

**THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA**

**Report by - WAYNE CLAPTON - 2001 Churchill Fellow**

**THE BOB AND JUNE PRICKETT WINSTON CHURCHILL FELLOWSHIP**

**TO STUDY APPLIED PUBLIC HEALTH PRACTICE CANCER EPIDEMIOLOGY, STATISTICS  
AND REGISTRATION SYSTEMS IN MAJOR WORLD CENTRES OF EXCELLENCE - CANADA,  
UNITED STATES OF AMERICA, UNITED KINGDOM, FRANCE, GERMANY**

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## ACKNOWLEDGEMENTS

Firstly and most importantly, I would like to thank sincerely Mr “Dusty Bob” Prickett for the privilege of being awarded the 2001 Bob and June Prickett Winston Churchill Fellowship - aimed at benefiting the health of Australians. I was the tenth recipient of this fellowship and it was an honour to have it bestowed upon me.

Mr Prickett, himself a 1967 Churchill fellow who studied the essential public health function of sanitary engineering in USA, has been most generous to the Churchill Trust in general. All of its recipients, like me I'm sure, are truly grateful. Besides the financial support via the Trust to undertake this fellowship, “Dusty Bob” also provided me with advice about how to organise it before, during and after the fellowship. For this, I am very grateful. I'm sure other recipients have had the benefit of his advice and experience as well.

It may not be widely known that Mr Prickett also supports the community in other ways. For example, he is active with the Anti-Cancer Council of Queensland in their support and educational programs.

It was a considerable pleasure to have Mr Prickett visit and stay with us in Adelaide for the fellowship awards in August 2000. The only unfortunate aspect was that we did not have the opportunity to meet Mrs June Prickett, who, sadly, died from cancer in 1992. We have kept in touch with Dusty Bob by telephone and letter intermittently and I hope that this will continue. In particular, we look forward to hearing of the results of the application of his considerable skills in marble sculpting – the source of the name “Dusty”.

I would also like to thank sincerely all of the people who gave so freely of their time in having me visit them during my fellowship. Everybody was very busy in his or her own work. So I was very grateful that they gave me their time so generously and so graciously and looked after me so well during the time of my visit with them.

My sincere thanks also to all those associated with the Winston Churchill Memorial Trust (National Office, State Office, Winston Churchill Association, all of the various committee members and others) who work so hard and effectively to ensure that the program continues to be an overwhelming success and that all runs smoothly for the recipients – as it did for me.

Thanks also to my colleagues in Adelaide who had to pick up my work whilst I was away. Relief workers are not forthcoming in our area. Despite the imposition of extra work, everybody was pleased for me and totally supportive of my being away on this fellowship – in particular, Dr Colin Luke. I hope that what I have learnt will be helpful in making the work easier and more efficient for all of us now and in the future.

Finally, I would like to thank my wife Kay for her patience and support and for taking leave from her very busy job to accompany me during the fellowship. It would have been a lonely and far less enjoyable time without her.

## INTRODUCTION

This fellowship was undertaken over 11 weeks from the 24<sup>th</sup> February 2001 to 12<sup>th</sup> May 2001 in five countries (Canada, United States of America, United Kingdom, France and Germany). More than 160 people were seen formally in/from over 20 institutions and a substantial number of additional people were seen informally.

In this report, I have not attempted to describe in detail the nature of institutions visited, fine details of their work or the people in them, or detailed descriptions of reports or other outputs from their activities. To assist the reader to find these details, I have prepared a comprehensive list of places visited, contact persons at each place and contact details for most of the people seen. In addition, I have provided Internet website addresses for each institution and for some other important reference materials. This somewhat lengthy list can be found in the appendix. Readers are encouraged to refer to this for the background material and details of places in which they are interested.

The direction of this report is to discuss some important issues of relevance to cancer epidemiology and cancer registration systems by drawing upon aspects of those issues as seen in the institutions visited and the lessons learnt whilst visiting them. Unfortunately, a complete coverage is not possible and some issues of potential interest to the reader may be missed. However, by the distillation of the selected issues in an integrated fashion, it is hoped that some useful recommendations can be derived for cancer registration in Australia and thus benefit the health of Australians. Hopefully the reader will find this a useful approach.

Before starting, the reader who is new to this area may benefit from a couple of brief, simple definitions of terminology used in this report. As everyone will know, cancer is an uncontrolled growth of abnormal cells in the body. If allowed to progress, this may cause severe illness and may cause the death of the person affected.

Cancer is a major health problem in the Australian community. In 2001, the South Australian Cancer Registry reported that there were 7,536 new cases of cancer diagnosed and 3,158 deaths due to cancer in South Australia in 2000. These figures have increased since 1999. While there have been some encouraging trends in terms of reductions in female breast cancer mortality and in the incidence of male lung cancer and in melanomas due to the benefits of screening and other prevention programs, as well as improvements in treatment, the overall rates for cancer incidence and mortality continue to rise. Furthermore, for the most part, unfortunately, the causes of cancer are unknown.

