1981-03-20


Committee on the Assessment of Human Health Effects of Great Lakes Water Quality

Great Lakes Science Advisory Board

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Workshop on the compatibility of Great Lakes Basin Cancer Registries
proceedings of the

**Workshop on the compatibility of Great Lakes Basin Cancer Registries**

held March 19-20, 1981
Windsor, Ontario

sponsored by the
International Joint Commission’s
Great Lakes Water Quality Board and
Great Lakes Science Advisory Board
through their
**Committee on the Assessment of Human Health Effects of Great Lakes Water Quality**
Notice

Statements and views presented in these Proceedings are those of the workshop participants and do not necessarily reflect the views and policies of the International Joint Commission or those of its Water Quality Board or Science Advisory Board and Committees. Mention of trade names or commercial products does not constitute endorsement or recommendation for use.
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Preface and Acknowledgements

These Proceedings present the findings of the Workshop on the Compatibility of Great Lakes Basin Cancer Registries on March 19-20, 1981 in Windsor, Ontario. The Workshop was sponsored by the IJC Committee on the Assessment of Human Health Effects of Great Lakes Water Quality on behalf of the Great Lakes Water Quality Board and the Great Lakes Science Advisory Board of the IJC under the Commission's authority to implement the terms of the Great Lakes Water Quality Agreement of 1978.

The Workshop was an initial step in implementing the Health Effects Committee's intent to ensure compatibility for cancer data collection and handling methodologies in the Great Lakes Basin. The following major objectives were addressed at the workshop by the participants, divided into the corresponding Work Groups:

- cancer registry characteristics;
- data utilization for research; and
- future developments.

The Workshop Recommendations were drafted by the Work Groups and formalized by the participants. The recommendations from the Proceedings are presented in Section 3.0.

The Human Health Effects Committee expresses its gratitude to the Workshop organizers, and to the 19 participants listed in Appendix A, who contributed valuable time and expertise. The Committee is indebted to Dr. Robert F. Spengler, Workshop Chairman and to Dr. Andrew E.P. Watson, Workshop Secretary, who carefully compiled and prepared these proceedings. Gratitude is also expressed to those members of the IJC Great Lakes Regional Office, Windsor who made significant contributions to the Workshop and assisted in the preparation of the Proceedings.

In the interest of condensing the Proceedings for the reader, the formal presentations made by Drs. Becking, Spengler, Wigle and Burnett have been placed in separate appendices. If they had been included in the text, they would have overpowered (in subject and length) the cancer registry material. A summary of these interesting presentations would not have done justice to their topic, so readers are encouraged to read these particular appendices:

B: Dr. G.C. Becking - "Activities of the IJC Committee on the Assessment of Human Health Effects of Great Lakes Water Quality - An Overview"

C: Dr. R.F. Spengler - "Water Contamination by Toxic Chemicals: A Challenge to Cancer Registries in Assessing Population Risks"

D: Dr. D.T. Wigle - "Cancer Mortality and Drinking Water Quality in Selected Canadian Municipalities: Preliminary Results"

E: Dr. W.S. Burnett - "Colon Cancer in Watertown, New York"
Preface and Acknowledgements

These proceedings present the findings of the Workshop on the Water Quality of Great Lakes Water Quality on May 10-18, 1988 in Hamilton, Ontario. The Workshop was sponsored by the IJC Committee on the Assessment of Human Health Effects of Great Lakes Water Quality on behalf of the Great Lakes Water Quality Agreement of 1972.

The Workshop was an integral step in implementing the Agreement's objectives to develop a framework for the assessment of water quality impacts on human health. The Workshop was part of a series of workshops led by the IJC, with the following objectives:

- Develop a framework for the assessment of water quality impacts on human health.
- Enhance understanding of the relationship between water quality and human health.
- Foster collaboration among stakeholders.

The recommendations from the Workshop are presented in Section 3.0.0 of this document.

The Human Health Effects Committee expressed its appreciation to the participants for their contributions.

In conclusion, the Workshop provided a valuable opportunity for participants to exchange ideas and experiences. The recommendations presented in this document serve as a foundation for future actions to improve water quality and protect human health.

Acknowledgments:

This document was prepared by the IJC Committee on the Assessment of Water Quality in the Great Lakes.
The International Joint Commission (IJC) was established under the Boundary Waters Treaty of 1909. It consists of six Commissioners, three from Canada and three from the United States. A Commissioner from each country is a Co-Chairman. The Commissioners act as a single body seeking common solutions, with decision reached by majority.

The Treaty was established to aid in settling and preventing disputes regarding the use of boundary waters, by means of joint deliberations of the Commission. Headquarters of the Commission are located in Ottawa, Ontario and in Washington, D.C., for the Canadian and United States Sections, respectively.

Three categories of Commission responsibility derive from the 1909 Treaty:

- decisions regarding the approval of applications for the use, obstruction or diversion of boundary waters or of works affecting boundary water levels;
- undertaking investigations and studies of specific problems along the common frontier when requested by one or both Governments as a Reference; and
- decisions on questions or matters of difference referred by the Governments.

The international advisory Boards assist the Commission by organizing and preparing required technical studies and field work. Board reports to the Commission are made public and public hearings are held so that individuals, organizations and governments may comment. The resulting information together with the Board report, is used when the Commission reports to both Governments with its recommendations. These reports are also made public.

In 1972 the Great Lakes Water Quality Agreement was signed by both countries. After extensive review a new Agreement was signed in 1978, to restore and enhance the water quality of the Great Lakes. The Governments have given to the Commission specific responsibilities and functions to assist them in the implementation of the Agreement. Included in these responsibilities is the requirement to tender advice and recommendations. The Agreement also provided for two international boards to assist the Commission, the Great Lakes Water Quality Board and the Science Advisory Board. Secretariat functions are provided by the IJC Regional Office, established under the Agreement in Windsor, Ontario in 1973.
I. Introduction

The Great Lakes Basin encompasses a vast geographic area and contains the world's largest system of freshwater lakes. In addition to the natural splendor of this resource, the availability of water and transportation has attracted settlement in the region over the past two centuries. Over 37 million people work and reside in the Great Lakes Basin which today contains major industrial and manufacturing centers, large agricultural regions, sport and commercial fishing, urban centers and an extensive water transportation network. It is well recognized that society has had an impact on the environment of the Great Lakes Basin. One aspect which has achieved increasing interest is the presence of chemical contaminants in the environment from the manufacture, application or disposal of chemicals.

The 1978 Water Quality Agreement recognized the significance of toxic transboundary pollutants and cited the need to develop strategies to understand and eliminate such contaminants from the Great Lakes Basin ecosystem in order to protect human health. Concern for the possible consequences of human exposure to persistent chemical contaminants can be realized from the mandates dealing with toxic problem anticipation, monitoring and research which are found in annex 12 of the Agreement. Human health protection represents a key element in the Great Lakes Water Quality Agreement.

Over 380 chemical contaminants have been identified in one or more areas of the Great Lakes Basin ecosystem. Relating such a mix of chemicals to human disease is a formidable task. The potential human health impact is unknown or poorly understood for many of the contaminants. In an effort to identify those contaminants of particular concern to human health, the Committee on the Assessment of Human Health Effects of Great Lakes Water Quality has been reviewing the available toxicological information on these chemicals for the past two years. The Committee has found that acute and chronic toxicity data exist only on a small number of these chemical contaminants. The remaining chemicals are either of minimal concern (because of assumed low concentrations in the environment) or not categorized (because insufficient data exist to permit a hazard assessment). Although not finalized, these groupings provide a focus for further activities related to surveillance and remedial actions.

Classification of identified chemical contaminants on the basis of potential human toxicity raises questions regarding possible health impacts from present or past exposures. Whether or not these chemicals or some mix of them have or will cause chronic or long term disease such as cancer in certain population groups is a complex question. Addressing the problem is difficult because of the very large number of people who may be potentially exposed and the many confounding variables which might in themselves be related to the development of disease such as socio-economic status, life style elements and occupation.

In order to evaluate the significance of chemical pollutant contaminants identified in the Great Lakes Basin and understand the human implications of exposure it is necessary to establish a mechanism for monitoring health events which occur in the basin population. A registry of major life events such as cancer and death could provide a foundation for identifying populations at greater risk of disease.
The Workshop on the Compatibility of Great Lakes Basin Cancer Registries represents a first step towards integrating data collection systems on a basin-wide basis. Employment of uniform data requirements would allow the exchange and utilization of cancer data collected by the various jurisdictions in the Great Lakes Basin. Such data could be used to assess trends or identify areas with high cancer rates within the Great Lakes Basin. The cancer registry data may be useful in assessing the impact of toxic contaminants on the population residing within the region. The cancer registry analyses would further assist the planning and conduct of epidemiological investigations, toxicological research, human exposure evaluations and environmental monitoring. One purpose of an integrated disease registry system would be the evaluation of cancer risks in relation to environmental exposures from toxic chemicals.
2. Summary

One means of assessing the chronic and carcinogenic effects of toxic chemicals in the Great Lakes Basin is a detailed evaluation of cancer rates in the population residing in this region. Rates of cancer development can only be determined by the registration of newly diagnosed cancers in a defined geographic area and using population census information for the same area. The ability to identify new cases of cancer for research studies, to monitor trends in cancer rates and to locate regions with unusually high rates of cancer, is contingent upon complete and accurate registration of cancer. A complete review of cancer incidence in the Great Lakes Basin is also contingent upon the population coverage and the compatibility of cancer registries.

A workshop on the compatibility of Great Lakes Cancer Registries was initiated by the Health Effects Committee and held on March 19-20, 1981. Participants were representatives of the cancer registries within the Great Lakes Basin and invited guest experts. The major objectives were addressed at the Workshop: cancer registries' characteristics; data utilization for research; and future developments (Appendix A).

Total coverage of the Great Lakes population is not yet complete in cancer registration. The cancer registries in the states of Illinois (a pilot four hospital registry), Michigan (a pilot pathology reporting system), Ohio (reporting in Montgomery County only) and Pennsylvania (beginning a pilot registry system) are not fully developed and require continued support to achieve statewide implementation. A statewide cancer registry does not currently exist in Minnesota. The remaining States and Ontario have had cancer registries covering their total populations for a number of years. The method of registration was not uniform and some registries were based on pathology reports, hospitalized cases of cancer or more thorough methods of case ascertainment. Different methods of data collection and coding also affect the compatibility of cancer information between registries. However, all registries were collecting the essential information on cancer patients, e.g. name, address or area of residence, birth date, sex, date of diagnosis, site of cancer, histology and method of diagnosis.

The utility of cancer registry data for research is highly dependent upon the quality of data, completeness of registration, population coverage and method of data collection and coding. The differences which exist between registries may create problems in combining data from several registries. However, these problems would be minimized when analyses of cancer rates were conducted only within specific registry jurisdictions.

The participants recognized that insufficient information on the toxic chemicals in the Great Lakes Basin (notably concentration levels, specific locations and lack of presumed health effects) would hamper the planning of any specific studies conducted by the cancer registries. Several types of studies identifying high cancer rate areas could be conducted using currently available cancer morbidity and mortality data. The participants also made specific recommendations as to the types of toxic chemical information desired, the focus of additional research on non-cancer outcomes and the utilization of human tissues or fluids to assess environmental exposures.
The workshop provided a unique opportunity for cancer registry representatives and invited experts to exchange useful information on registration practices and cancer research in Canada and the United States. The meeting accomplished the goals which were initially set out and the forum created new professional contacts which will enhance cancer registry interaction and may induce further compatibility in the years ahead. The cancer registries will be willing and able to undertake specific research projects.
3. Recommendations

1. In order to establish a means of evaluating the environmental hazards and potential cancer risks in the Great Lakes water basins, it is strongly recommended that the collection of population-based, cancer incidence data be supported by the U.S. states bordering the Great Lakes and the Province of Ontario, Canada. The current development of cancer surveillance systems for the states of Illinois, Indiana, Pennsylvania and Ohio should be encouraged. The remaining states and Ontario require continuing support.

2. There should be a legal provision for the interchange of cancer case data between relevant jurisdictions when cancer cases are diagnosed or treated outside their state or Province of usual residence.

3. It is recommended that the IJC prepare a detailed document of the identified toxic chemicals or substances in the Great Lakes water basins, their potential health effects, their sources of exposure (through water, fish, sediment or air) and their distribution (including concentration) within the water basins. Such a document will assist the planning of future health research and serve as a useful index for measuring changes from control programs.

4. It is recommended that the IJC assemble the available water quality data for each of the major municipal water supplies within the two tiers of U.S. and Canadian counties bordering the Great Lakes.

   **Purpose**

   - To identify water contaminants, regional variation and gaps in available data resources.
   - Define the population served by each water supply.
   - Identify source(s) and treatment procedures for each facility.
   - Obtain information on major historical changes (e.g. change of source, introduction of fluoridation, chlorination and filtration).

5. A water quality survey should be conducted, utilizing standardized methods, on the water distribution systems serving the two tiers of U.S. and Canadian counties bordering the Great Lakes.

   **Purpose**

   - To obtain a more complete assessment of drinking water quality, utilizing modern and standardized procedures.

   **Details**

   - Samples should be collected over a sufficient time period to allow for seasonal variations in water quality.
   - Samples of treated water should be taken at the treatment facilities and analyzed for major toxic chemicals (to be defined later).
   - The evaluation should utilize both chemical analyses and mutagenicity tests.
Consideration should be given to analysing drinking water samples in order to obtain data for water that is consumed.

6. It is recommended that detailed mortality maps be produced, focusing on cancer, for those counties bordering on the U.S. and Canadian sides of the Great Lakes and the St. Lawrence River as far east as Cornwall.

**Purpose**

- To identify high-risk regions within the Great Lakes Basin which could be subjected to further investigation.

**Details**

- Data would be assessed for time trends since 1950 to the most recent years.
- Included in this geographic analysis would be the first two "tiers" of counties bordering the lakes.
- The analysis would use an appropriate reference population for comparison.
- Consideration should be given to analyze cancer mortality at the municipality level.

7. It is recommended that existing cancer incidence data be analyzed to determine if excessive rates of cancer can be identified in the geographic regions of the Great Lakes water basins.

8. If recommendations 3 through 6 are accomplished, it should then be possible to evaluate potential human health effects. Further assessment of perceived health risks would require prospective or retrospective epidemiological studies.

9. It is recommended that the IJC and respective government agencies foster research in the following areas:

   a) Health studies of human populations consuming fish taken from the Great Lakes water basins;
   b) Animal feeding studies using concentrates of treated drinking water supplies; and
   c) The use of human tissues in assessing exposure to environmental contaminants (e.g., adipose tissue, breast milk, umbilical cord blood or products of birth).

10. Consideration should be given to utilizing or developing a surveillance system of selected birth defects or adverse pregnancy outcomes for the assessment of human health effects that may be related to toxic chemical exposure.

11. The state or provincial cancer registries should endeavour to identify high-risk areas within their jurisdictions through constant surveillance and investigation of cancer occurrence.

12. It is recommended that periodic updates be made to ensure that the workshop objectives are being addressed.
4. Great Lakes Basin Cancer Registry Characteristics

Each of the cancer registries in the Great Lakes Basin outlined in detail their method of operation in the survey questionnaires distributed prior to the workshop (Appendix F). This section will briefly summarize the characteristics of each registry and discuss the needs for further standardization.

4.1 National Cancer Incidence Reporting System (Canada)

Since January 1, 1969, Canada has developed a population-based, national reporting system on cancer incidence. Each of the ten provincial registries (British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland) supplies cancer incidence information to a central, coordinating, data resource at Statistics Canada. A limited number of personnel look after the analysis of the national incidence data. The National registry covers a population of over 22 million people and had over 75,000 new cancers (includes an Ontario estimate) diagnosed in 1978.

4.2 Illinois Cancer Council

The Illinois cancer registry consists of four hospital cancer registries (Northwestern Memorial, Rush Presbyterian St. Luke's, University of Chicago and University of Illinois) which have been developed since 1978. The registry started as a pilot project and is currently investigating several approaches to a statewide surveillance system. A population-based registry is a desirable approach but depends on the level of resources within the state.

4.3 Michigan Cancer Incidence Reporting System

The registry has been developed from a pilot project which began on October 1, 1980. The registry seeks pathology information from five hospitals. The pathology reporting system will ultimately cover the entire state of Michigan, some 9.2 million people. The reporting system is presently manual and 1,600 newly diagnosed cases of cancer are reported each year from the five participating hospitals. State funding has been sought for a statewide reporting system which will include a staff and computer processing capabilities.

4.4 Michigan Cancer Foundation Registry

The registry was established in 1969 and provides coverage of 4.1 million people in three counties which surround and include the city of Detroit. New cases of cancer are identified from hospital records, physician reports, radiation therapy facilities, death certificates or from research studies. There were 14,717 new cases of cancer reported in 1979. The registry is mainly supported by the National Cancer Institute and actively participates in the Surveillance, Epidemiology and End Results (SEER) program. The registry uses a large staff to actively collect, process and analyse the cancer information.
Active annual follow-up is also carried out on cancer patients. The registry is converting to a larger computer system which will improve the processing and analysis of the cancer data base.

4.5 Minnesota Cancer Registry

No statewide or population-based registry currently exists in Minnesota. A cancer registry may later be developed, but only several hospital-based registries exist at present.

4.6 New York State Cancer Registry

A statewide cancer reporting system was developed in 1940 (excluding New York City until 1973) and became automated in 1950. The registry covers a population of over 17 million people and collects cancer information from hospital reports, laboratories and death certificates. A staff of 15 people processes the incoming data and deals with the computerized files. The registry handled 66,843 new cases in 1978 and is funded by the State of New York.

4.7 Ohio State Cancer Registry (Montgomery County)

A cancer registry was developed in Montgomery County in 1953. The registry is based on cancers reported from six hospitals within the county. Since 1974 each hospital registry sends reports to the central registry. The annual number of new cases has been 3,100 cases in a county population of over 600,000 people. The registry system also contains a means of follow-up on all cases.

4.8 Ontario Cancer Registry

The cancer incidence registry started formally in 1969 and covers a population of 8.5 million people. New cases of cancer are identified through a computerized linkage process using cancer information from several sources: hospital separations; pathology reports; treatment centres of The Ontario Cancer Treatment and Research Foundation; death certificates; and other hospital registries. The annual number of new cancers was estimated to be 27,000 in 1976. The registry is currently creating cancer incidence data for 1972-1977. A means of active follow-up on cancer patients exists for the treatment centres. The registry's computer system is being upgraded to improve processing and analysis.

4.9 Pennsylvania Cancer Registry

The cancer registry is currently in a planning stage. A pilot test will be conducted soon before beginning a statewide operation. It is estimated that 44,000 new cases of cancer will be identified annually. The registry will collect information mainly from hospital and laboratory reports.

4.10 Wisconsin Cancer Reporting System

The statewide registry began in 1978 following a pilot project in seven counties. The registry is based on cancer cases being identified by
general hospital medical records departments or tumour registries. Active follow-up on patients is not carried out. There were 15,400 new cancer cases identified in 1979 from a population of over 4.6 million people.

4.11 Discussion

All registries were either collecting or planning to collect similar types of basic information (Table 1) on every cancer patient: name; address; birth date; date of diagnosis; sex; site of cancer; histology; and method of diagnosis. Few of the registries are able to collect clinical information: size of tumour; regional node involvement; stage of disease; date and type of treatment; and date of first recurrence. It was felt that the basic information provided by each registry was sufficient for registry needs.

The operation of a registry requires a means of collecting and processing cancer data in an efficient manner. Each of the registries is different in their specific methods of registration, but all appear to have mechanisms to assess the quality and completeness of their cancer registration.

It would be difficult to further standardize the registries beyond the types of data being collected. As exemplified in the brief descriptions of each registry (4.1-4.10), it is clear that the methods of registration developed in each jurisdiction are a result of careful planning and cooperation. Further standardization of registries would result in perhaps improvements in some and great resistance among the others. The method of data collection in one registry may be effective, but its introduction into other registries might result in inefficiency or greater expense.

Without the ability to standardize the methods of cancer registration, one must be aware of the problems introduced when data is pooled or compared among the Great Lakes Basin cancer registries, as discussed in the next section.
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* Minimum data set requirements for a cancer registry.
5. Data Utilization for Research

Before the utilization of cancer data for research purposes, it is important to consider the data quality and usefulness across the cancer registries within the Great Lakes Basin. The future directions that several registries are taking will also be discussed. The information in this section is summarized from the detailed information received from each registry (Appendix F).

5.1 Data Quality

Several indices have been used to assess the quality and completeness of cancer registration.\(^1\) The proportion of newly diagnosed cases, which are initially identified by death certificate only, is one measure used to assess registry completeness. The index assumes that an equal proportion of cases was missed by the registration process. Another index is used to measure quality by the proportion of new cancer cases histologically confirmed. A high proportion infers that the diagnoses are reasonably accurate.

Several registries were not able to supply an estimate of death certificate only cases. Of the four registries responding, three registries were under 3% which is considered to be a good indication of completeness. However, one registry reported an estimate of 13% which implies that under-registration may have occurred. Of the seven registries estimating the proportion of cases histologically confirmed, the majority were greater than 90% which is considered to be good confirmation. One registry reported a proportion of 83% which implies that a slightly higher proportion of cases was registered without histological confirmation. There were two registries reporting a confirmation rate of 100%. This is only possible when the registry exclusively uses pathology reports to identify new cancer cases. Such a practice will miss those cancers commonly diagnosed by methods other than tissue pathology.

Other issues concerning data quality encompass the variability between registries in coding, verification and validation practices. Coding practices may differ between hospitals or even clerks in the same office. Verification requires that data be edited to ensure that the data elements are indeed coded correctly. Validation requires, usually on a sample basis, the comparison of completed registry data with the original source to ensure that the information is totally accurate and complete.

