible with Macintosh System 7.0 or higher).

Edited by L. H. Sobin. CD-ROM published September 1998; ISBN: 0-471-29696-1, \$224.95 (Canadian) John Wiley's & Sons, Inc. (Order by calling 908-469-4400 or from the Internet at <http://catalog.wiley.com>)

4. SEER Program: Comparative Staging Guide for Cancer (new edition)

The new edition of this publication is estimated for completion in the **Spring of 2000**. Contact the SEER Program at the National Cancer Institute for more details. (<http://www-seer.ims.nci.nih.gov> or 1-800-4CANCER)

5. TNM Supplement 1993: A Commentary on Uniform Use

This manual promotes the understanding of and interest in the application of the TNM staging system and to show how simply, uniformly and precisely the system is structured.

Edited by P. Hermanek, D.E. Henson, R.V.P. Hutter, L.H. Sobin. ISBN: 3-540-56556-6 and 0-387-86886-6, \$45.00 (US) softbound. Springer Verlag, Berlin, Heidelberg, New York.

Order by calling 1-800-SPRINGER or from the Internet at <http://www.springer-ny.com/>.

A revision of this book is currently under way for publication in **mid-2000**.

6. Workbook for Staging of Cancer- 2nd Edition

This workbook provides cancer registrars, physicians and other health professionals with a tool to learn the concepts of TNM staging and apply them in a consistent manner. It is a companion to the 5th edition of the AJCC Cancer Staging Manual. This is the 2nd edition of the NCRA workbook and was available at the Annual NCRA meeting in Dallas.

Contact the National Cancer Registrars Association for ordering information:

National Cancer Registrars Association
Box 15945-295
Lenexa, KS
66285-5945
www.ncra-usa.org

7. A Comparison of Cancer Staging Systems-Illinois State Cancer Registry video conference April 26, 1999

On April 26, 1999, April Fritz presented a video conference session on various cancer staging methods used in the collection of cancer diagnosis information as required by the National Program of Cancer Registries in the United States. The presentation handouts are available for downloading on the NAACCR web site.

See the web site address at <http://www.naacr.org/events/index.html> or contact Ingrid Friesen at ingrid.friesen@statcan.ca.

8. StageIt version 5.0 Software

The American Joint Committee on Cancer (AJCC) has developed a new version of the StageIt software product. This software is an electronic version of the TNM System for the classification of malignant tumours. StageIt is designed to be an automated staging system, database and tutorial on staging. It includes all sites from the AJCC *Cancer Staging Manual, 5th edition* plus anatomical drawings for each site. This product is available through the AJCC Executive office.

The new AJCC web site is www.cancerstaging.org

SEER INQUIRY SYSTEM (SINQ)

SEER is working on a Windows-based SINQ at this time. The algorithms and design have been sent to the programmers and the questions are presently being developed. Once complete, the new SINQ will be accessible from the SEER web site and downloadable to a windows-based PC. There is no set date for completion.

In Canada, a database of 154 questions and answers is almost ready for distribution. It will be provided in CD-ROM format or diskette format (DOS) depending on the request. This database encompasses historical queries and present queries for the Canadian Cancer Registry.

Please contact Ingrid Friesen at Statistics Canada for further information.

CANADIAN COUNCIL OF CANCER REGISTRIES (CCCR) ANNUAL MEETING

What: CCCR 2000 meeting with representatives from Provincial/Territorial Cancer Registries, Statistics Canada, NAACCR, Health Canada and NCIC

When: June 12-13, 2000

Where: St. John's, Newfoundland

Co-Chairs: Mr. Gary Catlin (Statistics Canada)
Ms. Diane Robson (Saskatchewan)

INTERNET WEB SITES

Cancer Related Sites:

National Board for Certification of Registrars (NBCR)	www.nbc.org
TNM Internet Homepage	www.uicc.org/tnm
The College of American Pathologists (CAP)	www.cap.org
The Canadian Coalition on Cancer Surveillance (CCOCS)	www.hc-sc.gc.ca/hpb/lcdc/bc/ccocs/index.html
Index of Providers and Textbooks for Obstetrics and Gynecology	www.vh.org/Providers/Textbooks/OBGYNcology/
American College of Surgeons (Cancer Department)	www.facs.org
American Joint Committee on Cancer (AJCC)	www.cancerstaging.org
Cancer News on the Net	www.cancernews.com
Cancer Registry Training Program Web site	www.sph.emory.edu/GCCS/training
The Canadian Association of Pathologists- Online (CAP)	www.cap.medical.org
Canadian Strategy for Cancer Control	www.hc-sc.gc.ca/hppb/csc/csc.html

Provincial/Territorial Cancer Registries

Saskatchewan Cancer Agency	www.scf.sk.ca
MSSS Le fichier des tumeurs du Québec	www.msss.gouv.qc.ca/fr/statisti/indisp/tumeurs_index.htm
British Columbia Cancer Agency	www.bccancer.bc.ca
Alberta Cancer Board	www.cancerboard.ab.ca

Miscellaneous Other Sites:

Canadian Medical Association	www.cma.ca/eng-index.htm
Health Information Roadmap Documents	www.cihi.ca
- Responding to Needs	
- Beginning the Journey	
- National Consensus Conference	
- Launching the Process	
- Health Information Needs in Canada	
Canada Health Infoway	www.hc-sc.gc.ca/ohih-bis
Disease Surveillance On-Line (for Cancer, Cardiovascular diseases and other Notifiable Diseases)	www.hc-sc.gc.ca/hpb/lcdc/webmap/
The Canadian Community Health Survey (CCHS): extending the wealth of health data in Canada (Click on "Concepts, definitions and methods", then "Discussion papers or new surveys")	www.statcan.ca
PubMed (National Library of Medicine)	www.ncbi.nlm.nih.gov/PubMed

CANADIAN COALITION ON CANCER SURVEILLANCE (CCOCS)

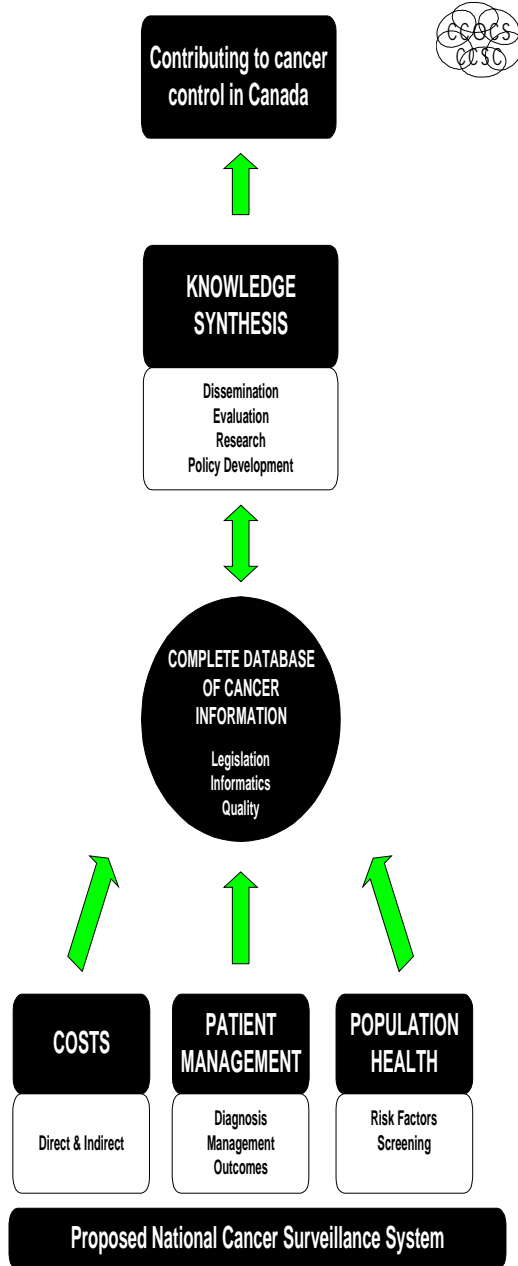
The Canadian Coalition on Cancer Surveillance (CCOCS) is comprised of key cancer stakeholders from across the country with a mandate of developing an integrated system across the nation to provide the information that the cancer control planners, policy makers, providers and the public require to plan and fund cancer services and programs. The ultimate vision of the CCOCS is to reduce the burden of cancer in Canada.

The CCOCS has prepared a Business Plan, which outlines the steps required to create a national cancer surveillance system. The system would be a network of networks or a national database, which will be achieved by linking existing provincial and national systems. The core data elements required to create a national cancer surveillance system fall under the following broad categories: patient management, population/public health and costs. This national network will be developed and maintained by appropriate information/technological systems, and adhere to strict quality management guidelines. Integral to the success of a national cancer surveillance system is the need to have legislation that maintains a balance between the needs of those who collect cancer information and the provision of confidentiality, security and privacy of the individual.

The final link of the surveillance system is the dissemination of this information to those who need to know. One means of achieving this is to create regular publications of cancer-related information. Beside is a diagrammatic representation of the proposed cancer surveillance system for Canada.

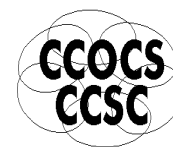
Presently, the CCOCS is pursuing activities consistent with the issues listed above. It is expected that the expanded data elements and the full integration of the new system will be operational by 2003. Funding opportunities are being sought out to make this a reality.

Also see next page for the last update from the CCOCS.



For more information, please refer to the CCOCS web site at:

<http://www.hc-sc.gc.ca/hpb/lcdc/bc/ccocs/index.html>



update

Patient Management Working Group

CCOCS hosted a Core Data Set Consensus and Implementation Workshop, held in Ottawa on June 4th, 1999. The workshop comprised national representation of oncologists, surgeons, cancer registries and academics who came together to endorse the Patient Management Working Group Core Data Set and to identify key strategies for its implementation nationally.

Staging:

Various staging activities are being conducted simultaneously, including:

- ★ Pilot studies in Nova Scotia, Ontario and Alberta to determine the feasibility of collecting stage information in cancer centers and hospital settings. [CCOCS - Project Leader, Funding - Health Canada]
- ★ 500 staging information packages were distributed at the Annual Royal College of Physicians' and Surgeons' Meeting held in Montreal, September 23-26, 1999
- ★ Collaborating on activities with NCIC - Staging Subcommittee
- ★ Minimum Investigations Required to Stage Project funded by Road Map Initiative (Statistics Canada). Results will be disseminated broadly once the project is complete.