Epidemiology is the study of the distribution and determinants of disease in the population. It is closely aligned with statistics. It is more concerned with how disease occurs in groups of people rather than in individuals. However, of course, groups are made up of individuals.

There are both descriptive and analytical forms of epidemiology. Descriptive epidemiology provides a picture of the burden of disease in the population over place and time and perhaps of associations between/among various aspects of that disease. Analytical epidemiology attempts to define causal pathways and associations between the disease and potential underlying causal factors. If preventable causes can be identified, action can be taken to prevent the disease occurring in the first place.

Applied public health practice is concerned with identifying the nature and extent of health problems in the community and in implementing public health programs to prevent and/or control the disease. Close collaboration should occur between applied public health practice and academic public health

practice, where workers teach students and perform research to discover and define the knowledge and evidence which can be applied to address health problems in the community. Ideally, all of this should be done in close association with colleagues in clinical healthcare, who assist and treat individual people unfortunate enough to have contracted a disease, and with health service planners, who aim to provide the most appropriate and efficient distribution of health services in the community.

A cancer registry is an important tool of descriptive epidemiology and applied public health practice. An analogy would be a census. The cancer registry collects data on all cases of cancer in the community and thus is able to provide the most accurate statistics on the burden of cancer in the community, how it is distributed in the community, and how this changes over time. Without these data, nobody would have any idea about the size of the problem, or what has happened subsequent to the introduction of prevention, control or treatment programs.

Just to complete the picture, there have been two basic forms of cancer registry up to now. The most common in the Australian situation is the population-based cancer registry. Data are collected for all people with cancer in each state. Usually, only minimal information is collected in this situation. Descriptive epidemiological information on incidence, mortality and survival is derived for the whole population. The figures produced are representative for that whole population and are used by applied public health practitioners, researchers, clinicians, health service planners, educators, students and other interested people.

Hospital-based, or clinical, cancer registries have been in operation in South Australia for some 10 years or more, though they are developing in some other States more recently. More detailed clinical and prognostic information is collected in this situation. The intention is to describe the burden of cancer in that hospital population, monitor the treatments performed, and assess the effects of the treatment interventions on patient outcomes. Whilst valid for that institution, the figures produced are not representative for the population as a whole. However, they can serve as very useful quality assurance tools for the clinicians treating people in that institution, and can provide the key for hypothesis generation and subsequent research projects.

## EXECUTIVE SUMMARY

### WINSTON CHURCHILL FELLOW DETAILS AND PROJECT DESCRIPTION:

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My Bob and June Prickett Winston Churchill Fellowship was used to study applied public health practice cancer epidemiology, statistics and registration systems in major world centres of excellence in Canada, United States of America, United Kingdom, France and Germany. This involved visiting institutions concerned with cancer epidemiology and cancer registration in Vancouver, Springfield, Chicago, Bethesda, Atlanta, London, Sheffield, Oxford, Lyon, and Mainz. At each place, it was usually the case that the people there had arranged for me to speak with a variety of people involved in various aspects of the work of their centre. In addition, I completed a short course in cancer epidemiology at the London School of Hygiene and Tropical Medicine. Over 160 people were interviewed formally in/from over about 20 institutions and there were many opportunities to interact informally with a significant number of other people during the course of the trip. No particular place(s) stands out as the highlight(s) of the trip. All places were good, all people were very helpful, and different lessons were learnt from each place and from the different people in each.

### MAJOR LESSONS, CONCLUSIONS and PLANS FOR DISSEMINATION

Cancer registries are an essential component of an informed, intelligent, responsive health system. They must exist and be resourced properly. However, for a cancer registry to operate effectively and efficiently (or to operate at all), there must be clear and strong legislative underpinning. This should require the secure collection and storage of this important public health information from specified notifiers and authorise the secure exchange and analysis of identified information among legally authorised and protected individuals and institutions. Without this, there is a significant risk that incomplete and inaccurate data will be collected, or people and institutions will refuse to notify the registry because they are not legally protected. The consequence is that the information derived from the registry most likely will be inaccurate and misleading. If so, the value of the registry is debatable. People whose information is recorded on the registry should have the right to know it is there and be able to view it, with properly qualified assistance (preferably their own doctor), so that any inaccurate information can be corrected – for the benefit of the person and the registry. Perhaps properly compensated medical practitioners should be required to notify. Registry operations should move towards more electronic forms of data capture from a variety of sources. There should be more real-time electronic processing, rather than the paper-based, manual batch processes, which have been the norm. Ideally, cancer registration should be integrated within a broad electronic health information system, which covers all aspects of disease prevention, health protection and healthcare in the community. However, for the foreseeable future, cancer registration needs to remain a separate specialised epidemiological operation, because it requires levels of ascertainment of cases and accuracy of case definitions and specific cancer coding far in excess of the levels achieved currently in most clinical and administrative information systems. Most of the problems of individual identification and duplication of records would be overcome with an Australian universal unique personal health identification number. This would greatly improve healthcare quality. It should be introduced as soon as possible, obviously with high levels of protection of individual confidentiality and privacy. Whilst some very good computer data processing systems were seen, it is my judgment that no particular complete system is transferable directly to Australia without significant modifications to cater for local infrastructure differences. It is essential that the Cancer Registry must put out accurate, useful, information early and regularly so that it is available for timely use in practice, research and planning; and de-identified data should be available on the Internet for users to analyse themselves.