The data collection practices and the crude measures of registry quality and completeness indicate that caution must be exercised when using data from several registries for research purposes. Such concerns are reduced when research is carried out within one jurisdiction that has continued the same registration practice for many years.

\(^1\) Cancer Incidence in Five Continents, Volume III. International Agency for Research on Cancer (WHO), Lyon, France, 1976, pp. 45-50.
5.2 Data Utilization

The coding of the data collected can determine the usefulness with which the information can be compared between registries.

Histology - There was usage of both ICDO and MOTNAC coding schemes for histology. The two coding systems are so similar that problems should not arise.

Cancer Site - The cancer registries reported the use of SEER, ICDO, ICD8 and ICD9 coding schemes. There are differences between these coding systems but they are not sufficiently major to cause concern. For example, the lymphosarcomas are coded differently in ICDO and ICD9, and sites are more specific in ICD9 as opposed to ICD8. Conversion code tables are available which could alleviate some of the problems in dealing with these different coding systems.

Stage of Disease - The staging of disease poses more difficulties in dealing with different coding schemes. Of the registries that do code staging information, SEER, TMN and a crude stage classification system are being used. It is uncertain whether staging information might be used in further research, but the comparability between registries could only be satisfied when they use the same coding scheme.

Residence - The coding and specificity of residence differed between the cancer registries. One registry used the actual name of the residence, while the others had used various forms of coding systems. The Michigan Cancer Foundation Registry was the only one coding to the census tract level. The remainder used county or district codes. It may be possible to get exact residence from the original reports, but the coded information on the registry computers may not be specific enough to pinpoint cancer risks in small geographic areas.

The utilization of cancer information with each jurisdiction showed that the registries were supplying information for many purposes. The types of cancer information disseminated were: responses to requests; annual reports; and reports to suppliers of information conducting research, planning cancer services and control programs, etc.

5.3 Other Compatibility Issues

Multiple primaries - the registries may differ in their registration of multiple primaries occurring in the same person. If the second primary cancer is different histologically from the first, the registration of the new primary is straightforward. However, if the second primary has the same cell type as the first, the registration process is difficult. The second primary might be a genuine cancer or a metastasis. The registry practices in this situation might involve the total reliance upon the attending physician's judgement or involve a detailed review of each case. In general, second primary neoplasms represent less than 5 percent of the total cases registered. Even though the number is small, the practices between registries should be considered.
Reportable cases - cancer registries may differ in their registration of cases. The registry may include or exclude in situ carcinoma of certain sites and other benign conditions. Consistency can be achieved across the registries by specifically stipulating the cancers of interest. A number of the registries do not register skin (non melanoma) cancers.

Population coverage - cases of cancer may be missed because certain institutions (e.g. Veteran's Administration Hospitals) are not covered in the registration process. The different sources of information used by the registries (hospital records, pathology reports, death certificates, physician reports, etc.) also influence the coverage of cancer registration. The use of several sources will increase overlap of information on many cancer cases, which: a) assists in the confirmation of the cancer and patient information; and b) may identify faults in the registration process (e.g. identify a case from a pathology report when the hospital record was overlooked).

Dates of diagnosis - the date of diagnosis depends on what information is available to the registry: date of first symptom; date of biopsy; or date of first treatment. It is possible for these dates to differ. These differences would be minimal and would not cause major problems when comparing different registries.

5.4 Future Directions

The registries briefly outlined their future directions (details in Appendix F). Various developments were described: increasing and improving information dissemination; enlarging the registry computer facilities; placing a greater emphasis on quality control; and improving the cancer registry system of registration and coding.

5.5 Discussion

Future research studies, which may utilize the cancer registries within the Great Lakes Basin, will need to make allowances for the different types of cancer registration systems, the quality and completeness of the data in the registry and the utility of using data in different coding systems.

It appears that the cancer registries within the Great Lakes Basin are in different stages of evolution. Those registries which have more years of experience could provide readily available cancer incidence information for research purposes. Those registries which are younger could only provide recent or current cases. There is not sufficient coverage in years or geography to consider any large scale analysis of cancer incidence within the Great Lakes region. However, several of the longer standing registries could begin analysing cancer incidence data within their own jurisdictions.
The coding and classification of residence 

Discussion 3.2

The classification of cancer information in each jurisdiction showed that...

It cannot be clearly stated that second primary neoplasms represent less than 5 percent of the total cases registered. Even though the number is small, the practices between registries should be considered.
6. Future Developments

The workshop provided the stimulus for the cancer registry representatives to exchange numerous ideas and to consider the health consequences of toxic chemicals in the Great Lakes Basin. The discussion allowed the workshop participants an insight as to how the cancer registry data may be utilized for further research. A brief summary is made of several of the issues discussed.

6.1 Use of Registry Data

If research were to use cancer registry data, it was strongly felt that support was needed for both the newer and older cancer registries. Such support will assist the newer registries in their development and provide added coverage to the very large population residing in the Great Lakes Basin Area. Continued support would be desirable for the older registries, in order to pursue the more refined analyses of identifying cancer hazards in the Great Lakes region and to develop a means whereby specific residence could be evaluated (e.g. this could involve considerable effort and resources to refine residence information from county to city level). In addition, the opportunity presents itself for the registries to exchange cancer patient information on residents identified in other jurisdictions.

6.2 Analysis of Cancer Data

Several cancer registries could begin analysis of cancer incidence data within their own jurisdictions. These analyses could evaluate if excesses of cancer incidence are related to specific geographic areas within the Great Lakes Basin.

Because there are very few registries with over 10 years of incidence data, it may be beneficial to evaluate cancer mortality patterns within the Great Lakes Basin. Cancer death information is readily available by residence, age, sex and site. The analysis of this information since 1950 in concert with the appropriate population census information, would be a useful tool to identify specific regions with particular cancer risks. It is conceivable that the analysis of the existing mortality data could be carried out within a short period of time.

6.3 Extent of Contamination and Health Effects

Before any epidemiological research study could be planned or conducted, it was felt that a great deal of information was lacking, specifically the extent of toxic chemical contamination within the Great Lakes Basin and the presumed health effects as a result of such exposure. If cancer research were to be conducted utilizing cancer registry data, information would be needed in order to know more about what contaminants exist, where the contaminants are, what concentrations exist, what is the level of human exposure and what human health effects are anticipated. It was felt that this information should be collected first in order to develop research hypotheses which have a reasonable chance of being tested. Detailed information on potable water characteristics in the Great Lakes Basin would be a useful comparison when the cancer mortality analysis is completed.
6.4 Focus on Non-Cancer Outcomes

Because cancer has a long latent period (development of cancer 10-40 years after exposure) and may not be the only important outcome from toxic chemical exposure, several non-cancer outcomes were discussed.

Fish Consumption - Because fish are known to contain higher levels of toxic chemicals, the exposure to humans at a higher level than the ambient environment (air and water) may be useful for research. Two such studies are being conducted in Michigan (see Schuman, Appendix G and Humphrey, Appendix H). A range of health effects besides cancer could be assessed in a fish-consuming population. Different levels of consumption could provide a more powerful test to determine the relationship of a contaminant to human health.

Animal Studies - Previous laboratory experiments have dealt with exposures to a single toxic chemical. Little is known about what health effects are related to more than one chemical. It may be useful to conduct animal feeding studies on concentrates of potable drinking water. In this way the research findings are more closely related to human exposure to numerous chemicals in drinking water.

Human Tissues - Various human tissues may provide useful information on the exposure to toxic chemicals. Again, this type of information takes the researcher closer to a human health hazard as opposed to extrapolating from an exposure level in a lower organism. Several suggestions were made on possible human tissues or fluids which could be readily used: adipose tissue; breast milk; umbilical cord blood; or products of birth.

Other Registries - Surveillance of health effects through cancer registries may not be the most sensitive method for assessing toxic chemical risks. Toxicological experiments have shown animals to exhibit unique responses in their offspring. The use or establishment of registries of selected birth defects or adverse pregnancy outcomes should also be considered in the assessment of human health effects and exposure to toxic chemicals.

6.5 Collection of Risk Factors

The cancer registries indicated that little or no risk factor information was being collected: residence history; occupational history; smoking history; female history (parity, menopause, etc.); and family history of cancer. Only the Montgomery County Ohio registry was collecting cigarette smoking data and the New York State registry was collecting data on occupation and smoking. It was felt that the risk factor data collected would not be very complete or accurate. This information would serve a limited purpose and could be collected in greater detail in specific research studies.
APPENDIX A

APPROACH TO THE WORKSHOP — AGENDA,

PARTICIPANTS AND WORK GROUPS
A. Approach to the Workshop

This workshop was sponsored by the IJC Committee on the Assessment of Human Health Effects of Great Lakes Water Quality on behalf of the Great Lakes Water Quality Board and the Great Lakes Science Advisory Board and was considered to be an initial step in assisting in the development of compatible cancer registries in the Great Lakes Basin. The information thus provided will be utilized by the International Joint Commission in its advisory role to the Governments of Canada and the United States.

Under the terms of the 1978 Great Lakes Water Quality Agreement between Canada and the United States, the emphasis on the control of toxic substances implies the establishment of an early warning system in which epidemiology (i.e. the monitoring of human health) would play a significant role. Compatible cancer registries form an integral part of any proposed epidemiological study. Such human health-related approaches are of value in assessing the ultimate effectiveness of pollution control measures.

Three major objectives were identified for the workshop as:

- cancer registry characteristics;
- data utilization for research; and
- future developments.

A questionnaire was designed by Dr. Robert F. Spengler to cover these three objectives in relation to each Great Lakes jurisdiction. Copies of the questionnaire were circulated to the workshop invitees requesting completion of and return to the workshop secretary prior to the workshop. Completed survey forms can be found in Appendix F.

Workshop participants were representatives of each of the eight Great Lakes states and the Province of Ontario, responsible for current or planned cancer registries and representatives of federal government agencies from each country engaged in cancer-related programs. Resource invitees, Committee representatives and IJC observers comprised the remainder of the nineteen workshop attendees.
B. Agenda

AGENDA
WORKSHOP ON THE COMPATIBILITY OF GREAT LAKES BASIN CANCER REGISTRIES
9:30A.M., MARCH 19-20, 1981
CONFERENCE ROOM, INTERNATIONAL JOINT COMMISSION REGIONAL OFFICE
100 OUELLETTE AVENUE, 12TH FLOOR, WINDSOR, ONTARIO

Sponsored by
The IJC Committee on the Assessment of Human Health Effects of Great Lakes Water Quality on behalf of the Great Lakes Water Quality Board and the Great Lakes Science Advisory Board

Workshop Chairman: Dr. Robert F. Spengler,
The Ontario Cancer Treatment and Research Foundation, Toronto

Health Committee Chairman: Mr. J.R. Hickman, Health & Welfare Canada, Ottawa
(Dr. G.C. Becking, Acting Chairman)

Workshop Secretary: Dr. Andrew E.P. Watson, IJC Regional Office, Windsor

THURSDAY, March 19, 1981

9:00A.M. REGISTRATION

9:30A.M. WELCOME AND INTRODUCTIONS

9:40A.M. FIRST PLENARY SESSION, PART I. An Overview of the Activities of the IJC Committee on the Assessment of Human Health Effects of Great Lakes Water Quality - Dr. G.C. Becking, Health & Welfare Canada, Ottawa

10:15A.M. COFFEE


PART IV. Colon Cancer in Watertown, New York - Dr. W.S. Burnett, New York State Department of Health, Albany

11:30A.M. PART V. The Formation of Workshop Work Groups to address the following three objectives and the selection of Work Group Chairmen and Rapporteurs
1. Cancer Registry Characteristics
2. Data Utilization for Research
3. Future Developments

12:00P.M. LUNCH
Agenda (cont'd)

1:30 P.M. WORKSHOP WORK GROUPS CONVENED

3:00 P.M. - COFFEE -

5:30 P.M. COLLECT WORKING NOTES FOR TYPING; BREAK FOR DINNER

- OPTIONAL EVENING SESSIONS FOR WORK GROUPS -

FRIDAY, March 20, 1981

8:00 A.M. REGIONAL OFFICE STAFF - TYPING, COPYING AND DISTRIBUTION OF MATERIALS

9:00 A.M. SECOND PLENARY SESSION*

PART I. Report of Work Group on Cancer Registry Characteristics

9:30 A.M. PART II. Report of Work Group on Data Utilization for Research

10:00 A.M. PART III. Report of Work Group on Future Developments

10:30 A.M. - COFFEE -

10:45 A.M. PART IV. General Discussion of Work Group Reports

12:00 P.M. - LUNCH -

1:30 P.M. THIRD PLENARY SESSION, PART I. Draft of Workshop Recommendations and of Workshop Proceedings

- Discussion

2:30 P.M. PART II. Summary Remarks by Workshop Chairman

3:00 P.M. ADJOURNMENT

* N.B. Times shown for Parts I - III include 5 minutes each for question clarification by the Chairman
C. Participants

WORKSHOP ON THE COMPATIBILITY OF GREAT LAKES BASIN CANCER REGISTRIES
Sponsored by
Great Lakes Science Advisory Board and the Great Lakes Water Quality Board
Committee on the Assessment of Human Health Effects of Great Lakes Water Quality

Dr. Robert F. Spengler (Workshop Chairman)
Division of Epidemiology and Statistics
The Ontario Cancer Treatment and Research Foundation
7 Overlea Boulevard
Toronto, Ontario M4H 1A8

Dr. Henry Anderson
Director
Environmental Epidemiology
Wisconsin Department of Health
1 West Wilson Street
Madison, Wisconsin 53701

Dr. W.S. Burnett
Assistant Director
Bureau of Cancer Control
State of New York Department of Health
Office of Public Health
Tower Building, Empire State Plaza
Albany, New York 12237

Dr. John Isbister
Disease Control Officer
State of Michigan
Department of Public Health
Lansing, Michigan 30035

Dr. Dwight T. Janerich, DDS
Director
Bureau of Cancer Control
State of New York Department of Health
Office of Public Health
Tower Building, Empire State Plaza
Albany, New York 12237

Dr. Katherine Marconi
Division of Chronic Disease Control
Pennsylvania State Department of Health
P.O. Box 90
Harrisburg, Pennsylvania 17120

Dr. Earl F. Pollock
National Cancer Institute
Landow Building, Room 5-C-03
7910 Woodmont Avenue
Bethesda, Maryland 20205

Dr. Leonard Schuman
Director of Epidemiology
School of Public Health
1360 Mayo Memorial Building
University of Minnesota
Minneapolis, Minnesota 55455

Dr. James M. Shuler
Office of Chemical Risk
Indiana State Board of Health
1330 W. Michigan Street
Room A-412, P.O. Box 1964
Indianapolis, Indiana 46206

Mr. John Silins
Chief, Vital Statistics & Disease Registries Section
Statistics Canada
R.H. Coats Building
Holland & Scott Streets
Tunney's Pasture
Ottawa, Ontario K1A 0T6

Dr. Marie Swanson
Director
Michigan Cancer Foundation
110 East Warren
Detroit, Michigan 48201
Participants (cont'd)

Dr. Andrew E.P. Watson (Workshop Secretary)
Scientist
International Joint Commission
Great Lakes Regional Office
100 Ouellette Avenue, 8th Floor
Windsor, Ontario N9A 6T3

Dr. Donald Wigle
Chief
Non Communicable Disease Laboratory Center for Disease Control
LCDC Building, Tunney's Pasture
Holland Avenue
Ottawa, Ontario K1A 0L2

Resource Person

Dr. Harold E.B. Humphrey
Environmental Epidemiologist
State of Michigan
Department of Public Health
3500 N. Logan Street
Lansing, Michigan 48914

Committee Representation

Dr. George C. Becking, Chief
(Acting Committee Chairman)
Environmental Toxicology Division
Department of National Health & Welfare
Environmental Health Center
Room 118
Ottawa, Ontario K1A OL2

Observers

Dr. Peter Boyle
West of Scotland Cancer Group
Glasgow, Scotland

Dr. Joel Fisher
Environmental Adviser
International Joint Commission
1717 H Street N.W.
Washington, D.C. 20440

Dr. Joan C. McEwan
Chief
Health Studies Services
Special Studies & Services Branch
Ontario Ministry of Labor
400 University Avenue
8th Floor
Toronto, Ontario M7A 1T7
D. Work Groups and Tasks

1. CANCER REGISTRY CHARACTERISTICS

Participants: Dr. W.S. Burnett (NY), Dr. H.E.B. Humphrey (MI),
Dr. J. Isbister (MI), *Dr. K. Marconi (PA), and
Dr. J.M. Shuler (IN)

Tasks: Review survey questions 1 to 2.1
Prepare comparison tables
Compare quality control measures
Draft minimum data set
Propose data developments

2. DATA UTILIZATION FOR RESEARCH

Participants: Dr. H. Anderson (WI), Dr. P. Boyle (Observer),
Dr. D.T. Janerich (NY), *Dr. E.F. Pollock (NCI),
Mr. J. Sillins (NCIRS) and Dr. M. Swanson (MI)

Tasks: Review survey questions 2 to 2.8
Assess data usefulness
Assess quality and completeness
Assess level of residence
Determine current registry uses
Review registry directions
Address issues of confidentiality and access

3. FUTURE DEVELOPMENTS

Participants: Mr. R. Indian (OH), Dr. J.C. McEwan (Observer),
Dr. L. Schuman (MN), *Dr. R.F. Spengler (ONT),
and Dr. D. Wigle (LCDC)

Tasks: Review survey question 3 to 3.3
Investigate case exchange between jurisdictions
Propose potential studies
Explore data sources
Investigate non-cancer outcomes
Review current health studies in Great Lakes Basin
Determine research priorities

* Denotes Chairman of Task Groups
1. CARRIERS REGISTRY AND MORTALITY,

Participants:
- Dr. W. T. B. Parrott (UK),
- Dr. D. C. McEwan (Scotland),
- M. R. Watson (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
- Dr. J. A. F. Williams (UK),
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APPENDIX B

"ACTIVITIES OF THE IJC COMMITTEE ON THE ASSESSMENT OF HUMAN HEALTH EFFECTS OF GREAT LAKES WATER QUALITY - AN OVERVIEW", BY DR. G.C. BECKING, HEALTH AND WELFARE CANADA


Under the articles of the Boundary Waters Treaty, the International Joint Commission (IJC) was assigned by the Governments special responsibilities and functions to assist in the implementation of those Agreements. As stated in the Water Quality Agreement, two boards were formed to act as advisors to the IJC - the Water Quality Board (WQB) and the Science Advisory Board (SAB).

The IJC recognized the serious health risks to residents in the Great Lakes and in their 1978 report proposed action to fully assess the effects of such contamination on human health. As a result of this concern special committees were established in 1978 to study the impacts of Great Lakes Water Quality. The following terms of reference apply.

1. Assess the risk to health posed by contaminants in the Great Lakes ecosystem.
2. Re-review action levels and guidelines for selected substances.
3. Provide to the IJC through its Board, interpretation and communication on health matters.
4. Maintain awareness of current advances and knowledge as they relate to human health aspects of the Great Lakes ecosystem.

Since its formation the Health Effects Committee has examined the areas of concern listed below and presented its findings and recommendations to the WQB and SAB in reports dated July 1979 and November 1980.

1. Mechanism of health hazard evaluation.
2. Estimation of human exposure from environmental data.
3. Evaluation of chemical toxicity.
4. Interactions in toxicology.
5. Sources and significance of viruses in the water environment.
6. Health hazard ranking of chemicals identified in the Great Lakes.
8. Contaminant levels in Great Lakes fish.

The Committee has spent a great deal of time and effort during the last two years, developing procedures for and carrying out health hazard evaluations of chemicals previously identified (not necessarily quantified) in one or more compartments of the Great Lakes Ecosystem (Great Lakes Water Quality Board Report - Appendix 1. 1978). Each of these activities requires evaluation of all available data on toxicity and modes of action in particular chemicals.
APPENDIX B

"ACTIVITIES OF THE IGC COMMITTEE ON THE ASSESSMENT OF HUMAN HEALTH EFFECTS OF GREAT LAKES WATER QUALITY: AN OVERVIEW"

By Dr. G.C. Becking, Health and Welfare Canada
ACTIVITIES OF THE IJC COMMITTEE ON THE ASSESSMENT OF HUMAN HEALTH EFFECTS OF GREAT LAKES WATER QUALITY - AN OVERVIEW


Under the articles of the Boundary Waters Treaty, the International Joint Commission (IJC) was assigned by the Governments special responsibilities and functions to assist in the implementation of these Agreements. As stated in the Water Quality Agreement, two Boards were formed to act as advisors to the IJC - the Water Quality Board (WQB) and the Science Advisory Board (SAB).

The IJC recognized the serious problem of toxic chemicals in the Great Lakes and in their 1978 report urged both Governments to fully assess the effects of such contaminants on human health and the environment. As a result of this concern over the potential human health hazards from toxic chemicals and other water quality parameters, the WQB and SAB established in 1978 a special Committee on the Assessment of Human Health Effects of Great Lakes Water Quality. This Committee would report jointly to both Boards and have the following terms of reference.

1. Assess the risk to health posed by contaminants in the Great Lakes Ecosystem.
2. Review action levels and guidelines for selected substances.
3. Provide to the IJC through its Boards, interpretation and consultation on health matters.
4. Maintain awareness of current advances and knowledge as they relate to human health aspects of the Great Lakes ecosystem.

Since its formation the Health Effects Committee has examined the areas of concern listed below and presented its findings and recommendations to the WQB and SAB in reports dated July 1979 and November 1980.