Radiotherapy Linkages Project:

Led by Dr. John Hay, this project's first step is to survey Radiotherapy facilities in Canada to establish a baseline of present information being collected and definitions used. Results of the survey will form the basis for the next phase of the project, which is to pilot the collection of radiation treatment information in two or three provinces.

Quality Management Working Group

The "MAXIMIZING Our Potential» Case Ascertainment Workshop was held in Ottawa, May 12 & 13th, 1999. Participants at this workshop included all Provincial Registry directors and at least one technical representative from each province. Speakers presented various methods used to validate and measure the accuracy of data. Day two centered on the development of implementation strategies needed to establish a quality management program for the Canadian Cancer Registries.

A Standards Development Project has been funded by the Road Map Initiative (Statistics Canada). Results will assist in the development of standards for case ascertainment.

Cancer Progress Report Working Group

The Cancer Progress Report Working Group, led by Dr. John McLaughlin, met in Toronto on June 16, 1999. Subsequent to this meeting, a report has been prepared and broadly

circulated for review. The CCOCS Advisory Committee approved the funding for a Cancer Progress Report Implementation Workshop to be held in the Spring 2000.

MIS Guidelines Working Group

The addition to the MIS Guidelines Functional Centers for Cancer, proposed by the MIS working group members, have been incorporated by the Canadian Institute for Health Information (CIHI) and will be circulated to the Provincial MIS Coordinators for final approval. CIHI has the goal of implementing the revised MIS guidelines by April 1, 2000. The CCOCS Advisory Committee approved the funding for a post-implementation meeting to be held in Spring 2000.

Legislative Framework Working Group

An academic-based lawyer team (Québec & Alberta) has been contracted to prepare a document which provides a compendium of current legislation, regulations and recommendations as it relates to the collection of cancer information. A final report, with recommendations, will be available April 1, 2000.

Partnerships...

The CCOCS has been officially invited to...

- ✓ Be a member of the Canadian Committee on Cancer Staging
- ✓ Participate in a focus group for the South Eastern Region Cancer Registry Project.
- ✓ Participate on the Canadian Strategy for Cancer Control (CSCC). Specifically, five CCOCS Advisory Committee members have been invited to sit on the Surveillance Working Group, led by Dr. Roy West.

Presentation/Conferences

Canadian Council of Cancer Registries Annual Director's Meeting- Ottawa, Ontario - May 10-11, 1999

- Second World Conference for Cancer Organizations, Atlanta, Georgia - May 19-23, 1999
- Canadian Association of Provincial Cancer Agencies- October 27th & 28th, 1999 - Québec City
- Advisory Committee Meeting - November 19th & 20th, 1999 - Toronto

Upcoming...

- ✓ Population/Public Health Working Group Meeting
- ✓ Cancer Progress Report Implementation Workshop
- ✓ MIS Post-Implementation Meeting
- ✓ An Interactive Workshop on Staging - Royal College of Physicians' and Surgeons' in Canada Annual Meeting - Edmonton - 2000

CALL FOR PAPERS

Journal of Registry Management, the official journal of the National Cancer Registrars Association, announces a call for original manuscripts for a year-long special series on **Quality Management of Registry Data**. Invited papers should cover a broad range of topics related to quality control and management of **data collected by and for population-and institution-based cancer, trauma and other health registries**. Registries are the best source of data to assess the magnitude of a population's health problems. Consequently, the quality of registry data is considered by many to be one of the most important elements in the establishment and maintenance of a registry. We encourage authors to report on innovations and current practice with regard to all aspects of their quality control programs, from the acquisition of raw data from the medical record through to distribution of the final product.

In addition, the *Journal* seeks original manuscripts for publication in each issue on a broad range of topics related to health registry management, or the collection, quality review, reporting, and use of registry data. We encourage authors to report on topics related to staffing; productivity; computerization; database management, including managing large multiple registry databases and merging databases; contracting for registry services; as well as innovations in casefinding, abstracting, and follow-up. We invite practitioners, researchers, registrars, clinical research associates, and interested others to submit manuscripts on these and related topics, and on results of original research studies using registry data.

Manuscripts are accepted throughout the year; **authors interested in publishing manuscripts on Quality Management are encouraged to submit their manuscripts by May 1**, for consideration for publication in the August 2000 issue. Address all manuscripts and correspondence to Amy Fremgen, PhD, CTR, Journal of Registry Management, W 192 Hilltop Drive, Genoa City, WI 53128, Phone number 262-279-0173, email: afremgen@worldnet.att.net.

All papers will be subject to peer review.

1999 NAACCR WORKSHOP: YOUR CALL-FOR-DATA TOOLKIT

This NAACCR Workshop was run on September 22 and 23, 1999 in Arlington Virginia. 71 registrants attended the workshop, which was sponsored by NAACCR, NCI, CDC and Statistics Canada. The purposed of the workshop was to exchange and share the practical aspects of responding to the NAACCR Calls for Data. The workshop audience included participants from central cancer registries that are eligible to submit their data for *CINA* and registry certification and other parties associated with this process.

For more information on the workshop see the NAACCR web site at www.naaccr.org.