In varying combinations, the opinions expressed above already have been disseminated to the Australian Cancer Strategies group, the National Health and Medical Research Council Ethics Group concerned with implementing guidelines for the impending National Privacy Principles legislation, the Australasian Faculty of Public Health Medicine, and individuals in a number of other Australian Cancer registries via the Australasian Association of Cancer Registries network. Locally, I have put these views to managers and colleagues involved in public health, epidemiology and information systems for day-to-day work improvements and for implementation in a (hoped-for) redevelopment of the South Australian Cancer Registry.

## OUTLINE OF PROGRAM

A comprehensive detailed description of the program undertaken can be found in the appendix. The reader is referred to that for full details of dates, places, contact people, and people seen at each place, including their contact details for the most part. Internet website addresses are provided for each institution visited so that the reader can pursue any interests they may have in that particular place to the level of breadth and depth that they personally desire.

The following is a skeleton outline of my Fellowship over the period 24th February 2001 to the 12th May 2001:

### CANADA

#### Vancouver

- British Columbia Cancer Agency
- Canadian Cancer Society (BC and Yukon division)

### UNITED STATES OF AMERICA

#### Springfield, Illinois

- Illinois state cancer registry
- National American Association of Central Cancer Registries (NAACCR)

#### Chicago, Illinois

- National Cancer Data Base (NCDB) Division (Commission on Cancer, American College of Surgeons,)

#### Bethesda, Maryland

- Surveillance Epidemiology and End Results (SEER) program - National Cancer Institute

#### Atlanta, Georgia

- Georgia State Cancer Registry and the Georgia Centre for Cancer Statistics (GCCS), Emory University
- Division of Cancer Prevention and Control, (including the National Program of Cancer Registries (NPCR)), Centers for Disease Control
- American Cancer Society, National Home Office

### UNITED KINGDOM

#### London

- London School of Hygiene and Tropical Medicine (completed the short course "Current concepts in cancer epidemiology" and met with some people at the school)
- Thames Cancer Registry
- National Cancer Registration Bureau, Demography and Health Division, Office for National Statistics
- Telephone discussion with UK National Cancer Director (Professor Mike Richards)
- National Office, United Kingdom Faculty of Public Health Medicine
- Camden and Islington Public Health Unit
- NHS Executive Headquarters, Department of Health

### **Fareham (Titchfield, near Southampton)**

- National Cancer Registration Office
- Office of Registration of Births, Deaths and Marriages

### **Sheffield**

- Trent Cancer Registry

### **Oxford**

- Oxford Institute of Health Sciences
  - Oxford Cancer Intelligence Unit
  - Unit of Health Care Epidemiology
  - Public Health Resource Unit

## **FRANCE**

### **Lyon**

- International Agency for Research on Cancer (IARC)
  - Unit of Descriptive Epidemiology
  - Unit of Epidemiology for Cancer Prevention
  - Unit of Chemoprevention
  - Unit of Carcinogen Identification and Evaluation

## **GERMANY**

### **Mainz**

- Cancer Registry of Rhineland-Palatinate
- German Childhood Cancer Registry
- Institute for Medical Statistics and Documentation (IMSD)



## MAIN BODY OF REPORT

### ISSUES FOR CONSIDERATION – CANCER REGISTRATION

#### Legislation

Good legislative underpinning is one of the most important factors which will enable a cancer registry system to operate. This was seen to be present in most places visited and the reader is referred to the websites for specific information on these matters. The Australian system is supported by respective State legislation which requires notification of all cases of cancer to that state cancer registry and authorises the exchange of information among people assisting the registry with its operations.

There are differences elsewhere around the world, however. For example, the United Kingdom has not had specific cancer registry legislation in place until the introduction of the Health and Social Services Bill to Parliament in 2000/2001. Up until then, there had been an administrative arrangement. Unfortunately, the introduction of the Bill occurred at a time when there was general public concern about the practice of healthcare in general, and privacy and confidentiality issues in particular. Therefore the Bill, with its amendment to enable the Cancer Registries to collect identified information, was having significant problems getting through Parliament. The impending presence of a general election complicated the situation further.

Furthermore, the British General Medical Council announced that they would take very seriously any complaints by members of the public about the “unauthorised” exchange of personal health information. Worried about the possibility of litigation, some hospitals and other notifying institutions decided not to notify cancer registries until the matter was resolved. Obviously, this was a significant impediment to the operation of Cancer registries in Britain. Apparently, the public health community had been warning various governments about the need for legislation for many years. At the time as report, I am not sure that the matter has been resolved.

Legislation is not necessarily such an issue if identified information is not collected by the central repository. For example, places like IARC and the NCDB collect de-identified information from their sources and so the requirement for legislation is not necessarily a significant consideration in the performance of their work. However, ethical and moral considerations persist.