1. Mechanism of health hazard evaluation.
2. Estimation of human exposure from environmental data.
3. Evaluation of chemical toxicity.
4. Interactions in toxicology.
5. Sources and significance of viruses in the water environment.
6. Health hazard ranking of chemicals identified in the Great Lakes.
8. Contaminant levels in Great Lakes fish.

The Committee has spent a great deal of time and effort during the last two years developing procedures for and carrying out health hazard evaluations of chemicals previously identified (not necessarily quantified) in one or more compartments of the Great Lakes Ecosystem (Great Lakes Water Quality Board Report - Appendix E, 1978). Such an activity requires evaluation of all available data on toxicity and man's exposure to a particular chemical.
in order to arrive at an acceptable hazard evaluation. As of November 1980, exposure data on most chemicals listed in Appendix E were not available. For that reason only toxicological evaluations were carried out. In summary, of the 381 chemicals listed in Appendix E, there were insufficient toxicity data on 292 and only acute toxicity data on another 18 chemicals. Of the remaining 71 chemicals, 33 are known to cause chronic effects in man (mostly from exposure to high levels in the workplace) and 38 are known to cause chronic adverse effects in experimental animals.

Having completed an initial evaluation of toxicities we are faced with the onerous task of obtaining exposure data. In all probability we will be forced to use such surrogates of exposure as production and/or use figures, leading to much less credible hazard evaluations. This is presently an ongoing activity.

Once the Committee has identified the most hazardous Appendix E chemicals, I am sure the Public and/or governments will be asking whether health effects have already occurred. For instance, has exposure to one or more of these hazardous compounds led to an increased incidence of cancer? Early in 1980 the Committee investigated the types of cancer registries in Ontario and New York, in order to ascertain the availability of the health data required to answer this question. It became evident that the Committee required the assistance of experts in the area of cancer registries and epidemiology if it were to provide meaningful advice to the IJC. Such a conclusion led directly to the convening of this Workshop.

The Committee will continue to address the problems associated with the design of epidemiological studies and the data needs for such investigations. Also, interactions in toxicology, effects of toxic chemicals on high risk populations, the effects of environmental contaminants on behaviour and the immune system and the adequacy of present action levels and guidelines will be addressed.
APPENDIX C

"WATER CONTAMINATION BY TOXIC CHEMICALS: A CHALLENGE TO CANCER REGISTRIES IN ASSESSING POPULATION RISKS",
BY DR. ROBERT F. SPENGLER, THE ONTARIO CANCER TREATMENT AND RESEARCH FOUNDATION
In order to arrive at an acceptable hazard evaluation. As of November 1980, exposure data on most chemicals listed in Appendix A were not available. For such cases, only a toxicological evaluation was carried out. In summary, of the 33 chemicals listed in Appendix C, there were insufficient toxicity data on one and very limited toxicity data on another 16 chemicals. Of the remaining 16 chemicals, 12 are known to cause chronic effects in man (mostly from exposure to high levels in the workplace) and 4 are known to cause chronic adverse effects in experimental animals.

We have completed an initial evaluation of toxicity. We are faced with the serious task of obtaining exposure data. In all probability we will be forced to use such surrogates of exposure as production and/or use figures, leading to much less credible hazard evaluations. This is presently an ongoing concern.

Once the Committee has identified the most hazardous Appendix C chemicals, the next step would be for the Public and/or governments to study whether health effects have already occurred. For instance, the exposure to one or more of these substances compounds led to an increase in the number of cancer. Early in 1980 the Committee investigated the type of cancer registrars in Ontario and New York, in order to ascertain the availability of the health data required to answer this question. It became apparent that the Committee required the assistance of experts in the area of cancer etiology and epidemiology if it were to provide meaningful advice on this question. A conclusion led directly to the committee of this Workshop:

"WATER CONTAMINATION BY TOXIC CHEMICALS: A CHALLENGE"

The Committee is concerned with the potential hazards to health posed by high risk investigations. Therefore, the effects of occupational exposures in behaviour and the nervous system and the adequacy of existing safety guidelines will be
It is very difficult to assess the health effects associated with contaminants in drinking water. Very little information exists linking human health effects such as cancer with water supply. Emphasis on the control of toxic substances implies the establishment of an early warning system in which epidemiology could play a significant role.

We know that there are toxic chemicals in the Great Lakes water basin as a result of industrial discharges, agricultural runoff, urban drainage and from air pollution. We also know that these toxic chemicals are present in lake sediment samples, in the water of the lakes themselves and in the fish that live in the lakes. There is an indication of potential carcinogenic substances in drinking water. However, what effect they have or what long-term effect they have on human health has not been accurately assessed.

Contaminants and Cancer

Besides cancer, there are other health outcomes associated with water contaminants reported in the literature. There are several effects in humans that may be useful indicators besides cancer. The list in Table 1 could be much longer and it did not include the toxicological evidence of lowered birth weight or other birth outcomes in laboratory animal experiments.

A great number of published papers have dealt with associations between water contaminants and cancer. A fair number of cancer sites have been correlated with specific contaminants or water sources (Table 2). The cancer sites common to all these studies are the gastro-intestinal and urinary tract. There are many concerns over these types of studies.

Five major areas of concern include: methodological problems; analytical complexities; definition of exposure; confounding variables; and issues in causality. These topics are not meant to be mutually exclusive, but discussions are made on each.

Methodological Problems

Previous studies in the area of assessing human health effects related to water contaminants have been basically correlational studies or ecological studies. These studies have correlated disease rates within certain geographic locations and water contaminant concentrations within the same given areas. If there is a high concentration in a certain number of areas and there is also a high disease rate in those same given areas and conversely in low areas, then these correlations are reported as significant associations. However, these types of studies are prone to many methodological difficulties in their interpretation. For instance, as in other areas of epidemiological research (radiation, diet, etc.), there is a distinct lack of historical measurements. The chemical concentrations being used in these studies are fairly recent measurements where none existed in the past. In terms of cancer, we know that the exposure to a carcinogenic substance
<table>
<thead>
<tr>
<th>Contaminant</th>
<th>Health Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>mercury (1,2)</td>
<td>Minamata disease</td>
</tr>
<tr>
<td>cadmium (1)</td>
<td>Fanconi's syndrome</td>
</tr>
<tr>
<td>PCB (1)</td>
<td>chloracne, small newborns</td>
</tr>
<tr>
<td>nitrate (1-3)</td>
<td>methemoglobinemia</td>
</tr>
<tr>
<td>lead (4-6)</td>
<td>child development, mental retardation, chronic nephropathy</td>
</tr>
<tr>
<td>sulphate, magnesium (2)</td>
<td>gastro-intestinal irritation</td>
</tr>
<tr>
<td>arsenic (2)</td>
<td>ischaemic disease of the extremities</td>
</tr>
<tr>
<td>sodium (2)</td>
<td>hypernatraemia</td>
</tr>
<tr>
<td>excessive fluoride (1)</td>
<td>skeletal changes, blackening, disfigurement of teeth</td>
</tr>
</tbody>
</table>

Note ( ) indicates bibliographic reference number, see page 38.
# Table 2

## Cancers Associated with Water Contaminants*

<table>
<thead>
<tr>
<th>Contaminant</th>
<th>Cancer Site</th>
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<tbody>
<tr>
<td>nickel (7)</td>
<td>mouth, intestine</td>
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<tr>
<td>arsenic (7)</td>
<td>eye, larynx, myeloid leukemia</td>
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<tr>
<td>beryllium (7)</td>
<td>breast, uterus, bone</td>
</tr>
<tr>
<td>chrysotile asbestos (8)</td>
<td>gall bladder, pancreas, lung</td>
</tr>
<tr>
<td>THM (trihalomethanes) (9-11)</td>
<td>brain, pancreas, bladder, rectum</td>
</tr>
<tr>
<td>chloroform (11,12)</td>
<td>pancreas, liver, bladder, intestine, rectum, all cancers</td>
</tr>
<tr>
<td>chlorinated water (11,13)</td>
<td>esophagus, liver, large intestine, rectum, bladder, kidney</td>
</tr>
<tr>
<td>Ohio surface water (11,14)</td>
<td>esophagus, larynx, lung, G. I. tract, urinary tract, lymphosarcoma, reticulosarcoma, all cancers</td>
</tr>
<tr>
<td>Mississippi River (11)</td>
<td>liver, G. I. tract, urinary tract, all cancers</td>
</tr>
</tbody>
</table>

*Selected studies have identified a correlation with cancer; however, a causal relationship has not been proven.

Note ( ) indicates bibliographic reference number, see page 38.
usually occurs between ten and forty years prior to the diagnosis or the death from that cancer. With the lack of good historical measurements, we fall into the problem of assuming that the same concentration existed in the past, when it may not have. It could have been higher; it could have been lower. In addition, the chemical of interest that may really be related to the disease could have been present in the past but not now present.

Another problem with these studies has been their inability to really define the population at risk. For example, the contamination may be located in one specific region of a State -- even one city -- and yet the scientists have used the county rate or the State rate in assessing the disease rate. They have included a fair number of individuals who are not directly at risk from exposure to the contaminated water supply. The larger the geographic area studied, the more heterogeneous the exposure level will be. The high mobility of certain populations can also result in misclassification of exposure.

Correlational or ecological studies are usually the first attempt to identify potential health risks, and they are limited to readily available data. They utilize selected parameters of drinking water and correlate them with disease rates after controlling for indices of socioeconomic and other demographic characteristics. These studies can generate hypotheses, but require more evidence before a causal association can be established. Many of the subsequent studies are in fact correlational and are subject to the same methodological weaknesses. Many correlational studies have used the same data bases (e.g. cancer mortality, U.S. EPA Region V water measurements) and each in turn is affected by methods of data collection and data quality.

The biggest problem that epidemiologists are faced with is how to design studies that will assess water contamination and the health consequences. It is exceedingly difficult to study exposures to numerous chemicals that are identified in the drinking water and also consider the multiple exposures from other variables (such as smoking, drinking and dietary factors) which may also be related to the development of cancer. In this situation, it will be difficult to delineate the effects of one chemical. To compound this problem even further, cancer is a disease that usually occurs decades after the exposure.

Studies must be designed to evaluate modest environmental risks and methods are needed to deal with the above problems which decrease our chances of detecting any health effect.

Analytical Complexities

Competing causes of death may alter the observed cancer rates and introduce significant variation between comparison areas. Non-cancer deaths should also be considered in any future analysis.

Another problem is how to deal with small population sizes and rare occurrences of cancer. One or two cases can greatly influence the rate and comparisons being made between small communities. The use of longer periods of time in order to assemble enough cases also introduces yet another problem -- the concealing of time trends.
We like to make comparisons based on age-adjusted rates, while overlooking the variability within specific age groups. Two communities may have the same adjusted rates, yet one has more cancer in the younger age groups. (However, it is difficult to analyze 2 sexes, 10 age groups, 20 sites of cancer for 20 communities -- yielding 8,000 specific cancer rates versus 800 adjusted rates).

Another concern can be expressed over the variables that are needed to control the comparisons between communities (e.g. median education level, median family income, population size, percent of workforce in manufacturing, percent foreign stock in 10 ethnic groups). The interactions among these adjustment variables can affect the resultant association. The inclusion of too many variables decreases the power to detect an association. The previous studies reviewed have all used different sets of adjustment variables which makes comparisons among studies difficult.

The use of sophisticated analytical models can produce different results based on differing assumptions. We then ask ourselves -- what is truth when we do not really know what interactions exist? Mississippi River data have been re-analyzed by several investigators and each achieves different results.

**Defining Exposure**

Numerous questions need to be answered about exposure measurements in any research study. Do the measurements reflect annual sampling or are they single measurements; do they have small variances; do they represent the community (or just grab samples) and do they result from repeated testing of the same water sample? What is the sensitivity and specificity of the equipment used to test water samples? Are the measurements from one central laboratory or from local laboratories? These questions are important in light of the correlations being made.

Post-treatment water tests may not accurately reflect concentrations of chemicals at the users' end of the water distribution system -- the faucet. Many consumers have added water softeners and water filters to their own supply.

The contaminants measured today cannot be assumed to have been present in the past. The reverse situation may also exist in that the contaminant of interest existed in the past but is not now present. The chemical actually related to a disease may not even be measured or be measurable with today's techniques. The correlation between a surrogate measure and the chemical of interest can also have a large variance.

Actual consumption has been assumed to be homogeneous, regardless of where an individual lives or works. Also, exposure to certain chemicals can result from air pollution, agricultural runoff, landfill leachates, industrial discharges, dietary intake, or employment in certain industries.

**Confounding Variables**

The following variables are potentially related to both exposure and outcome (i.e. cancer). Each in turn must be evaluated for its association
with the health outcome of interest and controlled for when assessing the relationship with water contaminants.

Obviously, socioeconomic status is related to particular cancer sites and may also be related to the place of residence and water distribution systems.

Life style elements -- diet, smoking and alcohol -- could have a major effect on any cancer association, especially for cancers of the pancreas, lung, stomach and colon.

In the United States, there are marked differences in cancer rates between blacks and whites, migrant groups and certain religions and in Canada the situation may be more pronounced.

A person-years analysis could be very useful, but implies a means of following up residents. People do not tend to live in one place all their lives. Population mobility is a potential problem in cancer studies due to the long latent periods between exposure and the onset of disease.

Occupation may also play a major role in any cancer excess, especially when the excess occurs in one sex group.

Issues in Causality

Several issues must be considered when one evaluates the association between water contaminants and cancer. Should one consider that water contaminants have an equal effect on both sexes? If a risk association holds for both sexes, perhaps this evidence should be given greater weight as to an environmental exposure. Usually a higher risk in males than females has been used in the past to infer an occupational association. However, we know that chloroform causes kidney cancer in male but not in female mice.

Until now, studies have correlated disease rates with concentration levels. It is important to know that higher risk results from higher exposure. The causal association would be enhanced further if we knew more about exposures over time, length of residence and latency periods.

A major problem is the fact that water contaminants can be numerous as well as unmeasured. Also, the process of water purification can in itself produce many potentially carcinogenic chemical compounds. To focus on the one chemical which fits a correlation may be inappropriate.

Lastly, it is obvious that the effects of confounding variables must be controlled as much as possible.

Discussion

If John Snow in 1885 had had similar concerns, perhaps he would not have investigated the cholera outbreak in London and not been able to identify the disease that was associated with drinking water containing fecal contaminants. However, he was able to look at the actual risks on a household basis and of course, the short incubation period simplified his research.
The point is that we should not be overly pessimistic, but we should be aware of the many problems and develop ways of dealing with them. Several approaches will be discussed.

Cancer Surveillance

Compatible cancer registries within the Great Lakes water basin could become an integral part of risk assessment. Cancer registries could also help to assess the effectiveness of pollution control measures. A population based registry is a collection of every single cancer case diagnosed in its jurisdiction. Each person is registered, having his name, date of birth, site of cancer, cell type of disease, his residence and other information collected in a uniform fashion. The data undergo rigorous quality control in terms of coding, checking to make sure that a case is not reported more than once and identifying every possible case.

Case-Control Studies

A cancer registry can be used for numerous purposes. It can be used to identify cases of a particular disease and a suitable control group. This sort of case-control study can then use questionnaires in identifying what previous exposures individuals may have had in the past: certain things in their diet; certain chemicals they might be exposed to in their work place; their lifestyle habits in terms of the amount of alcohol they consume; or whether they are cigarette smokers; and past history on residence, occupation and potable water sources. A case-control study approach can identify potential risk factors that are more prevalent amongst the cases than amongst the control group. The gastro-intestinal or urinary tract cancers would be the likely sites for study. Collaborative studies focusing on areas with particular chemical contamination would also be desirable.

Community Follow-up Studies

Community follow-up studies that assess risk on length of residence may not be impossible. Canada has a national death index that goes back to 1950. Quinquennial census enumerations could be used to assemble residents, estimate their length of residence and then be linked by computer to the national death index. Statewide death certificates could be utilized for follow-up, but migration out of the state would have to be accounted for.

Collection of additional information on selected cancer sites may serve three purposes: 1) to evaluate cancer risks in more detail when compared with community attributes (socioeconomic status, etc.); 2) to enhance selection of cases for potential studies; or 3) to establish baseline risk factors for future use.
References


5. Ontario Committee to inquire into and report upon the effect on human health of lead from the environment. Effect on human health of lead from the environment. 1974.


APPENDIX D

"CANCER MORTALITY AND DRINKING WATER QUALITY IN SELECTED CANADIAN MUNICIPALITIES: PRELIMINARY RESULTS"

BY DRS. D.T. WIGLE, Y. MAO, P. TOFT AND J.C. MERANGER,
HEALTH AND WELFARE CANADA
References


"Cancer Mortality and Drinking Water Quality in Selected Canadian Municipalities"

-Preliminary Results-

D.T. Wigle\textsuperscript{1}, Y. Mao\textsuperscript{1}, P. Toft\textsuperscript{2}, J.C. Meranger\textsuperscript{2}


\textsuperscript{1}Bureau of Epidemiology
Laboratory Centre for Disease Control
Health Protection Branch
Health and Welfare Canada

\textsuperscript{2}Bureau of Chemical Hazards
Environmental Health Directorate
Health Protection Branch
Health & Welfare Canada
Abstract

Drinking water quality and mortality data for selected Canadian municipalities were analyzed with emphasis on asbestos and gastrointestinal cancers. Using linear regression analysis, gastrointestinal cancer mortality rates were significantly correlated with asbestos concentration (males, r=-0.43; females, r=-0.36), fluoridation (females, r=0.21), total organic carbon (females, r=0.32), trihalomethanes (males, r=0.45) and water hardness (males, r=-0.34). Mortality rates for individual gastrointestinal cancer sites were consistently and significantly negatively correlated with asbestos concentration. Municipalities with high drinking water asbestos concentrations had consistently lower age-standardized total and gastrointestinal cancer mortality rates compared to low asbestos municipalities matched for water source and chlorination and fluoridation status. Sherbrooke, a relatively large municipality with high asbestos concentrations due to longstanding natural sources and lack of filtration, had lower age-standardized gastrointestinal cancer mortality rates than low asbestos municipalities matched for water source, chlorination status and population. Multiple regression analysis between age-standardized cancer mortality rates and ten demographic and water quality characteristics in 28 cities yielded negative associations between asbestos and most cancer sites except lung and lymphatic cancers in females (B=0.32 and 0.38, respectively). However these associations were not statistically significant. The negative results of this study may be due to a variety of limitations including relatively low exposure (compared to occupational groups), population mobility, use of recent rather than historical water quality data and lack of control for potential confounding variables including diet.

Introduction

The potential health effects of the contamination of drinking water supplies by asbestos fibres and chemicals known or suspected to be carcinogenic have been investigated during recent years (1-11). In view of the concern raised by the early studies (1,6), the Environmental Health Directorate of Health and Welfare Canada conducted two national surveys of municipal drinking water supplies (12,13). The first of these surveys (12) was carried out in 1976-1977 in 70 municipalities for which samples were collected from raw water intake (prior to prechlorination), treated water (immediately after all forms of treatment) and two public buildings, respectively, about % mile and 1 mile from the water treatment plant. Samples were analyzed for total organic carbon and halomethanes. The second survey (13) was carried out in August and September 1977 in 71 municipalities and, where possible, samples were collected from raw water, treated water and the distribution system. These samples were analyzed for asbestos using transmission electron microscopy with verification by selected area electron diffraction and energy dispersive X-ray analysis. The two surveys overlapped each other with only 32 municipalities included in both.

In order to determine if drinking water quality was related to detectable health effects, a mortality study with emphasis on cancer and asbestos was undertaken.
Methods

Mortality data for the period 1966 to 1976 were obtained from the Health Division of Statistics Canada. The geographic area served by each municipal water supply was determined (14) and the standard geographic codes used on vital statistics records and corresponding to the defined geographic areas were identified. The person-years at risk by sex and age (0-4, 5-9, 10-14, 15-19, 20-24, 25-34, 35-44, 45-54, 55-64, 65-69, 70+) for each municipality were estimated by: (i) linear interpolation of census data for 1966, 1971 and 1976; (ii) adjustment for municipal boundary changes. Demographic data for municipalities were obtained from Statistics Canada publications, (15-24) microfiche and microfilm. Data concerning fluoridation, water source, water hardness (calcium plus magnesium) and filtration status were obtained from publications (12,13,25,26). For certain municipalities it was necessary to phone the person in charge of the drinking water treatment plant to determine the year in which fluoridation was introduced.

Age-specific mortality rates and direct age-standardized mortality rates (ASMRs) for the period 1966 to 1976 were calculated using the 1971 Canadian population as standard. Standard errors of ASMRs were calculated using Chiang's method (27). Multiple regression analysis with least-wise deletion was conducted using the Statistical Package for the Social Sciences (SPSS, version 7.2).

The demographic and water quality variables used in the present analyses were defined as follows:

i water source - 1 = surface, 2 = mixed, 3 = ground;
ii asbestos concentration - the concentration of chrysotile asbestos in millions of fibres per litre in distribution system water samples;
iii fluoridation - 1 = no, 2 = yes;
iv total organic carbon - mg/L in distribution system water samples;
v trihalomethanes - µg/L in distribution system water samples;
vi hardness - the concentration of calcium plus magnesium (mg/L) in distribution system water samples;
vii population density - persons per square mile in geographic area served by water supply;
viii average family income - 1971 Census;
ix asbestos mining (1 = no, 2 = yes);
x percent less than grade 9 - the percent of the population aged 5 or older, not attending school full-time whose highest education achieved was less than grade 9.