CANADIAN CANCER REGISTRY (CCR) DATA QUALITY COMMITTEE

The Data Quality Committee of the Canadian Council of Cancer Registries has been working very hard over the last two years.

The Data Quality Committee (DQC) has the mandate to give recommendations and advice to the Canadian Council of Cancer Registries (CCCR) on matters relating to the quality and the standardization of the CCR data collection, storage, analysis and reporting. The CCR Technical Workshop also reports through the Data Quality Committee to this Council.

The DQC held monthly conference calls throughout 1998-99 (May 21, 1998, June 11, 1998, September 16, 1998, October 30, 1998, November 26, 1998, January 7, 1999, April 12, 1999, June 3, 1999, July 8, 1999, September 9, 1999, November 3, 1999 and December 9, 1999). Three face to face meetings were held on February 8-9 and September 16-17, 1999 and February 21-23, 2000 in Ottawa. The technical contacts in each registry are sent copies of the minutes of these meetings.

The current committee members are:

- ◇ Dr. Fred Alexander, (Alberta) Consultant Pathologist
- ◇ Ms. Darlene Dale (Ontario), Central Canada Representative and Chair
- ◇ Dr. Dagny Dryer (PEI), Atlantic Canada Representative
- ◇ Ms. Ingrid Friesen (Statistics Canada) Health Statistics Division Representative, Secretary
- ◇ Ms. Bertha Paulse (Newfoundland), Canadian Coalition on Cancer Surveillance Representative
- ◇ Mr. Robert Semenciw, Health Canada Representative
- ◇ Mr. Tom Snodgrass (Alberta), Western Canada Representative
- ◇ Ms. Ghislaine Villeneuve, (Statistics Canada), Health Statistics Division Representative

Some activities that the DQC is currently working on are:

- ◆ **Cancer Record:** The Cancer Record has been proven to be a very useful tool for the cancer registries across Canada. A survey was completed last spring to get opinions of the usefulness of the Cancer Record. Almost all of the feedback on the Cancer Record was very positive. Comments like:
 - ◆ Very informative
 - ◆ A reference tool
 - ◆ Keeping in touch with what other provinces are doing
 - ◆ Opportunity to share and exchange information
 - ◆ Official record of coding issues
 - ◆ Identifying and reviewing difficult or unusual coding questions
 - ◆ It's informative, well written and all the information is relevant and pertinent
- ◆ **SINQ:** Over the last year a student was hired to input the Canadian queries. Further work needs to be done to distribute the information to the registries and to maintain the database on a regular basis. This will hopefully be completed in the next few months, with a total of 154 questions and answers listed.
- ◆ **Coding queries.** Approximately 33 difficult queries were responded to over the last year and a half.
- ◆ **CCR Data Quality Indicators:** The DQC has reviewed the standard indicators at the three face to face meetings. The DQC would like to see some of the age/site/morphology indicators identified as errors rather than warnings and reported back to the original province. Further investigation and analysis of all these indicators needs to be done. Once this careful review has been done, the committee will review the standards.
- ◆ **In-Situ and Benign Reporting:** The DQC reviewed these data from the current CCR files. Discrepancies are obvious across the country. The DQC investigated what is actually being collected across the country and made recommendations to the CCCR.

- ◆ As part of the CCR processing, errors and warnings are sent back to the provinces. It is up to them to make the corrections and re-submit to the CCR. Follow-up needs to be done to determine if all corrections to the warnings actually get submitted to the CCR.
- ◆ The issues relating to the coding of **bladder tumours** continue to be discussed and it is hoped that some guidelines will be developed soon. Communication with April Fritz of the National Cancer Institute SEER Program has taken place.
- ◆ **Ambiguous Terms:** Some preliminary work has been done in reviewing the current list of ambiguous terms available through SEER and the American College of Surgeons (ROADS). More investigation is needed for the Canadian Registries to eventually develop a Canadian list. A small group has formed since the last CCR Technical Workshop, which is working on a review of the impact of these terms across the country. The results of this review were presented to the DQC at the last Face to face meeting in February 2000.
- ◆ **Case Ascertainment Protocol:** This proposal was brought forward to the CCCR and approved. One conference call has taken place to start the process. The first Protocol Workshop took place on February 10-11, 2000 in Toronto. A Steering committee was setup. The Registries involved are Alberta, Manitoba and Ontario.
- ◆ **Method/Date of Diagnosis:** The DQC is looking further into the definitions of these variables, as there is some variability across the country in the definitions used.

The Data Quality Committee reported to the Council at their annual meeting held in Ottawa in May 1999. Five specific recommendations were made to the Council (their response is at the end of each recommendation).

RECOMMENDATION # 1: *Approve the revised Data Quality Committee Terms of Reference.* Does Council agree with this change? **YES.**

RECOMMENDATION # 2: *Resources and input from all the registries must be allocated to work on the issue of ambiguous terms and well as resources from Statistics Canada.* Does Council agree that this would be of benefit and that resources from both the cancer registries and Statistics Canada should be allocated to the task? **YES in principle**

RECOMMENDATION # 3: *In light of the number of registries that are collecting benign CNS tumours (including brain),* Does Council still support the inclusion of these tumours on the CCR? **NO as it is up to each registry.**

RECOMMENDATION # 4: *The DQC would like to continue and expand its current activities.* Does Council agree? **YES.**

RECOMMENDATION # 5: *Dr. Dagny Dryer would like to remain as the Atlantic Canada Rep on the DQC.* Does Council agree with this continued appointment? **YES.**

The DQC was given the support to continue in these areas. The DQC is anxious to expand its work and to look at some of the issues in more detail. However this is often difficult due to resources; human, financial and time. The DQC held another face to face meeting at the end of February 2000 to work in more detail on some of these important issues.