The legislation underpinning the German Cancer Registry of Rhineland-Palatinate is of particular interest. It specifically prohibits the collection of identified information. Furthermore, the person’s medical practitioner is required to seek informed consent before any information is transmitted to the cancer registry and to inform every patient whose information has been transmitted. All patients have the right to decline to have their information recorded and/or to opt off the registry. No information is recorded on the registry until there is certification that informed consent has been obtained.

#### Privacy and Confidentiality

Privacy and confidentiality issues are major concerns for all Cancer Registries and are taken very seriously by all. It is precisely these sorts of issues that are at the root the British problem described above. Privacy and confidentiality legislation is becoming more widespread. For example, the impending National Privacy Principles will impose stringent requirements for privacy and confidentiality in the Australian private sector.

No one takes privacy and confidentiality issues more seriously than the German Cancer Registry. Throughout Germany, the excesses of invasion of personal privacy and confidentiality as practised by previous Nazi Fascist governments are still keenly remembered. The organisational arrangements for the registry require that the notification office is separate from the registration office. They are housed in completely separate buildings. Only the notification office has access to patient names for a very short period of some six to eight weeks while any problems of details of accuracy of the notification are resolved. Subsequently, all names are removed permanently from the files.

However before this is done, a complex computer algorithm creates an identification key for each patient based on the information present. For further protection, this is an encrypted. This identification key is then used to match with the files in the registration office, either to update existing files with new information or to create new records.

From a technical viewpoint, this de-identified encrypted matching has been shown to be reasonably accurate. However the people in the German Cancer Registry all feel that identified information would be easier to work with and more reliable.

A major concern for the German registry is that it has a serious ascertainment problem. They estimate that overall they capture only about 70 percent of all possible cases. Obviously, they are very concerned about this and feel that this is due to a combination of doctors not reporting cases (even though they are obliged to do so) and/or patients declining to be registered or opting off. The registry is instituting educational and other program addressed at trying to overcome these problems.

It is instructive to make a quick comparison with the German Childhood Cancer Registry. Here, the parents of children with cancer, their doctors and other carers want the system of data collection and support it wholeheartedly. There is a close connection between the registry and the treating oncology clinics. Parents must consent to their child's information being recorded on the cancer registry; however it is virtually unknown for consent to be withheld. As a result, the ascertainment level of cases on the registry is close to 100 percent with very valid, very representative and useful information and research studies available from this registry.

As a general comment, essentially, society has to make a decision as to whether to have good health information, where there may be some small compromise of privacy and confidentiality in a global sense; or whether privacy and confidentiality is to be protected at all costs. The German people have decided that the latter is the more appropriate way to go; but it can be seen that some costs are borne in terms of the quality of data obtained under such a system.

With stringent legislative controls and good systems of security in place for the protection and control of access to and dissemination of data, and with provisions for people to access and review their own data, it is possible to maintain the highest levels of protection of privacy and confidentiality and provide a high quality and useful health information system for the benefit of all. Without good information, the health system will fail.

## **Outputs**

All Cancer registries produce an annual report and/or other outputs, such as interim reports and newsletters on interesting results. Of course, major publications from places like IARC appropriately only come out every few years -- for example the "Cancer Incidence in Five Continents" series.

There was considerable variation in the frequency of reporting and the currency of the information reported. Until recently, some of the British Cancer registries had not reported for many years and what was reported was far from current. For example, provisional registration figures for new cancers for 1992 were not published until August 1997 and confirmed registrations for 1991 were not published until December 1997.

With the development in the UK of the NHS Cancer plan, (funded to the tune of about 200-500 million pounds per year for the first three years!), population-based Cancer registries are considered to be essential to its implementation and for the monitoring of its progress. However it was found that Cancer registration in England was unable to meet adequately the demands of the National Cancer Agenda. A thorough review of Cancer registration, the Gillis review, was commissioned in April 1999 and the report completed in April 2000. The web site <http://www.doh.gov.uk/cancer> contains this report, the NHS Cancer Plan, the "Action Programme" (see below) and other reports relating to cancer in the UK.

The Gillis Review report formed the basis for an "Action Programme for Cancer Registration" which was released in April 2001, coincidentally, while I was in London. The government had agreed that the current arrangements for Cancer registration in England were no longer sufficient to support the National Cancer Program. However it was recognised that Cancer registries should remain the cornerstone for data collection and analysis in supporting the implementation of the NHS Cancer Plan and the wider public health agenda for Cancer. A new approach and priority for Cancer registration was regarded as being essential. The action programme specified a more streamlined approach to data acquisition, including the introduction of more efficient electronic data collection methods, better accountability and better coordination of Cancer registration throughout Britain. A total of 2 million pounds, in addition to existing funding, was to be provided to implement the action plans. The Cancer registries and/or provider trusts (hospitals) will be able to bid for parcels of these funds to implement changes.