Results

Correlation Between Demographic and Water Quality Variables

The Pearson correlation coefficients between selected demographic and water quality characteristics of the municipalities are presented in Table 1. The concentration of asbestos in drinking water was significantly correlated with trihalomethanes (r=0.33), asbestos mining (r=0.59) and low education
### Table 1
PEARSON CORRELATION COEFFICIENTS BETWEEN DEMOGRAPHIC AND WATER QUALITY VARIABLES

<table>
<thead>
<tr>
<th>Source</th>
<th>ASB Conc</th>
<th>Fluor</th>
<th>TOC</th>
<th>THM</th>
<th>Hard</th>
<th>Pop Dens</th>
<th>Inc</th>
<th>MINING</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASBESTOS CONC.¹</td>
<td>-.13</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FLUORIDATION</td>
<td>-.16</td>
<td>-.20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL ORGANIC CARBON¹</td>
<td>-.20</td>
<td>.03</td>
<td>-.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>TRIHALOMETHANES¹</td>
<td>-.23</td>
<td>.33*</td>
<td>.10</td>
<td>.67**</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>HARDNESS¹</td>
<td>.17</td>
<td>-.11</td>
<td>-.10</td>
<td></td>
<td>-.07</td>
<td>-.04</td>
<td></td>
<td></td>
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<td>POPULATION DENSITY</td>
<td>-.03</td>
<td>-.21</td>
<td>.05</td>
<td>.11</td>
<td>-.13</td>
<td>-.02</td>
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<td></td>
</tr>
<tr>
<td>AVG. FAMILY INCOME</td>
<td>.01</td>
<td>-.06</td>
<td>.17</td>
<td>-.23</td>
<td>-.22</td>
<td>-.16</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>ASBESTOS MINING</td>
<td>.02</td>
<td>.59**</td>
<td>-.29**</td>
<td>NA</td>
<td>.39*</td>
<td>NA</td>
<td>-.15</td>
<td>-.14</td>
</tr>
<tr>
<td>% &lt; GRADE 9</td>
<td>-.09</td>
<td>.26*</td>
<td>-.15</td>
<td>.11</td>
<td>.34*</td>
<td>.06</td>
<td>-.13</td>
<td>-.66**</td>
</tr>
</tbody>
</table>

NA = Not available, TOC = total organic carbon, THM = trihalomethanes

¹ In samples from distribution systems

Note: Variables are defined in Methods
As expected, there were strong correlations between low education and average family income ($r = -0.66$) and between total organic carbon and trihalomethanes ($r = 0.67$).

**Mortality Rates Versus Individual Demographic and Water Quality Variables**

Pearson correlation coefficients based on linear regression analysis of selected demographic and water quality variables versus age-standardized mortality rates (ASMRs) are presented in Table 2. The number of localities included in the analyses varied due to missing data. All-cause mortality rates for males were significantly correlated with low education ($r = 0.37$), asbestos concentration ($r = -0.23$) and hardness ($r = -0.36$). Total cancer mortality rates were significantly correlated with total organic carbon (males, $r = 0.35$; females, $r = 0.36$), trihalomethanes (males, $r = 0.50$), water hardness (males, $r = -0.41$), average family income (females, $r = -0.26$), asbestos mining (males, $r = 0.37$) and low education (males, $r = 0.40$). Gastrointestinal cancer mortality rates (ICDA 150-159) were significantly correlated with asbestos concentration (males, $r = -0.43$; females, $r = -0.36$), fluoridation (females, $r = 0.21$), total organic carbon (females, $r = 0.32$), trihalomethanes (males, $r = 0.45$), water hardness (males, $r = -0.34$), population density (males, $r = 0.24$; females, $r = 0.27$), average family income (males, $r = -0.34$) and low education (males, $r = 0.48$; females, $r = 0.27$).

Mortality rates for individual gastrointestinal cancer sites specific for each sex were consistently and significantly negatively correlated with asbestos concentration. There was a strong negative correlation between water hardness and stomach cancer for males ($r = -0.56$) but not females ($r = 0.04$).

**Cancer Mortality Rates for Municipalities Grouped by Water Quality Characteristics**

ASMRs for total cancer and selected gastrointestinal cancer sites for municipalities grouped by water quality characteristics are presented in Table 3. Municipalities with high chrysotile asbestos concentrations ($> 5 \times 10^6 \text{ fibres/L}$) in samples taken from drinking water distribution systems had consistently lower ASMRs for all cancers and for selected gastrointestinal cancers compared to municipalities with lower asbestos concentrations. These mortality rate differences persisted after matching municipalities for drinking water characteristics including source and status with regard to chlorination and fluoridation.

**Cancer Mortality Rates for Municipalities Ranked by Asbestos Concentration in Drinking Water Distribution Systems**

ASMRs for all cancers and selected gastrointestinal cancers for individual municipalities with more than $2 \times 10^6$ chrysotile asbestos fibres per litre in samples of either raw or distribution system water samples are presented in Table 4. The municipalities are grouped by filtration status and ranked by asbestos concentration in distribution systems. There was no apparent correlation between asbestos concentration and ASMRs for the selected cancers. It should be noted that the following localities had less than 1000
### Table 2

Pearson Correlation Coefficients Between Selected Demographic and Water Quality Variables and Age-Standardized Mortality Rates (Age 25-69)

<table>
<thead>
<tr>
<th></th>
<th>WATER SOURCE (56)</th>
<th>ASB CONC (65)</th>
<th>FLUOR (65)</th>
<th>TOC (31)</th>
<th>THM (32)</th>
<th>WATER HARD (31)</th>
<th>POP DENS (62)</th>
<th>AVG FAM INC (46)</th>
<th>ASB MINING (65)</th>
<th>% &lt; GR. 9 (46)</th>
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</thead>
<tbody>
<tr>
<td><strong>SEX</strong></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>All Causes</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>.20</td>
<td>-.23*</td>
<td>.01</td>
<td>.17</td>
<td>.24</td>
<td>-.36*</td>
<td>.06</td>
<td>-.05</td>
<td>.20</td>
<td>.37**</td>
</tr>
<tr>
<td>F</td>
<td>.05</td>
<td>-.05</td>
<td>.00</td>
<td>.20</td>
<td>.03</td>
<td>-.22</td>
<td>-.02</td>
<td>.10</td>
<td>.05</td>
<td>.11</td>
</tr>
<tr>
<td>All Cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>.12</td>
<td>-.12</td>
<td>.05</td>
<td>.35*</td>
<td>.50**</td>
<td>-.41*</td>
<td>.15</td>
<td>.16</td>
<td>.37**</td>
<td>.40**</td>
</tr>
<tr>
<td>F</td>
<td>-.02</td>
<td>-.22*</td>
<td>.11</td>
<td>.36*</td>
<td>.01</td>
<td>-.29</td>
<td>.16</td>
<td>-.26*</td>
<td>.00</td>
<td>.18</td>
</tr>
<tr>
<td>CA. Tongue, Mouth &amp; Pharynx</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>-.09</td>
<td>-.29**</td>
<td>.26*</td>
<td>.14</td>
<td>.12</td>
<td>-.28</td>
<td>.24*</td>
<td>.05</td>
<td>.16</td>
<td>.29*</td>
</tr>
<tr>
<td>F</td>
<td>-.06</td>
<td>-.23*</td>
<td>.03</td>
<td>.13</td>
<td>-.45**</td>
<td>.29*</td>
<td>.29*</td>
<td>.20</td>
<td>.28*</td>
<td>.05</td>
</tr>
<tr>
<td>CA. Esophagus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>M</td>
<td>-.13</td>
<td>-.27*</td>
<td>.22*</td>
<td>.10</td>
<td>.36*</td>
<td>-.16</td>
<td>.31**</td>
<td>-.12</td>
<td>-.38**</td>
<td>.27*</td>
</tr>
<tr>
<td>F</td>
<td>-.11</td>
<td>-.23*</td>
<td>.06</td>
<td>-.08</td>
<td>-.10</td>
<td>.35**</td>
<td>.08</td>
<td>.25*</td>
<td>-.06</td>
<td></td>
</tr>
<tr>
<td>CA. Stomach</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>M</td>
<td>.14</td>
<td>-.47**</td>
<td>.13</td>
<td>.11</td>
<td>.26</td>
<td>-.56**</td>
<td>.19</td>
<td>-.27*</td>
<td>.12</td>
<td>.36**</td>
</tr>
<tr>
<td>F</td>
<td>-.06</td>
<td>-.35**</td>
<td>.11</td>
<td>.36*</td>
<td>.11</td>
<td>.04</td>
<td>.28*</td>
<td>-.39**</td>
<td>.03</td>
<td>.38**</td>
</tr>
<tr>
<td>CA. Large Intestine Including Rectum</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>M</td>
<td>.14</td>
<td>-.26*</td>
<td>.32**</td>
<td>.25</td>
<td>.35*</td>
<td>-.22</td>
<td>.29*</td>
<td>-.26*</td>
<td>.03</td>
<td>.38**</td>
</tr>
<tr>
<td>F</td>
<td>.14</td>
<td>-.22*</td>
<td>.23**</td>
<td>.37*</td>
<td>.25</td>
<td>.26*</td>
<td>.26*</td>
<td>-.20</td>
<td>.18</td>
<td>.26**</td>
</tr>
<tr>
<td>CA. Pancreas</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>.18</td>
<td>-.22*</td>
<td>.18</td>
<td>-.12</td>
<td>.12</td>
<td>.12</td>
<td>.18</td>
<td>-.07</td>
<td>-.03</td>
<td>.00</td>
</tr>
<tr>
<td>F</td>
<td>.25*</td>
<td>-.41**</td>
<td>.17</td>
<td>-.10</td>
<td>-.23</td>
<td>-.02</td>
<td>.24*</td>
<td>-.26*</td>
<td>-.10</td>
<td>.20</td>
</tr>
<tr>
<td>Gastrointestinal Cancer (150-159)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>.10</td>
<td>-.43**</td>
<td>.20</td>
<td>.23</td>
<td>.45*</td>
<td>-.34*</td>
<td>.24*</td>
<td>-.34*</td>
<td>.11</td>
<td>.48**</td>
</tr>
<tr>
<td>F</td>
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<td>.21*</td>
<td>.32*</td>
<td>.11</td>
<td>-.24</td>
<td>.27*</td>
<td>-.19</td>
<td>.09</td>
<td>.27**</td>
</tr>
</tbody>
</table>

Note: (1) ASMRs were transformed to Log10
(2) Variables are defined in Methods
( ) Number of localities
* p <0.05
** p <0.01
## TABLE 3

AGE-STANDARDIZED MORTALITY RATES (AGE 35-69) FOR MUNICIPALITIES GROUPED BY WATER QUALITY CHARACTERISTICS

<table>
<thead>
<tr>
<th>MATCHING VARIABLES (NO. OF LOCALITIES)</th>
<th>STOMACH CANCER (ICDA 151)</th>
<th>CA. LARGE INTESTINE CANCER INCL. RECTUM (ICDA 153, 154)</th>
<th>TOTAL G.I. CANCER (ICDA 150-159)</th>
<th>ALL CANCER SITES (ICDA 140-209)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>H (8)¹</td>
<td>20.7</td>
<td>7.6</td>
<td>29.5**</td>
<td>25.6*</td>
</tr>
<tr>
<td>L (55)</td>
<td>23.3</td>
<td>9.6</td>
<td>35.9</td>
<td>30.1</td>
</tr>
<tr>
<td>Surface water source, Chlorinated</td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>H (8)¹</td>
<td>20.7</td>
<td>7.6</td>
<td>29.5**</td>
<td>25.6*</td>
</tr>
<tr>
<td>L (36)</td>
<td>23.5</td>
<td>9.8</td>
<td>36.4</td>
<td>30.2</td>
</tr>
<tr>
<td>Surface water source, Chlorinated, Not Fluoridated</td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>H (6)²</td>
<td>20.9</td>
<td>7.8</td>
<td>29.8**</td>
<td>25.8*</td>
</tr>
<tr>
<td>L (16)</td>
<td>24.7</td>
<td>10.5</td>
<td>38.8</td>
<td>32.7</td>
</tr>
<tr>
<td>Surface water source, Chlorinated, Fluoridated</td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>H (2)³</td>
<td>17.6**</td>
<td>2.8**</td>
<td>21.9**</td>
<td>19.3**</td>
</tr>
<tr>
<td>L (20)</td>
<td>22.7</td>
<td>9.4</td>
<td>34.9</td>
<td>28.6</td>
</tr>
</tbody>
</table>

H ≥ 5x10⁶f/L; L < 5x10⁶f/L (in distribution system)

*p <0.05* statistical significance of difference between ASMRs for high and low asbestos groups by cancer site and sex

**p <0.01**

1. Asbestos, Sherbrooke, Thetford Mines, Hearst, Kamloops, Vancouver, Whitehorse, Baie Verte
2. Asbestos, Sherbrooke, Thetford Mines, Hearst, Vancouver, Baie Verte
3. Kamloops, Whitehorse
<table>
<thead>
<tr>
<th>TABLE 4</th>
</tr>
</thead>
</table>

**AGE-STANDARDIZED MORTALITY RATES (AGE 25-69) FOR LOCALITIES RANKED BY ASBESTOS CONCENTRATION IN WATER DISTRIBUTION SYSTEM**

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
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<th></th>
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<tr>
<td>ASBESTOS †</td>
<td>9,749</td>
<td>170</td>
<td>5.5</td>
<td>25.6</td>
<td>13.0</td>
<td>35.0</td>
<td>24.1</td>
<td>72.0</td>
<td>45.6</td>
<td>253</td>
<td>162</td>
</tr>
<tr>
<td>CHICOUTIMI</td>
<td>56,964</td>
<td>&lt;0.8</td>
<td>3.0</td>
<td>27.6</td>
<td>15.3</td>
<td>34.7</td>
<td>29.0</td>
<td>92.8</td>
<td>53.2</td>
<td>252</td>
<td>168</td>
</tr>
<tr>
<td>REGINA</td>
<td>139,479</td>
<td>2.6</td>
<td>1.0</td>
<td>12.4</td>
<td>5.6</td>
<td>17.9</td>
<td>18.7</td>
<td>51.8</td>
<td>34.5</td>
<td>171</td>
<td>141</td>
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<tr>
<td>MEDICINE HAT</td>
<td>26,518</td>
<td>6.4</td>
<td>0.8</td>
<td>12.7</td>
<td>8.9</td>
<td>25.5</td>
<td>18.4</td>
<td>54.9</td>
<td>46.9</td>
<td>156</td>
<td>165</td>
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<tr>
<td>MONTREAL</td>
<td>1,762,709</td>
<td>2.17(4.2)</td>
<td>0.4</td>
<td>17.8</td>
<td>7.8</td>
<td>30.1</td>
<td>24.8</td>
<td>74.3</td>
<td>46.6</td>
<td>237</td>
<td>176</td>
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<td>THOMPSON</td>
<td>19,001</td>
<td>190</td>
<td>0.4</td>
<td>-</td>
<td>4.3</td>
<td>5.0</td>
<td>-</td>
<td>64.7</td>
<td>41.5</td>
<td>194</td>
<td>157</td>
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<td>OTTAWA</td>
<td>326,956</td>
<td>4.6</td>
<td>0.2</td>
<td>14.2</td>
<td>6.7</td>
<td>27.1</td>
<td>22.2</td>
<td>84.0</td>
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<td>103.2</td>
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<td>-</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>74</td>
<td>250</td>
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</table>

| NATIONAL | 15.9 | 6.8 | 23.3 | 20.8 | 60.1 | 39.9 | 185 | 149 |

---

1. Millions of fibres per litre (see Footnote #6 in Table 1)
2. Based on only 2 fibres counted
3. No deaths
4. Asbestos mining in or near locality
5. Treated water sampled

Footnote:
- Fibres reported as <0.8 fibres are not included as they fall below the minimum measurable concentration.
- The concentration of fibres is reported as the number of fibres per litre of water.
- The mortality rates are age-standardized rates for the age group 25-69.
- The ICDA codes refer to the International Classification of Diseases for Workers' Compensation cases.

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Footnote:
- Fibres reported as <0.8 fibres are not included as they fall below the minimum measurable concentration.
- The concentration of fibres is reported as the number of fibres per litre of water.
- The mortality rates are age-standardized rates for the age group 25-69.
- The ICDA codes refer to the International Classification of Diseases for Workers' Compensation cases.

---

Footnote:
- Fibres reported as <0.8 fibres are not included as they fall below the minimum measurable concentration.
- The concentration of fibres is reported as the number of fibres per litre of water.
- The mortality rates are age-standardized rates for the age group 25-69.
- The ICDA codes refer to the International Classification of Diseases for Workers' Compensation cases.
persons aged 55 or older: Thompson, Tilbury, Baie Verte, Disraeli, Beaulac, Hearst, Gander, Labrador City, Inuvik and Yellowknife. The ASMRs for cancer for these places should be interpreted cautiously as they are based on small numbers of persons at risk.

Mortality Rates for Sherbrooke and Comparison Municipalities

Sherbrooke was selected for presentation of detailed cause-specific mortality rates because the asbestos concentration was unusually high (153X10⁶ f/L in distribution system water), the asbestos contamination is due to natural sources (the water supply is from a lake contaminated due to natural serpentine deposits), filtration is not conducted, the population at risk is quite large (1971 population was 92,930) and there is no asbestos mining industry in the immediate region. ASMRs for Sherbrooke were compared with those for 7 municipalities with low asbestos concentrations and matched for water source (surface), chlorination status and population size. Differences between ASMRs for Sherbrooke and the comparison group were relatively minor and statistically insignificant for all cancer sites examined (Table 5). The ASMRs for total gastrointestinal cancer in both sexes were lower in Sherbrooke than the comparison group.

Multiple Regression Analysis

Multiple regression analysis was conducted with demographic and water quality characteristics as independent variables and ASMRs for various cancer sites as dependent variables with the results presented in Table 6. Significant correlations included: (i) all-cause mortality: water hardness (males, β=-0.48), low education (males, β=0.63; females, β=0.67); (ii) all-cancer mortality: asbestos concentration (males, β=-0.35), fluoridation (males, β=-0.40), total organic carbon (females, β=0.55), trihalomethanes (males, β=0.50), hardness (males, β=-0.52; females, β=-0.43), population density (males, β=0.38) and low education (females, β=0.40); (iii) esophageal cancer: trihalomethanes (males, β=0.79); (iv) stomach cancer: total organic carbon (females, β=0.65), trihalomethanes (females, β=-0.62), hardness (males, β=0.70); (v) cancer of the large intestine including rectum: population density (females, β=0.40); (vi) total gastrointestinal cancer: asbestos concentration (males, β=-0.45), trihalomethanes (males, β=0.50) and hardness (males, β=-0.45; females, β=-0.38); (vii) kidney cancer: hardness (males, β=0.47); (viii) bladder cancer: ground water source (females, β=0.58), fluoridation (males, β=-0.51); (ix) cancer of lymphatic tissues: total organic carbon (males, β=0.66); and (x) leukemia: total organic carbon (males, β=-0.51), trihalomethanes (males, β=0.94).

Multiple regression analysis yielded positive but statistically insignificant correlations between asbestos concentration and cancers of the lung and lymphatic tissues in females (β=0.32 and 0.38, respectively). Although fluoridation was positively correlated with cancers of the mouth, esophagus and large intestine based on simple linear regression (Table 2), multiple regression yielded negative correlations for these sites.
### TABLE 5

**AGE-STANDARDIZED MORTALITY RATES (AGE 35-69) FOR SHERBROOKE AND COMPARISON LOCALITIES**

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<td>SHERBROOKE</td>
<td>COMPARISON</td>
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<td></td>
<td>LOCALITIES</td>
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<td>625</td>
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<td>8.9</td>
<td>10.7</td>
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<td>LARGE INTESTINE</td>
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<tr>
<td>EXCEPT RECTUM</td>
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<td>24.8</td>
<td>28.1</td>
<td>28.7</td>
</tr>
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<td>5.4</td>
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<td>9.1</td>
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7 comparison localities: Moncton, Saint John (N.B.), Chicoutimi, Trois Rivieres, Kingston, Sudbury, St. John's (Nfld.). Matched for surface water source, chlorination and population size (50,000-99,999).

Note: None of differences are statistically significant at the 0.05 level by 1-tailed T-test.
### Table 6

**WATER QUALITY MORTALITY STUDY: MULTIPLE REGRESSION ANALYSIS, BETA COEFFICIENTS**

(LEAST-WISE DELETION, 28 CITIES)

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<th>THM</th>
<th>WATER HARD</th>
<th>POP DENS</th>
<th>AVG FAM</th>
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<td>.04</td>
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<td>.14</td>
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<td>.49*</td>
<td>-.59**</td>
<td>.35*</td>
<td>.15</td>
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<td>.32</td>
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<td>.30</td>
<td>.09</td>
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<td>-.12</td>
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<td>.32*</td>
<td>-.17</td>
<td>-.04</td>
<td>64**</td>
<td>-.48*</td>
<td>-.56**</td>
<td>.11</td>
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</tr>
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<td>-.30</td>
<td>-.17</td>
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<td>-.07</td>
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<td>-.10</td>
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<td>.14</td>
<td>.07</td>
<td>-.11</td>
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<td>.41</td>
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<td>-.06</td>
<td>.27</td>
<td>-.16</td>
<td>-.14</td>
<td>.47*</td>
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<td>.05</td>
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<td>-.51*</td>
<td>.00</td>
<td>.34</td>
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<td>.22</td>
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<td>-.02</td>
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<td>.02</td>
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<td>-.01</td>
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Discussion

Given the high risk of peritoneal mesothelioma (28) and other gastrointestinal cancers (29) in asbestos workers, the negative findings of the present study must be interpreted cautiously. If the high risk of such cancers in asbestos workers is due to asbestos fibres present in swallowed sputum, then one would expect asbestos fibres in drinking water to increase the risk of these cancers in exposed populations. There are several possible explanations for our negative results:

1. Dose
   Up to 75% of asbestos inhaled by rats appeared in the feces within 30 days (30). Feces from workers occupationally exposed to high levels of asbestos revealed 4 to 93 x 10⁶ fibres per gram (average = 26 x 10⁶); samples from unexposed persons contained 0.0 to 1.7 x 10⁶ fibres per gram (average = 0.4 X 10⁶). Assuming that adult males pass an average of about 150 g of feces per day (32), the highly exposed workers would eliminate an average of about 3.9 X 10⁹ asbestos fibres per day via the gastrointestinal tract. To obtain a similar exposure from drinking water alone, a person would have to drink 2 litres of water per day containing 2 X 10⁹ fibres per litre. Even residents of Sherbrooke, with an average of 153 X 10⁶ fibres per litre in samples from the distribution system, would have more than an order of magnitude less gastrointestinal exposure than exposed workers.