The input and support of the Technical group is very important for the Data Quality Committee. Please do not hesitate at any time to contact any members of the committee, as we will continue to hold regular conference calls as well as face to face meetings.

The report from the last Face to Face meeting in Ottawa (February 21-23, 2000) will be sent out shortly.

Darlene Dale, Chair, CCR Data Quality Committee

Manager, Ontario Cancer Registry
 Cancer Care Ontario
 620 University Avenue
 Toronto, Ontario, M5G 2L7
 Telephone: (416) 217-1228
 Fax: (416) 971-9800
 Email: Darlene.Dale@cancercare.on.ca

WORKSHOPS/CONFERENCES/ TRAINING

1. **Advanced Cancer Registry Training Program**
June 19-21, 2000

**Principles and Practice of Cancer
Registration, Surveillance and Control**
August 14-18, November 6-10, 2000

Pediatric Cancer Registry Training Program

Emory University- Atlanta, Georgia
Contact: Steven Roffers
sroffer@sph.emory.edu
Phone: 404-727-4535

Complete details are available on the training
program web site at: <http://cancer.sph.emory.edu>

2. **Canadian Health Record Association**
Annual Professional Development Conference
and General Meeting
May 25-27, 2000
Ottawa, Ontario

This conference will feature professional
development and networking opportunities for
certified members and student members. The
Annual General Meeting and the presentation of
the "Pinnacle Awards" will take place during the
conference. The theme of the conference is
"Capitalizing on Information - Maximizing Health
Data".

Contact: Constance Wrigley-
constance.wrigley@attglobal.net
or 416-447-4900 ext. 28.
Also check the CHRA web site: www.chra.ca

3. **North American Association of Central
Cancer Registries Annual Conference**
April 18-20, 2000
New Orleans, Louisiana
Hilton Riverwalk Hotel

The theme of the conference is "The Challenges
of Cancer Surveillance in the New Millennium:
Uniformity and Diversity". Workshops will take
place the weekend before the conference. The Chair
of the Program Committee this year is Patricia
Andrews.

4. **INFOcus 2000**
June 24-27, 2000
Vancouver Trade and Convention Centre, British
Columbia

This conference is being organized by the Canadian
Institute of Health Information (CIHI) and the
Canadian Organization for Advancement of
Computers in Health (COACH). The theme of the
conference is "*Harmonizing Health Information
Initiatives*". The intent of INFOcus is to bring a
variety of stakeholders together to provide a
comprehensive educational opportunity and
facilitate the sharing of information and
networking. Some of the conference topics will
include:

- Standards
- Information Management in Health
organizations
- ELSI (Ethics, Legal and Social Issues) Policies
- Telehealth
- Electronic Health Record
- Security and confidentiality
- Knowledge transfer: education and training
- Evidence based health services

The Conference Coordinator is Steve Huesing at
780-489-4553 or visit the web site
www.infocus.ab.ca.

5. **NCRA Annual Education Conference 2000**
Albuquerque, New Mexico
May 9-13, 2000
*Preparing for the 21st Century: Education is
Knowledge*
More information is on the NCRA web site:
www.ncra-usa.org

6. **13th International Federation of Health Records
Organizations (IFHRO) Congress**
October 2-6, 2000
Melbourne, Australia

The theme of this Conference is "*Into the New
Millennium- A New World Record*". This IFHRO
conference occurs only once every four years and
is a once-in-a-lifetime opportunity for health record
professionals from around the world to meet and
share with each other.

For more information, visit the Health Information
Management Association of Australia's web site:
www.himaa.org.au.

TNM STAGING WORKSHOP – APRIL 1999

7. 2000 NAACCR Regional Registry Skills Workshops

The NAACCR Education Committee, through the Public Health Institute Cancer Surveillance and Control Program (CSCP), under contract with the Centers for Disease Control and Prevention, presented a two day Regional Registry Skills Workshop on February 24-25, 2000 in Claymont, Delaware and on March 16-17 in Alabama. The topics included were:

- Active and Passive Casefinding- 1-1.5 hours
- Coding Issues- Art of Abstracting- 2 hours
- Staging- 2.75 hours overview of summary stage, EOD, TNM
- Multiple Primaries- 3 hours
- Death Clearance-3 hours

There are more workshops planned for **Oregon in July and New Mexico in May.**

Contact:

Richelle Ostman-Lujan (Committee Support)
rfo4naacccr@aol.com
916-440- 8768

Betsy Kohler (Chair of Education Committee)
at bk2@doh.state.nj.us
609-588-3500

NAACCR web site: www.naacccr.org

A three day staging workshop was held in Ottawa on April 28–30, 1999. The purpose of the workshop was to provide training to individuals involved in a Health Canada staging contract entitled: “Cancer Surveillance Database Enhancement: Cancer Staging Data Collection”. The contract’s purpose is to pilot the TNM staging manual which was prepared at the Ottawa Regional Cancer Centre.