In the USA, calls for data from the peripheral registries and/or other data suppliers usually are at 12 to 18 months after the close of year. So places like SEER or NCDB or NAACCR may be reporting data which might be a one to two years or more behind the year of publication. This is in contrast to South Australia, where a year's data (e.g., 1999) has been published within about eight months of the following year (ie, in 2000). Obviously USA is a much bigger country than Australia, and they do collect more data items than we do. However they were impressed by the timeliness of the Australian data.

Most places produce pre-analysed information on paper and electronic versions of their Annual Report and other outputs. The electronic outputs may be found on the Internet on other media, such as CD-ROM's.

A number of places make their de-identified data available for people to investigate independently of the pre-prepared reports. SEER makes their data available in de-identified form on CD-ROM. Investigators can look at the IARC data on the Internet or in stand-alone mode on CD-ROM, via their "GLOBOCAN" software. Members of the European Network of Cancer Registries (ENCR) are able to view standard data sets which are accumulations of their contributions to the database at IARC. A new development, the "Eurocim" software, enables them to do quite sophisticated analyses on the data, via the Internet.

Generally, interactive access to Cancer Registry data is missing in Australia. It is a facility which Australian cancer registries should consider implementing as soon as possible. Preferably, access should be via the Internet, as most likely this will be the least costly way of doing it. Enabling

remote access by users to de-identified data is one way of ensuring that they get the information they require out of the Cancer registry data.

Increasingly, users want to be involved in specifying the outputs from and even the inputs to the Cancer registry and in making the registry accountable for delivering the information they require. The UK reports mentioned above does just this. Similarly, there have been reports in North America along similar lines. For example, the National Cancer Policy Board of the Institute of Medicine et al report entitled "Enhancing data systems to improve the quality of cancer care", published in 2000, addresses similar issues. (The full text of this report can be found at the Internet web site address <http://www.nap.edu/books/0309071917/html/> , which is part of <http://www.nap.edu/catalog/9970.html> , which is part of: <http://www.nap.edu> )

To me, this suggests that Cancer registries need to be far more proactive in their interactions with users to ensure they are delivering what is required in addition to the usual basic annual incidence, mortality and survival figures.

### Types of Data Items Collected

While the usual demographics, site, morphology and dates of diagnosis and death were present, there tended to be more data items collected than is the case in the Australian population based Cancer registries, though there are some similarities with the data collected in hospital-based registries in Australia.

In North America, in particular, places like SEER, NCDB and the NPCR collect further information on stage and treatments given. A comparison of the data required to be collected by these three systems can be found at the Internet web site

<http://www.nap.edu/books/0309071917/html/>

<http://books.nap.edu/books/0309071917/html/148.html#pagetop>

[http://bob.nap.edu/html/enhancing\\_data\\_systems/](http://bob.nap.edu/html/enhancing_data_systems/)

(PDF)

[http://books.nap.edu/html/enhancing\\_data\\_systems/appe.pdf](http://books.nap.edu/html/enhancing_data_systems/appe.pdf)

(PDF format)

It can be noted that the NCDB in particular collects a large amount of information, which is considered necessary as they are monitoring clinical performance and outcomes. The Commission on Cancer of the American College of Surgeons uses these data to accredit hospitals for cancer care.

Considerably more data are being considered in the UK. For example, a proposed National Cancer Minimum Data set had 144 items in the basic section and some 55 other items in cancer specific sections. (See: <http://www.nhsia.nhs.uk/cancer/dataset/pages/cancerdataset.asp?om=m4> for the latest version) It was not entirely clear to me just how many of these data items the cancer registry would need to collect and how many would be part of a wider cancer health information system as part of the National Cancer Information Strategy (<http://www.doh.gov.uk/cancer/cis.htm> and <http://www.doh.gov.uk/cancer/index.htm> )

My comment to Professor Mike Richards, the National Cancer Director, was that there were significant system impediments against collecting the mass of data which was being proposed and that this would be a significant barrier to reporting timely information. His response was that they were planning to re-engineer a number of components and processes of the health system in general to improve performance and to make it easier for the required data to be collected.

Irrespective of the system available, however, there is a cost in collecting a large amount of information in terms of time, effort and money. It could be argued that the success of the timeliness of the Australian Cancer registries' reporting of data is due to the fact that a minimal set is collected. The more data items collected, the longer it takes to collect them and ensure their accuracy and validity. Analysis and reporting of the data then is slowed in a corresponding manner. Perhaps detail is more appropriately collected in a hospital-based registry situation, with the population-based registry only looking at the big picture epidemiological items?

### **Data Capture Methodologies**

There was some variation in the sources of data and the way they were captured. Some places derived their notifications from both medical records departments and pathology laboratories (as is generally the case in Australia). Others only obtained information from one of these sources. For example, it is only recently that the Trent Cancer registry started to get pathology reports as well as hospital notifications.

It was interesting to note that there were variations in the way that the data were accessed. It was more the case in USA than elsewhere that there were tumour registrars placed in hospitals where they extract the information required from the hospital files and complete data forms for submission to the central registry. Often, these people are part of a hospital-based registry located within the hospital. However, the Thames Cancer Registry also had their people out in hospitals extracting data and completing forms for submission to the registry. The tumour registrars extract the data and might often code it on the spot.