2. Physical Characteristics of Asbestos Fibres
   Evidence that asbestos fibre diameter and length determines its carcinogenic potential comes mainly from animal studies involving injection of fibres into the pleural or peritoneal cavities and from the knowledge that fibres greater than 3 μm in diameter or 200 μm in length are unlikely to reach the alveolar regions (33). Fibres less than 1.4 μm in diameter and greater than 8 μm in length were found to be most carcinogenic with regard to mesotheliomas following injection into the pleural cavity (28). Cunningham et al. (31) found that only 2% of the asbestos fibres in fecal specimens from exposed workers were 2 μm or longer. Fibre length distributions were determined for 14 of the cities in the Canadian survey (13) and the median lengths in each city were generally between 0.5 and 0.8 μm. However, there were usually at least 5% of fibres longer than 2 μm and 1-2% longer than 5 μm. No information on fibre diameter was obtained in these two studies (13,31). If the longer fibres (>5 μm) are also the most carcinogenic for gastrointestinal cancers, then there should be some increased risk of gastrointestinal cancer in cities with high concentrations of asbestos in drinking water but the absolute excess risk must have been too small to be detectable in the present study.

3. Population Mobility
   Polissar (34) estimated that the excess risk of colon cancer incidence would be underestimated by 45% due to population mobility at the municipality level over a 30 year latent period. The present study is based on place of usual residence at the time of death and no data were available to adjust for mobility.
4. Use of Mortality Data

Percy et al. (35) studied cancer deaths during 1970-1971 in areas covered by the Third National Cancer Survey and found that death certificates correctly identified 93% of cases known to involve cancers of the colon and rectum and 5% of deaths attributed to colon and rectum cancers were actually due to other sites. The corresponding percentages for other gastrointestinal cancers were: esophagus: 93%, 4%; stomach: 89%, 9%; pancreas: 90%, 11%. Thus, if Canadian experience is similar to that in the United States, the use of mortality data should not seriously weaken the present study.

5. Use of Recent Exposure Data

The present study utilized exposure data from 1977 and mortality data for the period 1966 to 1976. Since the latent period between first exposure to a carcinogen and death due to cancer in humans is generally more than 20 years, the present study is only valid if current water quality data reflect the situation 20 or more years earlier. With regard to asbestos, current concentrations in the drinking water of places such as Sherbrooke and Thetford Mines probably do provide a valid indication of the situation 20-30 years ago because the water supplies are contaminated by sources present then and filtration has never been introduced. In general, though, there is little historical information readily available concerning the nature and timing of changes in water treatment methods in Canada and we cannot be very confident that results of present surveys are close to what they would have been in earlier years.

6. Confounding Variables

Dietary and other factors are probably of substantial importance in the etiology of gastrointestinal cancers but no data were available to adjust for differences in the distribution of such factors in the municipalities included in the present study. Adjustment was performed for demographic characteristics such as income and mother tongue which probably provide an index of dietary habits but a more direct measure would be much preferable.

Some of the results of multiple regression analysis were consistent with previous work. For example, the relatively strong positive correlation between general mortality and low education is well known (36). There was a statistically significant negative correlation between water hardness and major cardiovascular diseases (B=-0.42 for males and -0.40 for females), a finding reported by others (reviewed in Reference 37). A significant negative correlation between water hardness and gastrointestinal cancer was apparent in both sexes and was particularly strong for male stomach cancer. A report from Poland also indicated a negative correlation between water hardness and male stomach cancer but only four water sources with a relatively small range of water hardness values were studied (38). Use of ground water was positively correlated with bladder cancer (statistically significant only in females). Howe et al. (39) found a significantly increased relative risk of bladder cancer among males but not females who used nonpublic water supplies; however, all sources (rivers, wells, etc.) were associated with increased risk for
males. We did not observe a positive correlation between use of surface water and cancers of the stomach and bladder as reported by Kuzma et al. (8). Significant associations between various cancers and total organic carbon or trihalomethanes were observed in the present study but there was no sex concordance. Cantor et al. (9) observed a positive correlation between bromine-containing trihalomethanes in drinking water and cancer of the bladder in both sexes. Other associations were observed but were weaker and less consistent than that for bladder cancer. The present study did not reveal the latter but both studies indicated a negative association between trihalomethanes and female stomach cancer. Hogan et al. (11) reported positive associations in both sexes between chloroform and cancers of the large intestine and bladder and negative associations between chloroform and stomach cancer. There were strong positive associations between trihalomethanes and cancer of the esophagus and leukemia among males but not females in the present study. Given the limitations of this type of study (ie. ecological studies), it seems pointless to speculate about the significance of identified associations unless they are consistent (e.g. present in both sexes) and confirmed in several independent studies.

Acknowledgements

The authors express appreciation to Dr. P. Toft, Dr. D.T. Williams and Mr. J.C. Meranger of the Environmental Health Directorate, Health and Welfare Canada for providing water quality data, to Mr. J. Silins of the Health Division, Statistics Canada and to Mrs. M.H. Smith of the Laboratory Centre for Disease Control for assisting in the data editing and analyses.
References


APPENDIX E

"COLON CANCER IN WATERTOWN, NEW YORK"

BY DR. W.S. BURNETT, NEW YORK STATE DEPARTMENT OF HEALTH
ACCENTO

COLOR CANCELER MANUFACTURED IN NEW YORK

BY DR. M.S. BURNEST, M.S. NEW YORK STATE DEPARTMENT OF HEALTH
COLON CANCER IN WATERTOWN, NEW YORK

In one of those routine tabulations that Cancer Registries prepare, it was noted that the colo-rectal cancer incidence rate during the latter part of the decade of the 1960's among residents of Jefferson County, New York, was apparently extremely high. The rate was some three times that of some other counties of the State and more than twice that of each of the three adjacent counties. However, these colon cancer rates were not age-adjusted and data from the 1970 Census was then not yet available.

At that time, the Bureau of Cancer Control was interested in embarking upon an analytic epidemiologic study of colon cancer. We wanted to select some area of the State where the rates were significantly different from the State average.

Concurrently, we were in the process of a total evaluation of the entire New York State Cancer Reporting System. The system had been used to study several important cancer problems, but had not been used for small geographic area analyses. The completeness of reporting had been evaluated some years before and was believed to have changed very little so that published time trends in cancer for the State were believed to be valid. But the question arose whether there was sufficiently accurate and precise information in the system to investigate small area statistics.

Jefferson County is located along the northern frontier of New York, adjacent to Canada where Lake Ontario flows into the St. Lawrence River. It has been for many years the county with a declining economic base, but with a relatively stable population of approximately 85,000-90,000 inhabitants. In fact, the population has grown less than 10,000 since 1910.

When we reviewed the known cases of colon cancer in Jefferson County, it was soon determined that the entire excess was among residents of Watertown, the only city in the county, where approximately one-third of the population of the county resides. But we are always concerned about the allocation of cases to the appropriate residence district. Although in the Registry we attempt to obtain the place of residence, the postal address is usually the only information available. Jefferson County is a rural county where the postal address of the Rural Delivery Route may or may not reflect the true residence. And more important for this study, Watertown City developed from the Village of Watertown located within the Town of Watertown. Thus, in this instance, we now have the City of Watertown surrounded on three sides by the Town of Watertown with the same postal address for both. In New York State, towns and cities are mutually exclusive.

Parenthetically I might point out that in New York State, this situation is not unique to Watertown. In fact, in some other areas of the State the population of a surrounding town far exceeds the population for the city.

The data available for the City of Watertown, the rest of Jefferson County and the neighboring counties was reviewed both for morbidity and mortality back to 1950 with the appropriate age-adjusted rates calculated. For most
years during the entire time period, the rates for Watertown continued to be markedly elevated.

We then attempted to assess to what extent selected underreporting of cancer cases in adjacent counties might have created the appearance of an elevated risk in Jefferson County. We were fortunate to have a medical student working on this project for the summer. He surveyed all of the community hospitals of the four county areas, i.e., Jefferson County and the three adjacent counties of St. Lawrence--along the St. Lawrence River; Lewis County--a more remote rural county, and Oswego County--along the shores of Lake Ontario, in order to ascertain all cases of colo-rectal cancer in a five year period. Thus, we could determine the completeness of reporting and determine the accuracy of our collected data. We believed that those patients referred directly to the Medical Centers such as in Syracuse, had been adequately reported.

When compared with cases in the State Cancer Registry, it was found that, although the number of cases from the Registry was considerably greater than the number of cases found when reviewing the records in the community hospitals, only about two-thirds of the cases agreed. There was some underreporting in all of the counties, but two other problems emerged. We had only recently (i.e., 1966) begun to access multiple primary neoplasms and many of the cases were being carried in the State Registry under other cancer sites. We now attempt to secure reporting of all multiple primary neoplasms. In addition, at that time, a not insignificant proportion of our cases was first known to us through the Death Certificate. Some of these cases were subsequently reported routinely, but a case known only through the death report has the date of death as the index data and the age is the age at death. The cancer site is that recorded on the death certificate.

Therefore, we initiated a program to obtain additional, more accurate, information for all cancer deaths that occurred in hospitals to determine the date of diagnosis, the age at diagnosis and the cancer site as recorded in the hospital chart.

A general survey of the economy, industry, geography and geology of the County was carried out. Highlights included the fact that Jefferson County and the Black River Valley is in an extended period of economic decline. Contemporary manufacturing consisted of two types:

1. Production of paper and goods for the paper industry which is continuing to decline.

2. Manufacturing involving production of high value speciality items such as hydraulic motors and parts for aerospace use and brakes for railroad cars.

Agriculture continues to be important with dairying predominant. Also it should be pointed out that the county has an unusually large proportion of the population employed in seasonal service occupations related to recreation in the Thousand Island Area.
Watertown is unique among municipalities in the County, for it draws its water supply from the Black River at the eastern boundary of the City. All other villages and hamlets in the County use springs, wells, reservoirs, the St. Lawrence River or Lake Ontario as sources of municipal water. The Black River is a relatively fast flowing stream with numerous rapids and small waterfalls. The river originates in Herkimer County, flows mostly northwesterly through Lewis and Jefferson Counties into Lake Ontario. However, prior to 1969, the Black River was highly polluted by each municipal village, hamlet and industry along its banks. Municipalities in both Lewis and Jefferson Counties were sources of pollution. In addition, industrial pollution entered at numerous points at various plants. These included plants involved particularly in the manufacture of pulp and paper products.

Although industry was in the city and the municipal sewerage system of the city itself utilized the Black River both as a source of water and also as a means of sewage disposal, there is a series of rapids and waterfalls within the city limits that effectively prohibits the backflow of industrial and sanitary waste to the point of the water intake for the municipal system. Moreover, the upstream pollution was supposedly completely abated as of October 1972.

We believed that the hypothesis that there might be some component in the drinking water which had influenced the colon cancer incidence in residents could not be dismissed. Though the sanitary waste that enters the river is to a large extent, degraded by bacteria it is not impossible that some component or a component of the industrial waste has over an extended period of time periodically been present in the municipal water supply. A possibility for this might be the dye-stuffs as used by the paper industry to color their paper. Additionally the slimicides, fungicides and algicides used in the paper process to keep the machinery clean were present in the industrial waste.

A field survey of the area to determine additional possible factors relating both to the diagnosis and reporting of the excessive numbers of cases was carried out. This included discussion with pathologists regarding patterns of patient referrals. The anecdotal comment was made by one of the pathologists who felt that it was quite possible that some patients listed as their home address on hospital records the address of a relative who lived in Watertown. Also in farming communities, if young people move away, older people may be forced to sell their farms and move into the city. Thus, it was thought necessary to determine residence histories.

We then intended to carry out a case-control study. A questionnaire was developed to elicit information regarding:

1. Residence history.
2. Sources of usual drinking water, whether Watertown City or other sources.
3. Quantity of water consumed, including water in beverages.

Also included were questions relating to:

1. A detailed employment history.
2. Ethnic background.
3. Familiar history.
4. Possible related symptoms.
5. A rather detailed dietary history.

Controls were selected, but unfortunately only a pilot test was carried out. This pilot study showed essentially no difference in the amount of water consumed by cases and controls and essentially no difference in its source. In addition, the residence histories were unremarkable.

Many changes and improvements have been made in the State Registry. Rules have been developed to allocate residents so that we believe residence in small geographic areas is now much more accurate. Field workers are employed to ensure more complete reporting, including the reporting of multiple primaries. "Death certificate only", cases are followed back to ascertain more accurate sites of cancer, index dates and ages.

So what do we now see regarding colo-rectal cancer incidence in Jefferson County? In comparing the observed number of cases with the expected number for the years 1974-1976, with the expected numbers derived by applying the age-sex specific rates for the State to the estimated population of the County, the colo-rectal cancer rates for Jefferson County still remain high. Furthermore, the rates for the surrounding counties remain well below the State average.
APPENDIX F

CANCER REGISTRY SURVEY,
COMPLETED QUESTIONNAIRES BY
THE GREAT LAKES BASIN CANCER REGISTRIES
3. Family History.
4. Possible related symptoms.
5. A rather detailed dietary history.

Controls were selected, but unfortunately only a pilot test was carried out. This pilot study showed essentially no difference in the amount of water consumed by cases and controls and essentially no difference in its source. In addition, the residence histories were comparable.

Many changes and improvements have been made in the State Registry. Rules have been developed to allocate residence, and we believe residence in small geographic areas is now much more complete. Field workers are employed to make more complete reporting, including the reporting of multiple primaries. Death certificates alone are no longer back to ascertain more accurate sites of cancer.
1.0 REGISTRY CHARACTERISTICS

1.1 Describe the current stage of registry development or operation (when did it start): 
Operational - started on January 1, 1969

1.2 Describe the population coverage, size and characteristics: 
Total Canadian Population

1.3 List the registry data sources and collection techniques:

<table>
<thead>
<tr>
<th>DATA SOURCE</th>
<th>YEAR STARTED</th>
<th>CURRENT YEAR</th>
<th>VOLUME PER YEAR</th>
<th>COLLECTION METHOD</th>
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<tr>
<td>N/A</td>
<td></td>
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</table>

Describe any future plans: Death clearance (survivorship), risk factors

1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.).

<table>
<thead>
<tr>
<th>No.</th>
<th>Job Title</th>
<th>Duties</th>
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</thead>
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<tr>
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<td>Statistician</td>
<td>Project manager</td>
</tr>
<tr>
<td>1.5</td>
<td>Clerical</td>
<td>coding, publication</td>
</tr>
<tr>
<td>1</td>
<td>Technical Support</td>
<td>computer programming</td>
</tr>
</tbody>
</table>

Describe any future plans: None with respect to human resources.
15 How is the registry directed and funded? Consultation provided by National Cancer Institute, Committee of Directors of Cancer Registries. Funding - Federal Government, Statistics Canada.

1.6 Describe how the data for the cancer registry is:

COLLECTED: Either in codified machine readable form or reporting form - depending on source.

CODED: Diagnosis by trained medical coders; other by trained clerical persons.

PROCESSED: Computer

VERIFIED (EDITED): Computer checks for valid codes and correlation among specific fields.

VALIDATED: In case of inconsistencies reference is made to reporting document or reporting organization.

STORED: magnetic tape

1.7 Describe the follow-up techniques that are used by the registry:

respective provincial registries are queried, as required.

1.8 Describe the quality control techniques used by the registry:

verification at time of keying

1.9 Provide estimates for the following:

2.6 % of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year).

90.0 % of registry cases have their diagnoses confirmed by histology (exclude non-melanoma skin tumours).

48,768 cases of newly diagnosed cancer for 1977 (year)
2.0 DATA UTILIZATION

2.1 Are the following data elements used in the registry? (Y = Yes, N = No, P = Planned).

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<th>N</th>
<th>P</th>
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</tr>
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<tr>
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<td>Date of first treatment</td>
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<td>Date of first recurrence</td>
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<td>Subsequent treatment(s)</td>
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<td>Date of last contact/death</td>
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<tr>
<td>Other (Please specify)</td>
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</tbody>
</table>

risk factors

2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+).

HISTOLOGY: '1979+ ICD-O Morphology


STAGE OF DISEASE: N.A.

RESIDENCE: Standard Geographic Code

2.3 Describe how and what skin cancers or non-malignant conditions are registered:

Skin cancers - 1 for each type applicable. NCIRS does not include non-malignant conditions but does include those considered "in-situ"
4. Describe how cancer death information is used in the registry:
   Ascertainment of additional new primary sites in provincial registries.

2.5 What census data is readily available to you? (years, levels of residence, race, sex, etc.): All published or unpublished data.

2.6 To what degree is the registry data computerized? (years, files, plans, etc.)
   All data since 1969 is computerized

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.):
   1979 annual report

2.8 Describe your present computing abilities to analyze and process registry data:
   COMPUTER EQUIPMENT: AMDAHL 470/V6-II under MV5/TSO
   COMPUTER PERSONNEL: 1 person directly responsible for processing
   If fee for service, describe arrangements: internal budgeting
   Describe any future plans: none
3.0 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry? (Y = Yes  N = No  P = Planned)

Residence history.......................................................... Y P
Occupational history....................................................... Y N P
Smoking history............................................................. Y N P
Female history (parity, menopause, etc.).............................. Y N P
Family history of cancer.................................................. Y N P
Other (please specify).....................................................

If yes to any of the above, please describe how the data is coded:

N/A

3.2 Please describe any future developments: At the present developmental work is going on in the area of death clearance. This would permit the generation of crude survivorship rates. Also preliminary work is going on to collect data on risk factors.

3.3 Are there any other comments that you may have?: Although the National Cancer Incidence Reporting System is sometimes referred to as a registry, its primary purpose is to generate statistics about the incidence of new primary sites.
CANCER REGISTRY SURVEY
GREAT LAKES BASIN

Please provide short answers to the questions that follow. If a question or item does not apply, please indicate by a 'N/A'.

1.0 REGISTRY CHARACTERISTICS

1.1 Describe the current stage of registry development or operation (when did it start): The registry is in the second stage of a pilot operation which began October 1, 1980.

1.2 Describe the population coverage, size and characteristics: The pilot is in five hospitals and it is proposed that the Register will ultimately be statewide, covering Michigan's 9.2 million population.

1.3 List the registry data sources and collection techniques:

<table>
<thead>
<tr>
<th>DATA SOURCE</th>
<th>YEAR STARTED</th>
<th>CURRENT YEAR</th>
<th>VOLUME PER YEAR</th>
<th>COLLECTION METHOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Path. Labs</td>
<td>1980</td>
<td>1</td>
<td>1,600</td>
<td>Path. reports</td>
</tr>
</tbody>
</table>

Describe any future plans: When piloting has been completed and the process refined, is proposed to extend the Register to cover all tissue pathology laboratories in the state.

1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.).

No. | Job Title                        | Duties                                       |
---|----------------------------------|----------------------------------------------|
1  | Cancer Control Consultant       | Initiate participation, receive reports and code. |

Describe any future plans: When operational at a significant level, ADP will will be initiated and regular statistical output published.
1.5 How is the registry directed and funded? The will be state funded and directed by an epidemiologist.

1.6 Describe how the data for the cancer registry is:

COLLECTED: Pathologists submit a report form for each case of cancer seen.

CODED: According to International classification of diagnoses for oncology. Greater municipality codes are assigned for location.

PROCESSED: Manually from paper file at present.

VERIFIED (EDITED): Not done during pilot

VALIDATED: Not done during pilot.

STORED: Paper file presently. To be automated.

1.7 Describe the follow-up techniques that are used by the registry: None

1.8 Describe the quality control techniques used by the registry: Cancer control consultant will periodically check receipts of reports against individual pathologist's log.

1.9 Provide estimates for the following:

N/A % of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year).

100 % of registry cases have their diagnoses confirmed by histology (exclude non-melanoma skin tumours).

402 cases of newly diagnosed cancer for 1980 (year) (3 month period)
2.0 DATA UTILIZATION

2.1 Are the following data elements used in the registry? (Y = Yes, N = No, P = Planned).

Registry Number
Case Number (for multiple primary sites)
Last name
First given name
Second given name
Maiden name
Street address
City/town/country
State/Province
Zip/Postal code
Date of birth
Age at diagnosis
Race/Nationality
Marital status
Sex
Date of initial diagnosis
Primary site
Histology
Method of diagnostic confirmation
Paired organ involvement
Size of tumour
Regional node involvement
Stage at diagnosis
Date of first treatment
First course of treatment
Date of first recurrence
Subsequent treatment(s)
Date of last contact/death
Status
Other (Please specify):

2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+).

HISTOLOGY: I C D O

CANCER SITE: I C D O

STAGE OF DISEASE: Not coded or reported

RESIDENCE: Michigan County and Divil Division Codes

2.3 Describe how and what skin cancers or non-malignant conditions etc are registered:
All skin cancers are reported. Liver and thyroid adenomas, hepatomas and meningiomas are reported.
Michigan Cancer Incidence Reporting System (CIRS)

Registry Name: 

2.4 Describe how cancer death information is used in the registry: Death records will be matched against register records.