The workshop took a “hands on” approach as real cancer cases were presented and staged. Laurie Clowater and Judy Morriss lead the staging sessions and explained the process step by step. The efforts by Debbie Read and staff were certainly worthwhile. A great deal was learned by those who are new to staging and for those who have had some experience – it showed how much is yet to be learned!

After the workshop ended, the staging continues back in our own centres. At the Nova Scotia Cancer Centre (Halifax and Sydney sites) the project members include coding staff from both the clinic and registry. One of the expectations of the contract is to stage 100 cases of the four major cancer sites (breast, lung, prostate and colorectal). Using the staging forms from the manual, the coding group collaboratively stages randomly selected cases and then will have oncologists from the centre do the same. In doing so, we will be able to identify staging discrepancies and issues which will need clarification by the medical staff. As the coders stage the cases, questions are logged and a spreadsheet of staging results is maintained to evaluate the process and outcome.

*Joanne S Hamm
Nova Scotia Cancer Registry*

CANADIAN CANCER REGISTRY TECHNICAL WORKSHOP ACTIVITIES

18th CCR Technical Workshop: Statistics Canada, Ottawa, Ontario

The 18th Technical Workshop of the Canadian Cancer Registries was held on November 5 -7, 1998 in Ottawa. The organizing committee, consisting of Ingrid Friesen and Jeri Kostyra (co-chairs), Elaine Hamlyn, Maurice Levesque, Manuela Das Neves, Carol Russell, and Laura Towers, did an impressive job planning the ambitious three day agenda. There were 65 participants in attendance at the workshop, which included 48 Provincial/Territorial representatives from all Provinces/Territories (except the Yukon), 9 Statistics Canada staff, and 8 invited speakers.

Day one of the agenda was focused on updates from the Canadian Council of Cancer Registries, the Cancer Record, the Canadian Coalition of Cancer Surveillance, the Data Quality Committee, the North American Association of Central Cancer Registries, and the National Cancer Registries Association. Results of the 1997 Workshop recommendations were presented. Several of the suggestions from the previous workshop have been accomplished, with some recommendations still in progress, and others which cannot be accomplished at this time. Provincial/Territorial Cancer Registry presentations were given by representatives from each province as well as a report of hospital based Cancer Registries. Dr. Jane Thomas gave an interesting presentation on the development of Synoptic Pathology Reports. She discussed the "What, Why, and How" of the development of synoptic pathology reports as well as the advantages, and disadvantages of their utilization. The afternoon session included updates on the CCR from Statistics Canada including discussion on the CCR Procedures manual, Death Clearance, CCR submission. An update on the implementation of ICD-10 for mortality was also presented. Dr. Fred Alexander presented a follow up from the 1997 Bladder Coding Consistency Study. Dr. Alexander also reviewed the Bladder Coding Checklist from the 1997 Technical workshop and discussed some of the difficulties coding bladder tumours using the present ICD-O-2 system. April Fritz presented a brief update on the development of ICD-O-3. Recommendations and the site of the next workshop were discussed at the business meeting at the end of an informative first day.

The focus of the second day of the agenda was on Coding and Staging with the emphasis on Lymphomas and Leukemias. The Inter-Provincial Coding Consistency Study was presented with 15 lymphoma cases and 15 leukemia cases being discussed. Dr. Bruce Burns' informative presentation covered the topic of Classifying and Coding Malignant Lymphomas. The focus was on the possible solutions to some of the difficulties encountered coding lymphomas and leukemias. Dr. Burns also discussed some of the "Buzz-Words" frequently encountered on pathology reports as well as the changes from the Working Formulation to REAL/WHO. A very informative session on coding and abstracting Malignant lymphomas and Acute leukemias was presented by April Fritz and included a "hands-on" session on coding, staging, and abstracting. April Fritz also led the afternoon session with her presentation on AJCC TNM Staging and Coding for Registrars (5th Edition). This session, a part of the Speakers Bureau from the Commission on Cancer, included handouts and staging exercises, which were worked on throughout the afternoon. A brief business meeting concluded a busy second day.

The third day of a busy agenda began with a presentation from the Ottawa Regional Cancer Centre on Staging Implementation for Cancer Centres. An Introduction and General Principles of TNM Staging and Extent of Disease coding were presented by April Fritz and included an overview of TNM Staging and EOD coding. A "hands-on" TNM staging and EOD coding session followed her presentation. The final item on the agenda was the business meeting, which brought forward recommendations for the next workshop and the Data Quality Committee.

As you can see, it was a very busy and informative three days. A complete report on the entire workshop was compiled and sent to each participant and directors of the Provincial and Territorial Registries.

Thank you to the planning committee and presenters who did a wonderful job making the 18th technical workshop a great success!

*Jo-Anne Walker, HRT, CTR
Manitoba Cancer Registry*

19th CCR Technical Workshop:
Edmonton, Alberta

The workshop ran from October 13-15, 1999 in Edmonton, Alberta. The workshop took place at the **Cross Cancer Institute**. There were over 60 participants in attendance over the course of the three days. Dr. Pamela Catton conducted some hands-on training for Staging using the TNM Staging books. There were several speakers and the presentations including the Provincial/Territorial reports. A special topic for the workshop was Gynecological Tumours.