This approach is different from that seen in other registries (including Australia) where raw data such as completed notification forms from hospital medical records departments and/or complete pathology reports are sent directly to the registry for interpretation, collation and coding.

The German Cancer registry was interesting in that they derived notifications from medical practitioners, who are required to report Cancer cases to the Cancer registry, and who are paid a consultation fee at the level they might receive for completing a brief medical report. In Australia, medical practitioners voluntarily assisted the Cancer registries with their enquiries, but to date, are not required to notify cases and are not paid for their involvement.

Systems of health care delivery are changing rapidly. There is a move towards more outpatient care and the organisation of diagnostic services (e.g., imaging and pathology) is becoming more amalgamated and centralised, compared with how they have been in the past. In this environment, I believe that medical practitioners will become a most important resource for the capture of primary Cancer Registry data in the future. In conjunction with hospitals, they are the most likely to have all of the patients' information from various sources in one place. With increasing development of electronic health records, it may be somewhat easier to capture these data from the medical practitioners files than previously. Of course, this will require substantial changes in legislation and the privacy and confidentiality aspects will need to be addressed comprehensively. Another important aspect is that the medical practitioners will need to be paid for their services, as is the case for other work they do.

## **Data Entry, Data Coding and Data Processing Methodologies**

Different ways of doing this were observed. For example, places like SEER, NCDB, NPCR and IARC collect higher-level data from their sources. As such, the data received are usually batches of data already entered at the source. Exhaustive edit checks are then run in batch mode to ensure that the data are accurate and valid, with feedback sent to the registries about errors detected. In most cases, the edit check program is provided to the registries so they can perform checks before they submit the data. This prevents an endless cycle of error detection and correction.

At source registries, data might be entered either via keypunching (with inbuilt error detection software) or via a scanning system which transforms the paper form into an electronic image. In a number of cases, the scanner would extract the data from the form as data, which then could be manipulated electronically as individual data items. Quite good scanning systems were seen at the BC Cancer agency, Illinois State Cancer Registry, and the Thames Cancer registry.

Specialised cancer coding either was performed at the source hospital by the tumour registrars, or at the central registry by Cancer Registry Officers trained in cancer coding. Trials of automated coding by computer interpretation of text have been performed at the Trent Cancer Registry. For simple common items, such as "adenocarcinoma", recognition and accuracy have been quite good. For more complex and/or less common terms, this was not the case and human intervention was required. They did indicate, however, that new versions of this program were becoming more accurate and could identify a wider range of terms.

While most places were moving towards some form of electronic capture of data from their sources, there did not appear to be a great rush to have fully automatic updating of central registry files without some form of human intervention to ensure that the data were accurate.

It is well known in the cancer registry community that IARC produces their "CANREG" software to enable cancer registries, particularly in developing countries, to establish a cancer registry information system (data entry and editing, data storage and extraction, and simple analyses). Up to now this has been a DOS based program; but a Windows-based program was almost complete when I was there, and a networked form of this system was being planned. Whilst very useful for a single user system in developing countries, there are limitations of this software for the more complex networked and interfacing systems of the developed world.

### **Data Coding Systems changes**

The ICD-O-2 coding scheme was used widely. In USA, it was planned to introduce ICD-O-3 coding on the 1<sup>st</sup> January 2001. Just before I left the USA at the end of March, I heard that there had been some problems with this timetable and a delay was being considered. In the UK, plans are being made to introduce the coding scheme within the next year or two.

There were different ways in which coding system changes were handled. In some places, a new coding system led to a re-code of all historical data into the new coding scheme. Obviously, this requires a significant amount of effort and cost. In other places, the data were kept recorded in the same coding scheme as when the case was diagnosed. The date of diagnosis becomes the key to indicate the coding scheme in which that data item was coded and thus how it is recorded. For example, at Trent, and at the ONS National Cancer Registration Bureau in Titchfield, data from 1966 might be coded and recorded in ICD-8 form, in 1993 as ICD 9, in 1998 as ICD 10 and so on. Mappings between the codes are done when the data are extracted for analysis. This is not an easy process as there are not one-to-one mappings between the coding schemes. Often there may be one-to-many relationships.

The historic data recorded on Cancer registries are perhaps the greatest asset that they have. It is not the case that when a coding system change comes in, all past data can be forgotten. Evaluation of time trends is one of the most important ways that Cancer Registries can show the effects of preventive, control or treatment interventions in a population sense. Therefore it is vital to be able to maintain a sensible translation between the old and the new coding schemes.

This is a problem which always has been a difficult one for Cancer registries, despite the fact that a number of translation programs do exist. For example, IARC has a number of programs, which enable translation forwards and backwards between ICD-O-1 and ICD-O-2 and so on. Particular difficulties arise where the Cancer Registry may have developed some interpretation of the rules of a particular coding scheme to suit local conditions. This has been the case in South Australia. Therefore translation programs, which rely on the standard set of rules being in place, will not work effectively.