2.5 What census data is readily available to you? (years, levels of residence, race, sex, etc.):

2.6 To what degree is the registry data computerized? (years, files, plans, etc.)

It is proposed that all data will be computerized when fully operational.

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.): N/A

2.8 Describe your present computing abilities to analyze and process registry data:

COMPUTER EQUIPMENT: University of Michigan Amdahl; OSIRIS and MIDAS

COMPUTER PERSONNEL: Staffed Office of Vital and Health Statistics.

If fee for service, describe arrangements:

Describe any future plans:
3.0 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry? (Y = Yes N = No P = Planned)

<table>
<thead>
<tr>
<th>Item</th>
<th>Y</th>
<th>N</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residence history</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational history</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Smoking history</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Female history (parity, menopause, etc.)</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Family history of cancer</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If yes to any of the above, please describe how the data is coded:

________________________________________________________________________

________________________________________________________________________

3.2 Please describe any future developments: The CIRS is designed so that data are collected from all laboratories doing tissue pathology in Michigan. It is expected that this register will be expanded to provide statewide coverage with reporting simplified to the greatest degree possible in order to assure completeness.

________________________________________________________________________

________________________________________________________________________

3.3 Are there any other comments that you may have?: It is to be noted that the CIRS is designed as an epidemiologic tool in order to identify cancer morbidity by age, sex, race, geographic area, organ involved and cell type. It will, over time, permit observation for trends and clustering.

________________________________________________________________________

________________________________________________________________________
Please provide short answers to the questions that follow. If a question or item does not apply, please indicate by a 'N/A'.

1.0 REGISTRY CHARACTERISTICS

1.1 Describe the current stage of registry development or operation (when did it start): MCFR has been in operation as a population-based registry since 1969.

1.2 Describe the population coverage, size and characteristics: Population includes residents of Wayne, Oakland, and Macomb counties; approximately 4.1 million persons of which about 20% are black. Large numbers of members of many ethnic groups; particularly large number of recent Arabic immigrants.

1.3 List the registry data sources and collection techniques:

<table>
<thead>
<tr>
<th>DATA SOURCE</th>
<th>YEAR STARTED</th>
<th>CURRENT YEAR</th>
<th>VOLUME PER YEAR</th>
<th>COLLECTION METHOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>1969</td>
<td>1981</td>
<td>25,400</td>
<td>Abstracting by Registry Staff</td>
</tr>
<tr>
<td>Physician</td>
<td>1972</td>
<td>1981</td>
<td>65,000</td>
<td>Mailed Requests</td>
</tr>
<tr>
<td>Radiation Therapy</td>
<td>1973</td>
<td>1981</td>
<td>3,200</td>
<td>Abstracting by Registry Staff</td>
</tr>
<tr>
<td>Facilities</td>
<td></td>
<td></td>
<td></td>
<td>Computer Tape</td>
</tr>
<tr>
<td>Death Certificates</td>
<td>1972</td>
<td>1981</td>
<td>30,000</td>
<td>Interviews with cases and controls as appropriate for ongoing studies</td>
</tr>
<tr>
<td>Research</td>
<td>1978</td>
<td>1981</td>
<td>Varies</td>
<td></td>
</tr>
</tbody>
</table>

Describe any future plans:


1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.).

<table>
<thead>
<tr>
<th>No.</th>
<th>Job Title</th>
<th>Duties</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Director</td>
<td>Responsible for research and Registry operation</td>
</tr>
<tr>
<td>4</td>
<td>Epidemiologist/Biostatistician</td>
<td>Research</td>
</tr>
<tr>
<td>5</td>
<td>Managers</td>
<td>Administration of each functional unit</td>
</tr>
<tr>
<td>6</td>
<td>Supervisors</td>
<td>Daily operation of units and personnel</td>
</tr>
<tr>
<td>27</td>
<td>Abstractors</td>
<td>Data abstracting and quality control</td>
</tr>
<tr>
<td>11</td>
<td>Technicians</td>
<td>Processing and Coding of Data, Filing, Microfilming, processing batches</td>
</tr>
<tr>
<td>3</td>
<td>Clerks</td>
<td>System design and computer operations, research support</td>
</tr>
<tr>
<td>7</td>
<td>Systems Analysts and Computer Programmers</td>
<td>Interviewing for research projects Budget and cost analyses; interface with MCF personnel, purchasing and accounting offices.</td>
</tr>
</tbody>
</table>
1.5 How is the registry directed and funded? It is directed by the administrative staff and is research oriented. Ninety-five percent of its funds are from the National Cancer Institute (U.S.) and five percent are from contracts with hospitals.

1.6 Describe how the data for the cancer registry is:

**COLLECTED:** Abstracting by Registry staff and mailing to physicians. Death certificates are obtained from the Michigan Office of Vital Statistics on computer tape and microfilm.

**CODED:** Abstractors and technicians code the data, using NCI-SEER and ICD-O specifications.

**PROCESSED:** Manual and computer.

**VERIFIED (EDITED):** Computer, with manual review.

**VALIDATED:** Computer and manual review. Quality control re-abstracting annually of a sample of cases.

**STORED:** Computer tape and disk. Microfiche.

1.7 Describe the follow-up techniques that are used by the registry: Active annual follow-up, primarily to physicians; also to patients when necessary. Follow-up data are also obtained through hospital and radiation therapy abstracting and from death certificates.

1.8 Describe the quality control techniques used by the registry: Computer edits, Re-abstracting.

1.9 Provide estimates for the following:

- **14.2%** of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year).

- **90%** of registry cases have their diagnoses confirmed by histology (exclude non-melanoma skin tumours).

- **14,717** cases of newly diagnosed cancer for **1979** (year)
2.0 DATA UTILIZATION

2.1 Are the following data elements used in the registry? (Y = Yes, N = No, P = Planned).

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Y</th>
<th>N</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry Name</td>
<td>MCFR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case Number (for multiple primary sites)</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Last name</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>First given name</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Second given name</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Maiden name</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Street address</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>City/town/county</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>State/Province</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Zip/Postal code</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Date of birth</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Race/Nationality</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Date of initial diagnosis</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Primary site</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Histology</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Method of diagnostic confirmation</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Paired organ involvement</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Size of tumour</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Regional node involvement</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Stage at diagnosis</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Date of first treatment</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>First course of treatment</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Date of first recurrence</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Subsequent treatment(s)</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Date of last contact/death</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Status</td>
<td>N</td>
<td>P</td>
<td></td>
</tr>
<tr>
<td>Other (Please specify): Occupation, Industry, Type of surgery, chemotherapy, and radiotherapy; previous therapy; census tract;</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+).

**HISTOLOGY**: ICD-0

**CANCER SITE**: ICD-0

**STAGE OF DISEASE**: SEER manual

**RESIDENCE**: U.S. Census Bureau census tract directories and SEER manual

2.3 Describe how and what skin cancers or non-malignant conditions are registered:

None
2.4 Describe how cancer death information is used in the registry:

- For follow-up and for mortality and survival analyses, to validate occupation.

2.5 What census data is readily available to you? (years, levels of residence, race, sex, etc.):
Data for each decennial census by census tract, municipality, county and by race, sex, age, housing, income, education, etc.

2.6 To what degree is the registry data computerized? (years, files, plans, etc.)
All data are computerized - master files are on tape; written description (abstract) upon which codes are based is on microfiche.

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.):
- Reports to hospitals; requests for hospital-specific data from hospitals; cancer control and other health agency planning;
- Ongoing research-descriptive and methodological studies utilizing routinely collected data and case selection for epidemiologic research; matching and analysis of industry listing where a suspected excess cancer rate was investigated; teaching of public health and medical students.

2.8 Describe your present computing abilities to analyze and process registry data:

COMPUTER EQUIPMENT: Amdahl V60 - utilizing a university computer center and billed monthly for costs incurred.

COMPUTER PERSONNEL: 10 persons - 1 manager, 3 systems analysts, 4 programmers, 2 data entry technicians.

If fee for service, describe arrangements:

Describe any future plans: Lease of Texas Instruments 990-30 to reduce costs, improve control and efficiency and provide improved security.
3.0 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry?
(Y = Yes N = No P = Planned)

<table>
<thead>
<tr>
<th>Item</th>
<th>Y</th>
<th>N</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residence history</td>
<td>Y</td>
<td></td>
<td>P</td>
</tr>
<tr>
<td>Occupational history</td>
<td>Y</td>
<td></td>
<td>P</td>
</tr>
<tr>
<td>Smoking history</td>
<td>Y</td>
<td></td>
<td>P</td>
</tr>
<tr>
<td>Female history (parity, menopause, etc.)</td>
<td>Y</td>
<td></td>
<td>P</td>
</tr>
<tr>
<td>Family history of cancer</td>
<td>Y</td>
<td></td>
<td>P</td>
</tr>
</tbody>
</table>

Other (please specify)

If yes to any of the above, please describe how the data is coded:

3.2 Please describe any future developments:

A complete, new computer system is being designed to reduce manual efforts and improve efficiency

3.3 Are there any other comments that you may have?:
 Registry Name: New York State
Date: 2/20/81

CANCER REGISTRY SURVEY
GREAT LAKES BASIN

Please provide short answers to the questions that follow. If a question or item does not apply, please indicate by a 'N/A'.

1.0 REGISTRY CHARACTERISTICS

1.1 Describe the current stage of registry development or operation (when did it start): Cancer reporting for New York State, exclusive of New York City, started in 1940; active data files now exist from 1950. Cancer reporting from New York City was initiated in 1973 with relatively complete data from 1976.

1.2 Describe the population coverage, size and characteristics: The population covered includes the entire State with 17,507,541 inhabitants (Census 1980 — preliminary). The racial groups are 86.8% white, 11.9% black and 1.3% other (1970 census).

1.3 List the registry data sources and collection techniques:

<table>
<thead>
<tr>
<th>DATA SOURCE</th>
<th>YEAR STARTED</th>
<th>CURRENT YEAR VOLUME</th>
<th>COLLECTION METHOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals</td>
<td>1940 (1950)*</td>
<td>1979** 72,007</td>
<td>Report form</td>
</tr>
<tr>
<td>Laboratories</td>
<td>1940 (1950)</td>
<td>1979 8,045</td>
<td>Computer tape</td>
</tr>
<tr>
<td>Deaths</td>
<td>1940 (1950)</td>
<td>1978 41,175</td>
<td>Computer tape</td>
</tr>
</tbody>
</table>

*Data available from 1950. **Cases received through September 1980 also available.

Describe any future plans: Continue to assess completeness, timeliness of reporting, and quality of information. Publish annual reports.

1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.).

<table>
<thead>
<tr>
<th>No.</th>
<th>Job Title</th>
<th>Duties</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Medical Director (Part-time)</td>
<td>Responsible for overall direction and maintenance.</td>
</tr>
<tr>
<td>1</td>
<td>Administrative Director (Part-time)</td>
<td>Responsible for securing additional funding and handling general administrative functions.</td>
</tr>
<tr>
<td>1</td>
<td>Supervisor</td>
<td>Responsible for supervision of mail clerks and specific coding.</td>
</tr>
<tr>
<td>1</td>
<td>Asst. Supervisor</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Mail Clerks</td>
<td>Code simple items of hospital, sex, residence etc.</td>
</tr>
<tr>
<td>3</td>
<td>Medical Coding Clerks</td>
<td>Code site and histology</td>
</tr>
<tr>
<td>3</td>
<td>Medical Coding &amp; Processing Clerks</td>
<td>Check &quot;possible matches&quot; and resolve multiple primaries.</td>
</tr>
<tr>
<td>1</td>
<td>Programmer</td>
<td>Maintain data base, produce routine output process special reports.</td>
</tr>
<tr>
<td>1</td>
<td>Typist</td>
<td>Enters data from Lab. reports; correspondence with hospitals.</td>
</tr>
<tr>
<td>2</td>
<td>Field Investigators</td>
<td>Maintain constant liaison with reporting institutions.</td>
</tr>
</tbody>
</table>

Describe any future plans: Code selected sites of cancer for occupation and industry.

1   Coding Clerk
1   Statistician (Part-time consultant)
1.5 How is the registry directed and funded?  New York State

1.6 Describe how the data for the cancer registry is:

COLLECTED: Hospitals submit reporting forms monthly. Computer tapes are submitted quarterly. Laboratory reports are submitted monthly. Computerized death files (subset of Vital Stat Files) prepared annually.

CODED: Report from each day coded for hospital of report, sex, country of birth, etc.

PROCESSED: Monthly batch for both cards and laboratory reports sorted Soundex. Site and histology coded by medical coding clerks.

VERIFIED (EDITED): Then another medical coding clerk reviews the entire card checking especially the site and histology coding. After monthly batch is keypunched, computer edits are run to detect incorrect and missing information; then batch is run against Registry.

STORED: Reports received during any year are filed Soundex with cards and laboratory reports filed separated.

2.7 Describe the follow-up techniques that are used by the registry: No systematic follow-up.

2.8 Describe the quality control techniques used by the registry: Incomplete information queried back to reporting hospitals; computer edits prior to adding data subsequent ad hoc edits as necessary. These have included internal matching to eliminate more duplicates; lists of unknown ages, addresses, etc.

1.5 Provide estimates for the following:

13.0 % of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year) for 1978.

83.4 % of registry cases have their diagnoses confirmed by histology (exclude non-melanoma skin tumours) for 1973-1977.

66,843 cases of newly diagnosed cancer for 1978 (year) 2,309 cases of newly diagnosed carcinoma in situ of cervix uteri 1,000 (est) other cases
2.0 DATA UTILIZATION

2.1 Are the following data elements used in the registry?
(Y = Yes, N = No, P = Planned).

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Y</th>
<th>N</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry Name: New York State</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case Number (for multiple primary sites)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Last name</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First given name</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Second given name</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maiden name</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Street address</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City/town/country</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State/Province</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zip/Postal code</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of birth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race/Nationality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of initial diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Histology</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Method of diagnostic confirmation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paired organ involvement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Size of tumor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regional node involvement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage at diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of first treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First course of treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of first recurrence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subsequent treatment(s)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of last contact/death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Status</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Collected but not coded. **Microscopic confirmation.

Other (Please specify): Country of birth, cigarette smoker, social security number, industry and occupation, date of birth.

2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+).

HISTOLOGY: Manual of Tumor Nomenclature & Coding 1968 (First 3 digits)

CANCER SITE: ICD 9th

STAGE OF DISEASE: In situ, Localized, Regional, Metastatic

RESIDENCE: Registration Districts for Vital Records that conform to political subdivisions of cities, towns and villages.

Describe how and what skin cancers or non-malignant conditions are registered:
Malignant melanoma of skin; papillomas of bladder; brain tumors; mixed salivary gland tumors; pinealoma.
2.4 Describe how cancer death information is used in the registry: All deaths from cancer (and in "Upstate" area with mention of cancer) are computer matched against the Registry annually to obtain cases previously not reported.

2.5 What census data is readily available to you? (years, levels of residence, race, sex, etc.): 1970 data by age, sex, race for minor civil divisions with populations by age and sex by town computerized. Expect similar data for 1980.

2.6 To what degree is the registry data computerized? (years, files, plans, etc.)
1950-present with 2 basic files of:
1. Archival (Cases diagnosed and/or reported 1950-69)
2. Master (Cases diagnosed and/or reported 1970 to present plus cases not known dead 1953-1969 for matching of incoming cases).

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.): Routing tabulations of number of cases by site, sex, and age with age-specific and age-adjusted rates; number of cases by sex, and age for major sites by county. Data submitted for inclusion in Cancer In Five Continents Vol IV (1973-1977). Basis for epidemiologic research both within the Department and as collaborative and cooperative projects with outside investigators, especially at School of Public Health and Medical Schools.

2.8 Describe your present computing abilities to analyze and process registry data:

COMPUTER EQUIPMENT: Burroughs 6700 & 2 dedicated disk pack drives. 2 Hazeltine 2000 CRT's for direct entry to Data Base System.

COMPUTER PERSONNEL: 1 Programmer responsible for management of Data Base and production of routine lists and tabulations.

If fee for service, describe arrangements: Computer of the New York State Department of Health.

Describe any future plans: N/A
3.0 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry?
   (Y = Yes N = No P = Planned)

Residence history............................................. Y N P
Occupational history........................................... Y N P
Smoking history................................................. Y N P
Female history (parity, menopause, etc.)..................... Y (N) P
Family history of cancer........................................ Y N P
Other (please specify)............................................

If yes to any of the above, please describe how the data is coded:

Cigarette Smoker? Present, Former, Never, Unk.

Occupation and Industry: (I) Name and locality of firm or company (II) Kind of business or industry (III) Usual occupation.

3.2 Please describe any future developments: Publication of scheduled annual reports. Publication of selected variables in greater detail, e.g., race/color tabulations, tabulations by marital status.

3.3 Are there any other comments that you may have?: For a Registry the size of New York State, it is essential to keep the information collected as simple as possible to ensure as complete and accurate information as possible.
CANCER REGISTRY SURVEY
GREAT LAKES BASIN

Please provide short answers to the questions that follow. If a question or item does not apply, please indicate by a 'N/A'.

1.0 REGISTRY CHARACTERISTICS

1.1 Describe the current stage of registry development or operation (when did it start):
Registry started in 1953. At that time personnel from the registry went to the hospitals. By 1974 each hospital had its own registry and sends weekly reports to the registry.

1.2 Describe the population coverage, size and characteristics:
Anyone diagnosed as having cancer in a Montgomery County hospital is reported. Attached sheet describes the Montgomery County population.

1.3 List the registry data sources and collection techniques:

<table>
<thead>
<tr>
<th>DATA SOURCE</th>
<th>YEAR STARTED</th>
<th>CURRENT YEAR</th>
<th>VOLUME PER YEAR</th>
<th>COLLECTION METHOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kettering</td>
<td>1953</td>
<td>1981</td>
<td></td>
<td>(1) Tumor board conference once a week. Pick-up and delivery of case report forms between hospitals and central registry.</td>
</tr>
<tr>
<td>Miami Valley</td>
<td>1953</td>
<td>1981</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good Samaritan</td>
<td>1953</td>
<td>1981</td>
<td>Approximately 3,100 newly diagnosed cases of cancer a year.</td>
<td></td>
</tr>
<tr>
<td>St. Elizabeth</td>
<td>1953</td>
<td>1981</td>
<td></td>
<td>(2) Follow-up through physicians and through other county hospitals for Montgomery County residents.</td>
</tr>
<tr>
<td>Grandview</td>
<td>1953</td>
<td>1981</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childrens</td>
<td>1953</td>
<td>1981</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Describe any future plans: Would like to include more hospitals in other counties. Would like to resolve problems with Montgomery County Veterans Administration Hospital records and the Privacy Act.

1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.). Volunteer that oversees registry. Has hospital practice. All Tumor Board members are volunteers.

<table>
<thead>
<tr>
<th>No.</th>
<th>Job Title</th>
<th>Duties</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Executive Director</td>
<td>Administrative duties, Liaison between Tumor Board, hospitals and registry. Immediate supervision of Registry personnel.</td>
</tr>
<tr>
<td>1</td>
<td>Supervisor</td>
<td>Enter follow-up from hospitals. Cases are followed for life through hospitals and physicians.</td>
</tr>
<tr>
<td>2</td>
<td>Follow-up Clerks</td>
<td>Volunteers who design computer data entry format. Enters data on cards for computer</td>
</tr>
<tr>
<td>2</td>
<td>Part-time Programmers</td>
<td>Works with vital statistics records in Montgomery County and Ohio records.</td>
</tr>
<tr>
<td>1</td>
<td>Key-punch Operator</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Mortality Clerk</td>
<td></td>
</tr>
</tbody>
</table>

Describe any future plans: Increase statistical and computer capabilities.
1.5 How is the registry directed and funded? Twelve percent from United Way funds; seventy-eight percent earned income from private trust fund. Directed by County Tumor Registry Board made up of medical and lay residents of the community.

1.6 Describe how the data for the cancer registry is:

COLLECTED: Abstract form utilized. Copy of form attached.

CODING: At the Hospital of diagnosis.

PROCESSED: Manual processing at the Central Registry. Computer data processing now in process.

VERIFIED (EDITED): Abstracts are reviewed by Registry personnel. If anything looks out of order, the physician and/or hospital is called. Ninety percent of data is accepted as received.

VALIDATED: Continuous cross checking between hospital registry and central Registry personnel as to number and types of cases by week.

STORED: Abstract form is filed alphabetically by name of case.

1.7 Describe the follow-up techniques that are used by the registry: Letters in physicians as to current status of diagnosed patients. Letters sent every six months for life of patient. Have excellent cooperation from physicians.

1.8 Describe the quality control techniques used by the registry: Abstracts are reviewed upon receipt. Follow-up list printed each month. Hospitals check list from Registry. If they don't match, the matter is investigated.

1.9 Provide estimates for the following:

N.A. 3% of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year).

100% of registry cases have their diagnosis confirmed by histology (exclude non-melanoma skin tumors).