The report of the Workshop was mailed to all participants in January 2000. If you did not receive your copy of the report or would like to receive one, please contact Ingrid Friesen.

Members of the Technical Workshop Planning Committee for 1999 were:

Manuela Das Neves, QC
514 842-1231 ext 5790

Ingrid Friesen (Co-Chair), Statistics Canada
613 951-8384

Elaine Hamlyn, NF
705 737-4261

Jeri Kostyra, MB
204 787-2157

Carol Russell, (Co-Chair) AB
403 432-8781

Kim Vriends, PEI
902 894-2167

20th CCR Technical Workshop

When: October 23-25, 2000

Where: Toronto, Ontario

Topics: Staging
ICD-0-3

Watch for the first mail-out in the Spring 2000!

Planning Committee 2000:

Darlene Dale Ontario
416-271-1228

Tina Dyer Ontario
416-217-1205

Ingrid Friesen Statistics Canada
613-951-8384

Elaine Hamlyn Newfoundland
709-737-4261

Cindy McLean British Columbia
604-877-6098 ext. 2385

Kim Vriends Prince Edward Island
902-894-2167

QUÉBEC CANCER REGISTRY IN THE CANADIAN CANCER REGISTRY

Since the early 80s, all cases involving hospitalization or day surgery must be reported to the Québec Cancer Registry. The objective is to collect a set of cancer-related data, especially on primary malignant tumours, as well as data on the persons suffering from this disease, in order to create a single file on each individual containing the history of his/her tumours from the initial reporting to death. The Ministère de la Santé et des Services sociaux is responsible for this Registry, but it is the medical archivists at some 130 hospital centres in the health care network who code the medical information. The information processing system developed specifically for the file is based on the individual and on his/her tumour or tumours and the data accumulated in the bank need to be revised to determine the incidence rate. This work has been completed for data from 1992 to 1998 and is currently under way for 1999 data. Some adjustment is being made to reflect the specific requirements of the Canadian Cancer Registry and we are included in the Canadian cancer data bank.

This update is being done by three medical archivists who perform the following functions in order to ensure the quality of the data in the file:

- validate the medical information in the file;
- maintain contact with medical archivists in the hospital centres that input into the file in order to:
 - justify rejections for topographical/morphological reasons and to facilitate decision-making;
 - **to answer their questions and act as resource-persons for problems with coding and interpretation of the pathology reports;**
- make the necessary changes for the Canadian Cancer Registry;
- update the descriptive guide on the applied coding rules;
- consult with specialized pathology resources in disputed cases;
- contribute to the publication of departmental monitoring reports on health;

The Québec Cancer Registry plays a leading role as an essential link in the chain of activities in the fight against cancer. The data collected are used by several agencies, research centres and researchers to evaluate the incidence of cancer and to provide indicators of the effectiveness of prevention activities related to this disease. The breast cancer screening program, aimed primarily at the early identification of breast cancer in women aged 50 to 69 years and women at risk, is one example of a project that makes use of the file. There are also research projects with Health Canada, the National Cancer Institute and regional Quebec public health branches. It is also possible to establish interregional, national and international comparisons based on the characteristics of the population.

To acquire as exhaustive a data bank as possible to meet demand, other activities are also under way:

- addition of complementary information sources, such as the Fichier des décès (deaths file) and laboratory reports; this is a priority once the backlog in the data bank update has been completed;
- **coalition with other agencies working in the cancer prevention field.**

If you require further information, please contact us or visit the Internet site of the Ministère de la Santé et des Services sociaux, where you can obtain more details on our activities:

www.msss.gouv.qc.ca/fr/statisti/indisp/tumeurs/cadnor.pdf

Québec Cancer Registry team:

Julie Boutin, Medical Archivist

Brigitte Morin, Registered Medical Archivist

Mélanie Vallières, Registered Medical Archivist

Telephone: (418) 644-8262

Fax: (418) 643-5468

E-mail: brigitte.morin@ssss.gouv.qc.ca

CANADIAN HEALTH RECORD ASSOCIATION ANNUAL MEETING

On June 11 and 12, 1999 Regina, Saskatchewan was pleased to host the CHRA annual professional development conference and general meeting. The theme was "Navigating the Winds of Change - Health Information Management in the 21st Century".

After the official welcome, Barbara McLean CCHRA (C) Chair of the CHRA 1998-99 Board of Directors, spoke on "The National Health Infostructure". She explained how the Canada Health Infoway empowers individuals and communities to make decisions about their own health by providing reliable health information and that it ensures equitable access to health information.

Funding of \$328 million has been provided to help make our health system more open and accountable and of this amount, \$95 million will be spent over the next 3 1/2 years on projects relating to Statistics Canada and CIHI, as well as other health related initiatives.

Katherine Mickeler CCHRA(A) Applications Consultant for Markham Stouffville Hospital spoke on the electronic health record. The system in use is referred to as "Clinical Health Administrative Records Management" (CHARM). There are no terminals in use at this facility and any one patient's complete information is available to all caregivers from any PC in the hospital. One drawback to this technology is the decreased productivity of coders who now need to code off a screen and decreased morale in general among the health records staff. However, the morale and productivity are currently being monitored. The discussion was concluded by a video entitled "Imagine" which detailed the possibilities of the future electronic record and it was indeed, very interesting.