### **Data Storage**

All places used some form of computer database for data storage and manipulation, often using a relational database structure. I did not discuss fine technical details about these items during my visits; but rather talked about general organisational arrangements. There is insufficient space here to go into any details of the various systems. The reader is referred to the websites for contacts to the various institutions if they want technical details.

However, I would like to make a few brief points about the BC Cancer agency in Vancouver. It is interesting because the registry database is integrated within the clinical health information system. The BC Cancer agency provides all the radiotherapy treatment for British Columbia in one of its four centres throughout the province. A single networked computer system services all of the agency. The Cancer Registry may be notified of cases of cancer from around the province via pathology reports and so on. These data will be entered on the Cancer Registry part of the database. If the person is admitted for treatment, an electronic clinical record is created for that patient. The Cancer Registry information is collected as part of this process and therefore the clinical record is the Cancer Registry record which is part of the clinical record. That is, they are one in the same with the only difference being that the person who has been admitted will have far more information on their record than if they had just been notified to the registry. Obviously, this enables follow-up information to be more easily obtained. Of course, there are levels of authorisation within the system as to who has access to the full information or to just segments of it.

### **Data Enquiry / Data Extraction Methodologies**

It was interesting to note that there were more formal procedures for dealing with inquiries from external parties wanting analyses done or access to data. For example, at the Office for National Statistics, the application form was about 20 pages long and charges applied to the requestor. At the BC Cancer agency, there was a 13 page protocol for the investigation of Cancer clusters -- not an uncommon request in the South Australian Cancer Registry. These sort of procedures need to be made more formalised in South Australia.

As would be expected, data extraction methodologies in most places enabled analysts to extract only the specific variables in which they are interested directly from the database. These sort of facilities need to be implemented in South Australia, rather than having to take an extract of the whole file.

## **Data Linkages**

Linkages of the Cancer registry database with other official databases are required to follow-up on what has happened to people with Cancer. For example, it must be known whether people have died to enable mortality and survival statistics to be computed. In Australia, registries link with the National Death Index in Canberra.

Similar National Death Indices exist in North America and in Britain. The one in Britain is at Southport where all deaths are recorded. There is interaction with the National Cancer Registration Bureau at Titchfield so that all Cancer deaths are flagged. Registries are informed of those events for the people on their registry.

The facility for matching also exists in North America. However, there are significant charges associated with this. Therefore some registries, like the Illinois State Cancer registry may do intra-state death linkages; but they cannot afford to do national linkages because the cost is too high. Whilst I didn't explore this in any detail, perhaps the National Program of Cancer Registries may be helpful in this regard in the future?

## **Analyses methodologies**

A variety of the usual expected statistical packages were used; for example, SAS, Stata, SPSS and so on. Analyses varied from the usual simple descriptive statistics to more complex multivariate methods, as expected. It was interesting to see the provision of quite complex statistical tools available on the Internet at IARC for the European Network of Cancer Registry people to explore their accumulated data.

SEER also is in the business of constructing database and analytical software for the use of consumers of the SEER data; for example, SEER-Stat.

## **Quality assurance and quality control**

There was a significant emphasis on these aspects in all places visited. In North America, the National American Association of Central Cancer Registries (NAACCR) plays a big part in this regard. They specify stringent quality criteria for registries and data are only accepted for accumulated analyses if those criteria are met. They also have in place a process of certification and registries strive to achieve the highest level possible. Certificates are presented to those who achieve the required standards.

As another example, SEER ensures their data quality via strict contractual arrangements with the registries from which they get their source data. A significant amount of time and money is invested into ensuring that the highest standards are met. Auditors travel around registries and inspect that required processes and procedures are in place.

In Britain, the UK Association of Cancer Registries (UKACR) also is concerned with quality assurance issues, as is the Office of National Statistics.

In all places visited, there were good systems of documentation for all aspects of the operations. This is something which requires further attention in South Australia.



## **Physical and Electronic Data Security**

In all places, public access to buildings containing the Cancer Registries was prohibited, with locked doors and reception and/or security staff monitoring and intercepting who comes and goes. Electronic security was enabled by having computer servers in locked rooms and having various levels of passwords in place for access to the computer systems. In some cases, the Cancer Registry system was not connected to the outside world. That is, there was no Internet or e-mail access from the registry database system. The usual regular back-ups and remote storage facilities were in place.

## **Resources, Staffing and Organisation**

Nobody seemed to be over endowed with resources and most people said they could have done with more. SEER did have a rather large budget of some \$20-30 million per year, I believe; but even they said they were stretched in some ways. In all places, there were the expected range of people, including clerical staff, cancer registry officers, coders, administrators, information technologists, analysts, research staff, and directors and managers. Thus all seemed to have at least representatives of the various skills required to run a registry and there seemed to be good access to epidemiological and statistical advice.

Given the large populations covered in all places (eg, Thames covers 12 million people), and numbers of notifications received, it seemed to me that most places were under-resourced. This certainly is the case in all Australian registries, where work is done with very limited resources.