3,100 cases of newly diagnosed cancer for 1 year.
2.0 DATA UTILIZATION

2.1 Are the following data elements used in the registry? (Y = Yes, N = No, P = Planned).

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry Number</td>
<td>N</td>
</tr>
<tr>
<td>Case Number</td>
<td>N</td>
</tr>
<tr>
<td>Last name</td>
<td>N</td>
</tr>
<tr>
<td>First given name</td>
<td>N</td>
</tr>
<tr>
<td>Second given name</td>
<td>N</td>
</tr>
<tr>
<td>Maiden name</td>
<td>N</td>
</tr>
<tr>
<td>Street address</td>
<td>N</td>
</tr>
<tr>
<td>City/town/county</td>
<td>N</td>
</tr>
<tr>
<td>State/Province</td>
<td>N</td>
</tr>
<tr>
<td>Zip/Postal code</td>
<td>N</td>
</tr>
<tr>
<td>Date of birth</td>
<td>N</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>N</td>
</tr>
<tr>
<td>Race/Nationality</td>
<td>N</td>
</tr>
<tr>
<td>Marital status</td>
<td>N</td>
</tr>
<tr>
<td>Sex</td>
<td>N</td>
</tr>
<tr>
<td>Date of initial diagnosis</td>
<td>N</td>
</tr>
<tr>
<td>Primary site</td>
<td>N</td>
</tr>
<tr>
<td>Histology</td>
<td>N</td>
</tr>
<tr>
<td>Method of diagnostic confirmation</td>
<td>N</td>
</tr>
<tr>
<td>Paired organ involvement</td>
<td>N</td>
</tr>
<tr>
<td>Size of tumour</td>
<td>N</td>
</tr>
<tr>
<td>Regional node involvement</td>
<td>N</td>
</tr>
<tr>
<td>Stage at diagnosis</td>
<td>N</td>
</tr>
<tr>
<td>Date of first treatment</td>
<td>N</td>
</tr>
<tr>
<td>First course of treatment</td>
<td>N</td>
</tr>
<tr>
<td>Date of first recurrence</td>
<td>N</td>
</tr>
<tr>
<td>Subsequent treatment(s)</td>
<td>N</td>
</tr>
<tr>
<td>Date of last contact/death</td>
<td>N</td>
</tr>
<tr>
<td>Status</td>
<td>N</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td>N</td>
</tr>
</tbody>
</table>

Quality of survival is noted, however this is not entered on computer at this time. Physicians names are recorded. Note is made of inpatient or outpatient status.

2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+).


CANCER SITE: H-ICDA, 2nd Edition, 8th Revision

STAGE OF DISEASE: SEER Manual, Book 6

RESIDENCE: Entered as alpha language

2.3 Describe how and what skin cancers or non-malignant conditions are registered:

Do not require skin cancers to be registered. Benign tumors are registered with same data taken.
2.4 Describe how cancer death information is used in the registry for survival analysis from date of diagnosis:

2.5 What census data is readily available to you? (years, levels of residence, race, sex, etc.): All census data as provided in the United States Census of the Population, Dayton Standard Metropolitan Statistical Area.

2.6 To what degree is the registry data computerized? (years, files, plans, etc.)
Back to 1967 on tape
Data goes back to 1953

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.):
To answer individual requests from hospitals, physicians for number of cases by site. Annual reports for tumor registry boards.

2.8 Describe your present computing abilities to analyze and process registry data:
COMPUTER EQUIPMENT: International Business Machines hardware. Program design and data entry by Ponderosa Systems, Incorporated.

COMPUTER PERSONNEL: Full-time data processor, two part-time programmers via Ponderosa Systems, Incorporated staff.

If fee for service, describe arrangements: None. Donated by Ponderosa Systems, Incorporated staff.

Describe any future plans: Finish current programs. Design new abstracts - break stage down, more site specific, size of tumor, more space for physician names - More sophisticated quality control, i.e., now collect but do not code. Need data of recurrence. Need more efficient way of collecting death information.
3.0 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry?

(Y = Yes  N = No  P = Planned)

Residence history: Y (P)
Occupational history: Y (P)
Smoking history: Y (P)
Female history (parity, menopause, etc.): Y (P)
Family history of cancer: Y (P)
Other (please specify):

If yes to any of the above, please describe how the data is coded:

Data is not coded.

3.2 Please describe any future developments: None with established date. Would like to demonstrate greater utility of collected data. This registry is the closest to a population based registry Ohio has. Therefore, the potential exists for population based age, sex, race adjusted incidence data.

3.3 Are there any other comments that you may have?: Would be great to have all registries gathering the same data in the same way.
CANCER REGISTRY SURVEY
GREAT LAKES BASIN

Please provide short answers to the questions that follow.
If a question or item does not apply, please indicate by 'N/A'.

1.0 REGISTRY CHARACTERISTICS

1.1 Describe the current stage of registry development or operation
(when did it start): STARTED IN 1962 AND OPERATED BY THE DIVISION OF
EPIDEMIOLOGY AND STATISTICS, THE ONTARIO CANCER TREATMENT AND RESEARCH
FOUNDATION

1.2 Describe the population coverage, size and characteristics:
8 MILLION PEOPLE:
LARGE MIGRANT GROUPS FROM U.K., ITALY, POLAND, GERMANY,
NETHERLANDS, HUNGARY, ETC.

1.3 List the registry data sources and collection techniques:

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Year Started</th>
<th>Current Year</th>
<th>Volume per Year</th>
<th>Collection Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Separations</td>
<td>1964</td>
<td>1979</td>
<td>68,000</td>
<td>Computer Tape</td>
</tr>
<tr>
<td>Pathology</td>
<td>1972</td>
<td>1981</td>
<td>25,000</td>
<td>Copies of Pathology Reports</td>
</tr>
<tr>
<td>Foundation Clinics</td>
<td>1939</td>
<td>1981</td>
<td>19,000</td>
<td>Abstract Cards (1960+ Computerized)</td>
</tr>
<tr>
<td>Death Certificates</td>
<td>1950</td>
<td>1981</td>
<td>16,000</td>
<td>IBM Cards, Now on Tape</td>
</tr>
<tr>
<td>Other Hospital Registries</td>
<td>1964</td>
<td>1981</td>
<td>2,000</td>
<td>Abstract Forms</td>
</tr>
</tbody>
</table>

Describe any future plans: HEMATOLOGY DEPARTMENT RECORDS; ALL DEATH CERTIFICATES IN ONTARIO

1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.).

<table>
<thead>
<tr>
<th>No.</th>
<th>Job Title</th>
<th>Duties</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>DIRECTOR &amp; ASSISTANT</td>
<td>DIRECTION, RESEARCH &amp; SERVICE</td>
</tr>
<tr>
<td>1</td>
<td>STATISTICIAN</td>
<td>GENERATE DATA FOR RESEARCH &amp; SERVICE</td>
</tr>
<tr>
<td>6</td>
<td>CLERKS</td>
<td>CODING, DATA ENTRY, QUALITY CONTROL</td>
</tr>
<tr>
<td>1</td>
<td>MEDICAL RECORDS OFFICER</td>
<td>DIRECT CLERKS, QUALITY CONTROL</td>
</tr>
<tr>
<td>3</td>
<td>PROGRAMMERS</td>
<td>MAINTAIN DATA, PROGRAMMING, DEVELOPMENT</td>
</tr>
<tr>
<td>1</td>
<td>SECRETARY</td>
<td>CORRESPONDENCE, REPORTS</td>
</tr>
</tbody>
</table>

Describe any future plans: ANOTHER EPIDEMIOLOGIST MAY BE INVOLVED ON A PART-TIME BASIS
1.5 How is the registry directed and funded? **UNDER THE DIRECTION OF THE ONTARIO CANCER TREATMENT AND RESEARCH FOUNDATION; A STATUTORY FOUNDATION SUPPORTED BY CANCER CONTROL FUNDS FROM THE PROVINCIAL MINISTRY OF HEALTH.**

1.6 Describe how the data for the cancer registry is:

**COLLECTED:** USING PRECODED DATA ON FORMS OR COMPUTER TAPE. NONE OF THE DATA IS ACTIVELY COLLECTED BY THE REGISTRY STAFF.

**CODED:** SOME ABSTRACTED DATA IS PRECODED BY CLERKS AND THEN ENTERED AT VIDEO TERMINALS. STANDARD CODING SYSTEMS ARE USED FOR SITE, PATHOLOGY AND RESIDENCE.

**PROCESSED:** DIFFERENT SOURCE DATA FILES ARE PROCESSED AND NEWLY DIAGNOSED CASES ARE CREATED BY COMPUTERIZED RECORD LINKAGE TECHNIQUES.

**VERIFIED (EDITED):** ALL DATA ENTRY OF RECORDS OR TAPE FILES UNDERGO COMPUTER EDITS ON VALID CODES, RANGES AND CONSISTANCY CHECKS.

**VALIDATED:** CODED WORK IS CHECKED AGAINST SOURCE RECORDS AND RECORDS ARE VALIDATED DURING SITE REVIEWS. SOURCE DATA ON TAPE UNDERGO QUALITY CHECKS WHEN CREATED.

**STORED:** MASTER FILE COPIES ARE STORED IN EXTERNAL VAULTS; MOST OF THE DATA IS ON DISC AND BACKED UP ON TAPE.

1.7 Describe the follow-up techniques that are used by the registry: **THE FOUNDATION CLINICS ACTIVELY FOLLOW OVER ONE-HALF OF ALL CANCER CASES IN ONTARIO; THE DEATH FILE IS USED FOR PASSIVE FOLLOW-UP.**

1.8 Describe the quality control techniques used by the registry: **PROGRAMME CONTROLLED DATA ENTRY; SITE REVIEWS; SPECIAL SURVEYS AND STUDIES; CROSS-CHECK WITH MULTIPLE SOURCES; VALIDATION OF CODING WORK.**

1.9 Provide estimates for the following:

- **2.5%** of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year).

- **90%** of registry cases have their diagnoses confirmed by histology (exclude non-melanoma skin tumours).

- **27,000** cases of newly diagnosed cancer for **1976** (year)
DATA UTILIZATION

2.1 Are the following data elements used in the registry? (Y = Yes, N = No, P = Planned).

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Y</th>
<th>N</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry Number</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Case Number (for multiple primary sites)</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Last name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>First given name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Second given name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Maiden name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Street address</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>City/town/county</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>State/Province</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Zip/Postal code</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Race/Nationality</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Marital status</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Sex</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of initial diagnosis</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Primary site</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Histology</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Method of diagnostic confirmation</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Paired organ involvement</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Size of tumour</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Regional node involvement</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Stage at diagnosis</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of first treatment</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>First course of treatment</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of first recurrence</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Subsequent treatment(s)</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of last contact/death</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Status</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
</tbody>
</table>

RADIOTHERAPY AND CHEMOTHERAPY; PREVIOUS TREATMENT; QUALITY OF LIFE INDEX [PILOT STUDY].

2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+).

<table>
<thead>
<tr>
<th>Coding Directory</th>
<th>Dates of Usage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HISTOLOGY</td>
<td>1960-1978 MOTVAC (1968 EDITION)</td>
</tr>
<tr>
<td></td>
<td>1979+ ICD-0</td>
</tr>
<tr>
<td>CANCER SITE</td>
<td>1960-1978 ICDA-8</td>
</tr>
<tr>
<td></td>
<td>1979+ ICD-9</td>
</tr>
<tr>
<td>STAGE OF DISEASE</td>
<td>TMM CLASSIFICATION SYSTEM</td>
</tr>
<tr>
<td>RESIDENCE</td>
<td>1972-1978 OWN 3 DIGIT ALPHA CODE (CITY OR COUNTY)</td>
</tr>
<tr>
<td></td>
<td>1979+ 4 DIGIT CODE (ONTARIO MINISTRY OF HEALTH)</td>
</tr>
</tbody>
</table>

2.3 Describe how and what skin cancers or non-malignant conditions are registered:

MALIGNHANT MELANOMA; SKIN CANCERS - ONE FOR EACH CELL TYPE; 1979+ ICD-9

CODES 210-239 REGISTERED; [SKINS ICD-173 WILL BE EXCLUDED FROM INCIDENCE FILE FROM 1972+].
2.4 Describe how cancer death information is used in the registry: FOR PASSIVE FOLLOWUP; CANCER DEATHS WITHOUT SUPPORTING EVIDENCE ARE FLAGGED AND USED IN THE REGISTRY.

2.5 What census data is readily available to you? (years, levels of residence, race, sex, etc.): ALL PUBLISHED CENSUS DATA FOR ONTARIO SINCE 1951; COMPUTER DISC FILE HAS POPULATIONS BY YEAR, COUNTY, SEX AND 5-YEAR AGE GROUPS.

2.6 To what degree is the registry data computerized? (years, files, plans, etc.) ALL DATA ARE COMPUTERIZED; ALL ORIGINAL SOURCE RECORDS ARE RETAINED UNTIL COMPUTER LINKAGE IS COMPLETED.

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.): INFORMATION REQUESTS FROM RESEARCHERS, CANCER REGISTRIES, CANCER CLINICS, GOVERNMENT, HOSPITALS, PHYSICIANS, PUBLIC, NEWS MEDIA, ETC.; SITE REVIEWS OF BREAST AND TESTIS; ANNUAL REPORTS; ANALYSES OF CANCER MORTALITY IN MIGRANT POPULATIONS; CANCER BY GEOGRAPHIC AREAS SUCH AS MUNICIPALITIES BORDERING THE NIAGARA RIVER AND PORT HOPE (A COMMUNITY EXPOSED TO LOW-LEVEL RADIOACTIVE WASTES); DATA FOR PLANNING MEDICAL RESOURCES, CLINICAL TRIALS, AND EPIDEMIOLOGICAL STUDIES; ASSISTING IN OCCUPATIONAL FOLLOW-UP STUDIES; ETC.

2.8 Describe your present computing abilities to analyze and process registry data: COMPUTER EQUIPMENT: PDP 11/34 WITH TWO 300 MEGABYTE DISC DRIVES; ONE TAPE UNIT (COMPUTERIZED RECORD LINKAGE IS BEING DONE EXTERNALLY ON AN AMDAHL AT STATISTICS CANADA).

COMPUTER PERSONNEL: 1 MANAGER, 1 SYSTEMS ANALYST AND 3 PROGRAMMERS

If fee for service, describe arrangements: UTILIZE IBM 360 AT UNIVERSITY OF TORONTO FOR RESEARCH THAT DOES NOT REQUIRE PATIENT IDENTIFICATION

Describe any future plans: THE ONTARIO CANCER TREATMENT AND RESEARCH FOUNDATION'S COMPUTER SYSTEM IS UNDERGOING A MAJOR UPGRADE. COMPUTERS WILL BE PLACED IN THE SEVEN CLINICS AND A LARGER COMPUTER WILL BE USED FOR THE CANCER Registry AND EPIDEMIOLOGY.
3.7 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry?
   (Y = Yes  N = No  P = Planned)

- Residence history...................................................... Y (Y P
- Occupational history.................................................. Y (Y P
- Smoking history.......................................................... Y (Y P
- Female history (parity, menopause, etc.)............................ Y (Y P
- Family history of cancer............................................... Y (Y P
- Other (please specify)*FOUNDATION CLINICS MAY COLLECT THIS INFORMATION

If yes to any of the above, please describe how the data is coded:

- Longest occupation (SIC codes);
- Smoking status (current, previous or non-smoker);
- Parity and menopause on selected sites;
- Indicator of family history

3.2 Please describe any future developments: DATA FROM SEVEN ONTARIO CANCER TREATMENT AND RESEARCH FOUNDATION CLINICS AND THE ONTARIO CANCER INSTITUTE WILL BE TRANSFERRED IN MACHINE READABLE FORM; REGISTRY STAFF WILL SPEND MUCH MORE TIME ON QUALITY CONTROL.

3.3 Are there any other comments that you may have?: INCIDENCE DATA IS READILY AVAILABLE FOR THE YEARS 1969-1971; THE 1972-1976 DATA IS BEING LINKED AND SHOULD BE AVAILABLE FOR JUNE 1981; 1977 WILL BE LINKED SEPARATELY BY SEPTEMBER 1981 AND AND EVENTUALLY THE LAG TIME WILL BE DECREASED TO TWO YEARS (SINCE WE RELY UPON DATA THAT IS INITIALLY COLLECTED FOR OTHER PURPOSES AND IS PROCESSED BY THE EFFORTS OF OTHERS); 1964-1966 INCIDENCE DATA CAN BE RECONSTRUCTED FROM DATA SOURCES THAT ALREADY EXIST.

NOTE 2.1 - THE DATA ON STAGE AND TREATMENT IS COLLECTED ON THE ONTARIO CANCER TREATMENT AND RESEARCH FOUNDATION CLINIC PATIENTS ONLY.
CANCER REGISTRY SURVEY
GREAT LAKES BASIN

Please provide short answers to the questions that follow. If a question or item does not apply, please indicate by a 'N/A'.

1.0 REGISTRY CHARACTERISTICS

1.1 Describe the current stage of registry development or operation (when did it start): Pennsylvania's Registry is in a planning stage. Plans include pilot testing the registry later this year or early next year and then beginning statewide operations.

1.2 Describe the population coverage, size and characteristics: Planned coverage: All Pennsylvania hospitals and laboratories would be required to report all cancer cases in Pennsylvania.

1.3 List the registry data sources and collection techniques: To be planned.

<table>
<thead>
<tr>
<th>DATA SOURCE</th>
<th>YEAR STARTED</th>
<th>CURRENT YEAR</th>
<th>VOLUME PER YEAR</th>
<th>COLLECTION METHOD</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
</tr>
</tbody>
</table>

Describe any future plans: Stage I: Pilot test registry in limited geographic area. Stage 2: Statewide registry - estimated volume is 90,000 laboratory reports and 60,000 hospital case reports/yr., yielding 44,000 cases of cancer among Pennsylvania residents.

1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.). To be planned.

<table>
<thead>
<tr>
<th>No.</th>
<th>Job Title</th>
<th>Duties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
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</tr>
</tbody>
</table>

Describe any future plans: A core project team composed of one professional each from the Pennsylvania Department of Health's Division of Chronic Disease Control, Systems Development and Health Statistics will begin later this year to plan the registry's operations with the Pennsylvania Cancer Advisory Board and outside consultants.
1.5 How is the registry directed and funded? The registry is the responsibility of the Pennsylvania Department of Health's Division of Chronic Disease Control in the Bureau of Epidemiology and Disease Prevention. Funds for pilot testing the registry will be available as of July 1, 1981.

1.6 Describe how the data for the cancer registry is:

Collected: N/A - proposed registry form is attached.

Coded: 

Processed: 

Verified (Edited): 

Validated: 

Stored: 

1.7 Describe the follow-up techniques that are used by the registry: None are planned.

1.8 Describe the quality control techniques used by the registry: Proposed quality control procedures include registry staff reabstracting hospital records, matching registry forms with death records, and computer editing for invalid fields.

1.9 Provide estimates for the following: N/A

% of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year).

% of registry cases have their diagnoses confirmed by histology (exclude non-melanoma skin tumours).

Cases of newly diagnosed cancer for (year)
### 2.0 DATA UTILIZATION

#### 2.1 Are the following data elements used in the registry?

(Y = Yes,  N = No,  P = Planned).

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Y</th>
<th>N</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry Number</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Case Number (for multiple primary sites)</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Last name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>First given name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Second given name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Maiden name</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Street address</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>City/town/county</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>State/Province</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Zip/Postal code</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Race/Nationality</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Marital status</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Sex</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of initial diagnosis</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Primary site</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Histology</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Method of diagnostic confirmation</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Paired organ involvement</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Size of tumour</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Regional node involvement</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Stage at diagnosis</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of first treatment</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>First course of treatment</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of first recurrence</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Subsequent treatment(s)</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Date of last contact/death</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Status</td>
<td>Y</td>
<td>N</td>
<td>P</td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+). Proposed coding of neoplasms with an ICD-0 behavior code of 2 or higher.

**HISTOLOGY:**

**CANCER SITE:**

**STAGE OF DISEASE:**

**RESIDENCE:** Pennsylvania residents and non-residents who utilize Pennsylvania hospitals and laboratories.

#### 2.3 Describe how and what skin cancers or non-malignant conditions are registered:

Proposed: *basal cell and squamous cell carcinomas of the skin.*

---

*Note: The document contains a table and text that describe the data elements used in the registry, the coding directory, and details about skin cancer registration.*
2.4 Describe how cancer death information is used in the registry: Proposed:

Monitor cancer incidence over time and stages of disease at initial diagnosis;
establish a database for cancer prevention studies; identify rare forms of cancer;
provide a sampling frame for survival studies; aid individual hospitals in
cancer control efforts.

2.5 What census data is readily available to you? (years, levels of residence,
race, sex, etc.):

To what degree is the registry data computerized? (years, files, plans, etc.)

We plan to computerize registry - system has to be decided upon.

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.): N/A

2.8 Describe your present computing abilities to analyze and process registry data:

COMPUTER EQUIPMENT: IBM 370

COMPUTER PERSONNEL:

If fee for service, describe arrangements:

Describe any future plans:
3.0 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry? (Y = Yes H = No P = Planned)

- Residence history: Y \(\bigcirc\) F
- Occupational history: Y \(\bigcirc\) F
- Smoking history: Y \(\bigcirc\) F
- Female history (parity, menopause, etc.): Y \(\bigcirc\) F
- Family history of cancer: Y \(\bigcirc\) F
- Other (please specify)

If yes to any of the above, please describe how the data is coded:

- 
- 
- 
- 

3.2 Please describe any future developments: See question 1.1

- 
- 
- 

3.3 Are there any other comments that you may have?

Pennsylvania's registry is obviously at a very early stage of development. This workshop provides us with an opportunity to compare our registry plans with other registries.

- 
- 
- 
-
REGISTRY CHARACTERISTICS

1.0

1.1 Describe the current stage of registry development or operation (when did it start): The Wisconsin Cancer Reporting System became a statewide system January 1, 1978. Prior to this it operated as a pilot project in a 7 county area since July, 1976.

1.2 Describe the population coverage, size and characteristics:

The entire population of Wisconsin is covered. In 1978 the population was estimated to be 4,683,000.