Lunch was spent with colleagues discussing various issues as well as getting reacquainted.

After lunch the presidents of many of the provincial health record associations, spoke on various developments of health information networks within each of their respective provinces. It was interesting to hear of what is happening across Canada.

Elizabeth Taylor CCHRA (C) Chair - COE and Deborah Del Duca CCHRA (C) CAE, CHRA Executive Director and Registrar spoke on "Education Reform". Over the last 10 years there has been a move from traditional

employment i.e. Hospitals, into other various health related fields. This move, in addition to the technology of the emerging electronic health record has necessitated an intense review of current health record training programs and of entry level functions that will be required of future graduates. Our profession is now in high demand but there is a low supply of professionals with an advanced skill set.

Education Reform has been done in 3 phases:

- I. 1991-1992 fact finding, research
- II. 1992-1995 development, role statements
- III. 1995-1999 implementation
- IV. Three key motions were presented and accepted at the 1995 annual general meeting:
 - 1) one type of role statement
 - 2) a degree program
 - 3) transition strategies i.e., Bridging.

The process of bridging is self-directed by the member with the objective being to acquire and demonstrate advanced competency compatible with the health information professional. As of today, four universities have agreed to offer degree programs in health information management. They include universities in Halifax, Toronto, London and Victoria. After the year 2000, HRA and HRT programs will no longer be recognized by the CCHRA. They will only offer certification exams for HIP graduates.

The last speaker of the day was Linda Kloss, RRA, Executive Vice President and CEO, American Health Information Management Association (AHIMA). She spoke on "Converging Visions- Canada and the U.S. Lead Health Information Management into the 21st Century". She mentioned that consumers will soon challenge "marketers" for control of their information and that learning and knowledge are the foundation for the new consumer society.

The goals of AHIMA are the same as those of the CHRA:

- prepare for future professional roles
- position profession for vital roles
- gain professional recognition
- revitalize our associations.

AHIMA estimates that by the year 2005, there will be a shortage of 50,000 positions. To summarize her presentation, Linda told a parable which encouraged everyone in attendance to see change as opportunity and to take ownership of our own careers and professional advancement.

The first day of the conference was well done considering the unexpected turn of events (i.e.

Saskatchewan by-elections and Minnesota storms) and I believe the topics were relevant and of great interest to everyone in attendance.

*Karen Robb CCHRA(C)
Supervisor of Statistics
Allan Blair Cancer Centre
Regina, SK*

NEWS FROM COAST TO COAST STAFF CHANGES

Wendy Doda (formerly Muscatello) has moved from the Ontario Cancer Registry to the Princess Margaret Hospital where she is the Coordinator of the Hospital Cancer Registry.

Tina Dyer has replaced Wendy Doda as the Coding Supervisor at the Ontario Cancer Registry as of June 14, 1999.

Eunice Dietrich of the Allan Blair Cancer Centre in Regina, Saskatchewan has retired as the Director of Health Records. Heather Stuart has replaced her from the Statistics area at the Saskatoon Cancer Clinic.

On November 1998, the New Brunswick Provincial Cancer Registry welcomed **Catherine Shea** to their Registry.

Colleen Wong has replaced Lisa Dykman as Data Analyst at the BC Cancer Agency in Vancouver, BC.

Congratulations to Lisa Dykman who has recently had a baby boy, and will be on maternity leave for a few months.

Laura Towers has also accepted a new position in the BC Cancer Agency Clinical Trials and has been replaced by **Cindy McLean** who is the Supervisor of Coding and Analysis at the BC Cancer Agency.

Judy Lee of the Canadian Cancer Registry at Statistics Canada has recently accepted an offer at the Canadian Institute of Health Information (CIHI) in Toronto, Ontario. She began her job with CIHI in January 2000.

Michel Cormier has replaced Judy Lee at the Canadian Cancer Registry as Project Manager with the Canadian Cancer Registry in mid-December 1999.

Perry Burke, a Health Record Administrator, joined the Health Statistics Division at Statistics Canada on January 4, 2000. He is assisting Patricia Wood, Mortality Classification Specialist, and Ingrid Friesen, Medical Classification Specialist.

Larry Ellison has joined the Canadian Cancer Registry at Statistics Canada and will be working on Survival Analysis and Data Quality.

READERS FEEDBACK FORM

Mailing list updates:

Do you need your address changed or corrected? Are there others whom you would like to have placed on the mailing list? (Please also note names to be deleted)

Name: _____

Title: _____

Organization: _____

Address: _____

City, Province and
Postal code: _____

Telephone: _____

Fax: _____

Email: _____

Please send questions or suggestions regarding any of the topics and/or articles:

Thank you for your assistance. Please mail your response to:

Ingrid Friesen
Managing Editor, Cancer Record
Health Statistics Division
18th Floor R.H. Coats Bldg.
Statistics Canada
Ottawa, ON K1A 0T6
Email: ingrid.friesen@statcan.ca
Phone: 613 951-8384
Fax: 613 951-0792