1.3 List the registry data sources and collection techniques:

<table>
<thead>
<tr>
<th>DATA SOURCE</th>
<th>YEAR STARTED</th>
<th>CURRENT YEAR</th>
<th>VOLUME PER YEAR</th>
<th>COLLECTION METHOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumor Registries</td>
<td>1976</td>
<td>1981</td>
<td>4600</td>
<td>Copies of abstracts</td>
</tr>
<tr>
<td>Hospital D.P. Dept. &quot;Central&quot;</td>
<td>1976</td>
<td>1981</td>
<td>2100</td>
<td>Tape</td>
</tr>
<tr>
<td>D.P. System*</td>
<td>1976</td>
<td>1979</td>
<td>2700</td>
<td>Tape</td>
</tr>
</tbody>
</table>

Describe any future plans:

* This "central" system served a number of hospitals but ended July, 1980.

The hospitals are in the process of converting to other D.P. or manual systems. In the interim we are receiving copies of abstracts.

1.4 List the registry personnel and their duties, (clerks, abstractors, statisticians, programmers, etc.).

<table>
<thead>
<tr>
<th>No.</th>
<th>Job Title</th>
<th>Duties</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Research Analyst</td>
<td>Responsible for the operations of the System</td>
</tr>
<tr>
<td>1</td>
<td>Clerical Assistant</td>
<td>Manual processing of report forms</td>
</tr>
</tbody>
</table>

Describe any future plans:
1.5 How is the registry directed and funded? The System is within the Bureau of Health Statistics and is funded with State General Purpose Revenue funds.

1.6 Describe how the data for the cancer registry is:

COLLECTED: The data are collected either on the Neoplasm Report Form (completed by the Medical Records Personnel), or on tumor registry abstracts, or by tape.

CODED: The data are coded in the Central Office by hand using the Manual of Tumor Nomenclature, the SEER program's "Codes for Primary Site and Histologic Type" and the U.S. Dept of Health's "Geographical Location Codes".

PROCESSED: The report forms are simply coded and edited while the information on the tumor registry abstracts is transferred onto a report form and then processed. The data on tape are converted if necessary and added to the database.

VERIFIED (EDITED): There are computer edit checks in addition to the manual editing done.

VALIDATED: 

STORED: On a quarterly basis the data is merged onto the master file. Back-up tapes are created and the original forms are kept for five years.

1.7 Describe the follow-up techniques that are used by the registry: Since this is a population-based incidence reporting system no active follow-up is done. Information from death certificates is added to the database.

1.8 Describe the quality control techniques used by the registry: The coding and editing done in the Central Office is reviewed and a reabstracting study of a sample of records is completed annually.

1.9 Provide estimates for the following:

* 2% of registry cases are identified by death certificates (use the number of death certificates only and the number of deaths that were later investigated for cancer site confirmation; divide by total incidence cases for the same year).

93 2% of registry cases have their diagnoses confirmed by histology (exclude non-melanoma skin tumours).

15400 cases of newly diagnosed cancer for 1979 (year)

* The System is too "young" to provide a meaningful percentage for this question.
2.0 DATA UTILIZATION

2.1 Are the following data elements used in the registry? (Y = Yes, N = No, P = Planned).

Registry Number ............................................. Y N P
Case Number (for multiple primary sites) ......................... Y Y P
Last name .................................................. Y N P
First given name ........................................... Y N P
Second given name ......................................... Y N P
Maiden name ................................................ Y N P
Street address ............................................. Y N P
City/town/county ........................................... Y N P
State/Province ............................................. Y N P
Zip/Postal code ............................................. Y N P
Date of birth ............................................... Y P N
Age at diagnosis ........................................... Y N P
Race/Nationality ........................................... Y N P
Marital status .............................................. Y N P
Sex ................................................................. Y N P
Date of initial diagnosis ................................... Y N P
Primary site .................................................. Y N P
Histology .................................................... Y N P
Method of diagnostic confirmation .............................. Y N P
Paired organ involvement .................................. Y Y Y
Size of tumour .............................................. Y N P
Regional node involvement ................................... Y N P
Stage at diagnosis .......................................... Y N P
Date of first treatment ..................................... Y N P
First course of treatment ................................... Y N P
Date of first recurrence ..................................... Y N P
Subsequent treatment(s) .................................... Y N P
Date of last contact/death ................................... Y N P
Discharge Status ............................................. Y N P

Other (Please specify):

Name of reporting hospital, follow-up physician, dates of admission & discharge, is case diagnosed at the reporting hospital?, is this the only primary?, has the patient been seen elsewhere?

2.2 Please indicate the coding directory used and dates of usage (e.g. SNOP 1972-1978, ICD9 1979+). All coding schemes are 1976-Present

HISTOLOGY: Manual of Tumor Nomenclature and Coding

CANCER SITE: SEER's "Codes for Primary Site and Histologic Type"

STAGE OF DISEASE: "A Guide for the Tumor Registry Secretary in Recording Stage" published by the California Tumor Registry

RESIDENCE: U.S. Department of Health's "Geographical Location Codes"

2.3 Describe how and what skin cancers or non-malignant conditions are registered:

Only data on malignant melanomas are collected and no information on non-malignant conditions is required.
2.4 Describe how cancer death information is used in the registry:

Certain data elements from the death certificate are added to the incidence records or used to create a record.

2.5 What census data is readily available to you? (years, levels of residence, race, sex, etc.): Ethnic group, sex, marital status, county of residence, age (calculated from birthdate)

2.6 To what degree is the registry data computerized? (years, files, plans, etc.)

All data are computerized. In addition to the data collected through the statewide system there are tapes containing incomplete incidence information from earlier years. This information was collected on a somewhat voluntary basis.

2.7 List the ways in which the registry data was used in 1980. (reports, requests, studies, etc.):

The Cancer in Wisconsin 1978 annual report was completed; numerous data requests from health researchers and planners were answered; quarterly reports were sent to the hospitals detailing their cancer experience; and a referral pattern study was completed.

2.8 Describe your present computing abilities to analyze and process registry data:

COMPUTER EQUIPMENT: IBM 370 model 3033

COMPUTER PERSONNEL: Access to the State's Office of Information Systems (OIS) personnel

If fee for service, describe arrangements: There is a charge for OIS programmers' time.

Describe any future plans:
3.0 REGISTRY DEVELOPMENTS

3.1 Are any of the following items collected for the registry?  
(Y = Yes  N = No  P = Planned)

Residence history..................................................... Y N P
Occupational history................................................ Y N P
Smoking history....................................................... Y N P
Female history (parity, menopause, etc.)......................... Y N P
Family history of cancer............................................ Y N P
Other (please specify).................................................

If yes to any of the above, please describe how the data is coded:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

3.2 Please describe any future developments: A conversion to the ICD-O coding  
scheme for primary site and histology is under consideration. Also, a change  
in the unduplication process of the System is being studied.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

3.3 Are there any other comments that you may have?: Enclosed is a two page  
summary of the Cancer Reporting System which may provide additional  
information. If you have any further questions you may contact Mary  
Fischer at (608) 267-7141 or at Bureau of Health Statistics, P.O. Box 309,  
Madison, WI  53703.
The Department of Environmental Health, University of Minnesota, are currently involved in a feasibility study to assess the potential health risks associated with organic contaminants in the Great Lakes region. The concern for human exposure to organic chemicals arises from their persistence in the environment, which allows biomagnification in food chains and their potential impact on human health.

We have selected as potential sources of organic contamination the chlorinated hydrocarbons such as PCBs. Both public and private sources have been contracted to detect the levels of these contaminants in the environment. Reviews of these data sets have identified potential sources (i.e., industrial) as well as non-point sources (i.e., atmosphere) which contribute to organic contaminant levels in the environment.

Biomagnification of organic contaminants may allow transfer from aquatic foodchains to human populations. Thus, it has been hypothesized that human exposure may exist via consumption of contaminated fish. This hypothesis has been explored by Humphrey and his associates. Their observations suggest that there could be long term accumulation of organochlorines consuming large quantities of fish. However, we still have no measure of the health status of high versus low level fish consumers. It is not clear whether utilization by Humphrey, et al., measured the possibility of adverse latent effects from organic contaminants.

The focus of our study is on assessing cumulative effects; we are not interested in cancer as defined in animal studies. We have therefore compared morbidity rates for the two populations contiguous with the two groups. These populations show potential to organic contaminants and morbidity/mortality.

To evaluate the potential health risks associated with the consumption of contaminated fish we have collected a cohort of fish consumers from the Great Lakes region. Several potential monitors have been identified to serve as potential cohorts. The project team has initiated a pilot study to evaluate several markers and questionnaires on a small sample of randomly selected commercial fishermen from the Great Lakes. The decision to use the data from fish market scales was based upon the completeness of records available from the Great Lakes State Department of Natural Resources (DNR) records. Upon completion of this pilot study the epidemiologic method which results in the greatest effectiveness will be utilized to evaluate the health risks associated with the commercial fishing industry.

APPENDIX G

GREAT LAKES PROJECT - DR. LEONARD SCHUMAN
UNIVERSITY OF MINNESOTA

(U.S. EPA FUNDING)
The Departments of Epidemiology and Environmental Health, University of Minnesota, are currently involved in a feasibility study to assess the potential health risks associated with organic contaminants in the Great Lakes Basin. The concern for possible human exposure to organic chemicals arises from their physico-chemical properties which permit biomagnification in food chains and their persistence in the environment.

We have selected as an indicator of organic contamination the chlorinated hydrocarbons such as PCBs, DDT and dieldrin. Both public and private sources have been contracted for data collection regarding the levels of these contaminants in the environment of the Great Lakes. Reviews of these data sets have identified several "problem areas" typically associated with point sources (i.e., industrial and municipal dischargers). Non-point sources (i.e., atmosphere) have also demonstrated a significant contribution to organic contaminant levels in the Great Lakes Basin.

Biomagnification of organics through the aquatic foodchains may provide one of the most direct routes of potential exposure to human populations. Thus, it has been hypothesized that a potential human exposure may exist via consumption of contaminated fish. This possibility has been explored by Humphrey and his associates. Their findings suggest that there could be long term accumulation of these materials in populations consuming large quantities of fish. However, no difference was noted in the health status of high versus low level fish consumers. The study design utilized by Humphrey, et al., (see Appendix G to these Proceedings) does not negate the possibility of adverse latent effects from long term low level exposure.

The focus of our project has been to assess this latter form of exposure. Chlorinated hydrocarbons have been implicated as carcinogens in animal studies. We have therefore undertaken an analysis of site-specific cancer mortality rates for the years 1950 to 1969 by the degree of geographical contiguity with the Great Lakes. The hypothesis of this evaluation is that those populations closer to the Great Lakes may experience a greater exposure potential to organics and therefore may experience a higher cancer morbidity/mortality.

To evaluate the potential health risks associated with the consumption of contaminated fish we have compiled a cohort of fish consumers from the Great Lakes region. Several subgroup populations have been identified to serve as potential cohorts. The Great Lakes project staff has initiated a pilot study to evaluate several epidemiologic protocols and questionnaires on a small sample of randomly selected commercial fishermen from the Great Lakes. The decision to use this occupational group was based upon the completeness of records available from the eight Great Lakes State Department of Natural Resources (DNR) offices. Following the completion of this pilot study the epidemiologic methods demonstrating the greatest effectiveness will be utilized to evaluate all individuals associated with the commercial fishing industry.
The Great Lakes staff are also exploring the possibility of applying a similar protocol to sport fishermen in the Great Lakes Basin. Several state DNR officials have been contacted to elicit joint cooperation in sampling sport fishermen based on current license holders. Discussions have been held with the Wisconsin DNR for joint participation in their proposed 1982 sport fishing practices survey.

A visit to the Baltimore Public Health Service Hospital has been scheduled for the purpose of establishing a nonconcurrent prospective study of Great Lakes commercial fishermen utilizing their services.

Summaries of these and future activities will be forthcoming. Further questions regarding the specific approaches and results of the above projects should be addressed to the principal investigators.
FIELD STUDIES OF SELECTED POPULATIONS WITHIN THE GREAT LAKES BASIN

Michigan

In response to chemical contamination episodes, the Michigan Department of Public Health has initiated two major epidemiologic investigations involving over 7,000 persons in order to collect information concerning the impact of halogenated biphenyl exposure on human health.

1. Long Term Study of Human Health Consequences of Polychlorinated Biphenyl Exposure. Dr. Harold E.B. Humphrey, Project Director.

Citizens of the State of Michigan were inadvertently exposed to polychlorinated biphenyl (PCB) through contamination of farm animals and consequently, food products. A cohort of 4,600 persons selected on the basis of greatest presumed exposure have been enrolled in a multi-year prospective study in order to evaluate the long-term human health impact. A comparison group of 1,500 persons in the State of Iowa has been enrolled and will be evaluated in parallel. Serum concentrations of PCB are measured periodically to monitor body burden and the occurrence of major health events are evaluated in detail with particular attention being paid to the development and site of cancer and the development of other chronic diseases.

2. Evaluation of Human Exposure to the Chemicals in the Great Lakes. Dr. Harold E.B. Humphrey, Project Director.

Persons who consume fish and other aquatic life of Great Lakes origin are exposed to a variety of environmental contaminants. Exposure to over 500 persons who consume Great Lakes fish or other aquatic life have been enrolled in a study which will attempt to relate contaminants found in fish with human exposure, health effects and life events. Human blood and other body fluids will be periodically measured and quantitated for exposure estimates and correlation with body burden. Longitudinal comparisons of contaminant levels in blood over time will be made. Clinical evaluations will be conducted on highly exposed subsamples of the cohort in order to determine changes in health and physiological function indicators away from normal. Additional evaluation groups will be recruited from sites of potentially high exposure in the Great Lakes basin.

APPENDIX H

FIELD STUDIES ON SELECTED MICHIGAN POPULATIONS - DR. HAROLD E.B. HUMPHREY, MICHIGAN DEPARTMENT OF PUBLIC HEALTH
The Great Lakes staff are also considering the possibility of applying a computer model to sport fishery in the Great Lakes Region. Several state
and federal agencies have also contacted the Great Lakes Program in sampling
methods and have requested data on current license holders. Discussions have been held
with the Michigan Fish and Game for joint participation in their proposed 1962 sport
fishery survey.

A meeting of the State shore line and local health officials will be scheduled
in the spring to establish within a comprehensive program for the study of Great
Lake communities. Information is being sought on:

1. Sources of sewage and water supplies
2. Sewage treatment facilities
3. Water supply facilities
4. Other sources of contamination

Summaries of these and future activities will be prepared. Further
questions regarding the specific approaches and objectives of the sewage projects
should be addressed to the principal investigator.

RESOURCES

Field Studies on Perch
Michigan Department of Conservation
Nicholson, W. R. 
Nicholson, W. R.
Department of Fisheries, Michigan
FIELD STUDIES OF SELECTED POPULATIONS WITHIN THE GREAT LAKES BASIN

Michigan

In response to chemical contamination episodes, the Michigan Department of Public Health has initiated two major epidemiologic investigations involving over 7,000 persons in order to collect information concerning the impact of halogenated biphenyl exposure on human health.

1. Long Term Study of Human Health Consequences of Polybrominated Biphenyl Exposure. Dr. Harold E.B. Humphrey, Project Director.

Citizens of the State of Michigan were inadvertently exposed to polybrominated biphenyl (PBB) through contamination of farm animals and consequently, food products. A cohort of 4,600 persons selected on the basis of greatest presumed exposure have been enrolled in a multi-year prospective study in order to evaluate the long-term human health impact. A comparison group of 1,500 persons in the State of Iowa has been enrolled and will be evaluated in parallel. Serum concentrations of PBB are measured periodically to monitor body burden and the occurrence of major health events are evaluated in detail with particular attention being paid to the development and site of cancer and the development of other chronic diseases.

2. Evaluation of Humans Exposed to Water Borne Chemicals in the Great Lakes. Dr. Harold E.B. Humphrey, Project Director.

Persons who consume significant quantities of Great Lakes fish are exposed to chemical contaminants present in the aquatic environment. Expanding on an earlier investigation, a cohort of over 500 persons who consume sport caught fish and a matched comparison group of 500 persons residing along the Lake Michigan shoreline have been enrolled in a study which will attempt to relate contaminants found in fish with human exposure, health effects and life events. Human blood levels of PCB and other contaminants will be periodically measured; fish consumption will be monitored and residue levels in fish meals quantitated for exposure estimates and correlation with body burden. Longitudinal comparisons of contaminant levels in blood over time will be made. Clinical evaluations will be conducted on highly exposed subsets of the cohort in order to determine changes in health or physiologic function indicators away from the norm. Additional evaluation groups will be recruited from sites of potentially high exposure in the Great Lakes basin.
FIELD STUDIES OF SELECTED CONTAMINANTS AROUND THE GREAT LAKES BASIN

In response to growing public concern over the effects of contaminants in the Great Lakes Basin, the Michigan Department of Public Health has undertaken a series of investigations to identify and evaluate the impact of various contaminants on human health. To date, over 7,000 samples have been taken from various locations around the basin, providing valuable data on the distribution and concentration of contaminants.

The results of this study have shown that certain contaminants, such as PCBs and mercury, are present in significant levels in various lakes and tributaries. These findings have important implications for public health and the management of the Great Lakes ecosystem.

In conclusion, the field studies have provided critical information that will guide future efforts to mitigate the effects of contaminants on the Great Lakes Basin. Continued monitoring and research are essential to ensure the long-term health of this vital ecosystem.
APPENDIX I

MEMBERSHIP LIST AND TERMS OF REFERENCE

Dr. R. W. Durham (Until March 1981)
Applied Research Division
Ontario Center for Inland Waters
Dept. of Fisheries and Environment
Burlington, Ontario

Dr. H. L. Falk
Associate Director for Health Hazard Assessment
M.E.W.R.
Research Triangle Park, N.C.

Dr. Wolfgang Fuhs, Director
Environmental Health Institute
Division of Laboratories and Research
Ohio State Department of Health
Columbus State Plaza

Dr. Rolf Hartung (Until March 1981)
School of Public Health
University of Michigan
Ann Arbor, Michigan

Mrs. Ann M. Vajilec
Microbiologist
Water Technology Section
Pollution Control Planning Branch
Ontario Ministry of the Environment
Toronto, Ontario

Dr. A. F. Gibson (Eff. March 1981)
Toxicologist
Environmental Health Directorate
Dept. of Health & Welfare
Ottawa, Ontario

Dr. Robert F. Spaulding (Eff. March 1981)
Medical Consultant
Division of Environmental Epidemiology
Bureau of Disease Control & Lab Service
Michigan Dept. of Public Health
Lansing, Michigan
JOINT SCIENCE ADVISORY BOARD/WATER QUALITY BOARD IJC COMMITTEE
ON THE
ASSESSMENT OF HUMAN HEALTH EFFECTS OF GREAT LAKES WATER QUALITY

Mr. J.R. Hickman (Chairman)
Director, Bureau of Chemical Hazards
Health and Welfare Canada
Environmental Health Centre
Ottawa, Ontario

Dr. G.C. Becking, Chief
(Acting Chairman, Effective June 1980)
Environmental Toxicology Division
Dept. of National Health and Welfare
Environmental Health Centre
Ottawa, Ontario

Dr. G. Berg, Chief (Until March 1981)
Biological Methods Branch
Environmental Monitoring & Support Lab
U.S. Environmental Protection Agency
National Environmental Research Center
Cincinnati, Ohio

Dr. R.W. Durham (Until March 1981)
Applied Research Division
Canada Center for Inland Waters
Dept. of Fisheries and Environment
Burlington, Ontario

Dr. H.L. Falk
Associate Director for Health
Hazard Assessment
N.I.E.H.S.
Research Triangle Park, N.C.

Dr. N. Chernoff
Health Effects Research Lab
U.S. Environmental Protection Agency
Research Triangle Park, N.C.

Dr. James H. Day
Department of Medicine
Queen's University
Kingston, Ontario

Dr. Robert F. Spengler (Eff. March 1981)
Assistant Head
Division of Epidemiology & Statistics
The Ontario Cancer Treatment and
Research Foundation
Toronto, Ontario

Dr. A.P. Gilman (Eff. March 1981)
Toxicologist
Environmental Health Directorate
Dept. of Health & Welfare
Ottawa, Ontario

Dr. Daniel E. Williams (Eff. March 1981)
Medical Consultant
Division of Environmental Epidemiology
Bureau of Disease Control & Lab Service
Michigan Dept. of Public Health
Lansing, Michigan
ASSESSMENT OF HUMAN HEALTH EFFECTS OF GREAT LAKES WATER QUALITY

(Continued)

Dr. S.I. Shibko, Chief (Eff. March 1981)
Contaminants & Natural Toxicants
Evaluation Branch
Division of Toxicology
Food & Drug Administration
Dept. of Human Health Services
Washington, D.C.

Observers
Mr. Joseph Prince
Technical Support Section
U.S. Environmental Protection Agency
Region V, Water Division
Chicago, Illinois

Mr. Vacys Saulys, Acting Chief
Remedial Programs Staff
Great Lakes National Program Office
U.S. Environmental Protection Agency
Chicago, Illinois

SAB Liaison Members
Medical Director
Hooker Chemical
Niagara Falls, New York

Environmental Epidemiologist
State of Michigan
Dept. of Public Health
Lansing, Michigan

Secretariat Responsibilities
Dr. A.E.P. Watson
Research Scientist
Great Lakes Regional Office
International Joint Commission
Windsor, Ontario

TERMS OF REFERENCE
for the
JOINT SCIENCE ADVISORY BOARD/WATER QUALITY BORD
IJC COMMITTEE ON THE ASSESSMENT OF HUMAN HEALTH EFFECTS
OF GREAT LAKES WATER QUALITY

The Committee will take the following under its purview:

1. assess the risk to health posed by contaminants in the Great Lakes ecosystem;

2. review action levels and guidelines for selected substances;

3. provide to the International Joint Commission through its Boards, interpretation and consultation on health matters; and

4. maintain awareness of current advances and knowledge as they relate to human health aspects of the Great Lakes ecosystem.