## **Training, Education and Staff Development**

Training and education is done very well in most places visited. NAACCR, SEER, NCDB, NPCR all provide and/or coordinate training programs. IARC also conducts very good courses in Cancer Registration for invited participants, often, but not entirely, from developing countries. The Georgia Center for Cancer Statistics at the Rollins School of Public Health at Emory University in Atlanta also provides a very good and comprehensive training programme for tumour registrars. Successful candidates obtain the qualification "Certified Tumour Registrar" or "CTR". Good training manuals and courses also are available in the UK.

Co-ordinated training programs are entirely absent in Australia. Individual registries either have some sort of training program or a rather ad hoc on the job process, usually conducted in a sort of apprenticeship fashion. After attending a course in Atlanta, one of the South Australian Cancer Registry Officers (Elaine Morton) has been trying to establish a national program via the Australasian Association of Cancer Registries (AACR). This is not in place as yet, though work is still being done in trying to establish this facility in Australia.

## **Hospital-based (Clinical) Cancer Registries**

These facilities are very prevalent in the United States. Hospitals wanting accreditation for cancer care from the American College of Surgeons are required to have in place a good quality Hospital-based Cancer Registry and to report when required to the NCDB of the College of surgeons, both

for routine data provision and special projects on particular aspects of cancer care. Along with the large number of hospital-based Cancer registries there are a number of cancer registry software houses, who write the computer systems for cancer registries. Some registries may have reporting requirements to the NCDB, SEER and the NPCR and so the systems have to be able to cope with these requirements by collecting and processing the different data items.

Hospital-based registries did not appear to be as prevalent in the United Kingdom, though they do exist. It will be interesting to observe whether the existing population-based registries become de facto hospital-based registries in terms of the markedly increased data collection requirements of the National Cancer plan.

### **“Corporate” Badge(ing)**

The term “Cancer Registry” is still widely spread throughout the world and is an accurate description of what is done. However, in Oxford, it is called the “Oxford Cancer Intelligence Unit”.

With increasing concerns about privacy and confidentiality and suspicions in general about data collections, perhaps Cancer Registries in general may need to reconsider the way they present themselves to the world? Perhaps the words “registry” and “surveillance” now invoke such negative feelings in the public that a new name might need to be considered for the Cancer Registry? Perhaps a name something like that used in Oxford might be appropriate, or “Cancer information and Statistics Service” or “Cancer Epidemiology Service” might be considered?

## **ACTIVITIES IN ADDITION TO CANCER REGISTRATION**

As can be seen from the summary program above and from the more detailed program in the appendix, I was fortunate to have the opportunity to explore some broader aspects of cancer epidemiology and public health in a number of places: - at the BC Cancer Agency in Vancouver, at the Division of Cancer Prevention and Control in the Centers for Disease Control in Atlanta, at the American Cancer Society in Atlanta, at the London School of Hygiene and Tropical Medicine in London, at the UK Faculty of Public Health Medicine in London, at the Institute of Health Sciences, including the Unit of Health-Care Epidemiology and the Public Health Resource Unit in Oxford, at the International Agency for Research on Cancer in Lyon, and at the Institute for Medical Statistics and Documentation in Mainz.

These activities broadened my experience of cancer epidemiology and public health in general and made it easier to see the relevance of cancer registration and how it fits into the overall picture. Reference to the “Details of Visits” in the appendix and scanning some of the Intranet websites will give the reader some appreciation of these institutions.

## MAIN LESSONS LEARNT AND CONCLUSIONS

It was interesting to discover that Australia does very well in cancer epidemiology and cancer registration with respect to:

- legislative infrastructure,
- organisational structures for capturing data,
- information collection timeliness,
- data completeness (high levels of ascertainment),
- data quality,
- timeliness and quality of annual reporting,
- applications of the cancer epidemiological information to public health practice and to supporting research and planning.

However there are areas of perceived deficiency in the following areas where overseas institutions are doing it better and where we might improve:

- computer systems functionality,
- quality assurance procedures,
- documentation,
- “marketing” of Cancer Registration,
- workflow and organisational arrangements,
- staffing,
- training,
- interim reporting, and
- making datasets available on the Internet to facilitate independent analyses by users.

## RECOMMENDATIONS

- Cancer registries are an essential component of an informed, intelligent, responsive health system. They must exist and be resourced properly.
- For a cancer registry to operate effectively and efficiently (or to operate at all), there must be clear and strong legislative underpinning.
- Legislation should require the secure collection and storage of this important public health information from specified notifiers and authorise the secure exchange and analysis of identified information among legally authorised and protected individuals and institutions.
- Without good legislation, there is a significant risk that incomplete and inaccurate data will be collected, or people and institutions will refuse to notify the registry because they are not legally protected.
- The consequence of sub-optimal ascertainment is that the information derived from the registry most likely will be inaccurate and misleading. If so, the value of the registry will be debatable.
- People whose information is recorded on the registry should have the right to know it is there and be able to view it, with properly qualified assistance (preferably their own doctor), so that any inaccurate information can be corrected – for the benefit of the person and the registry.
- Essentially, society has to make a decision as to whether they want to have good health information, where there may be some small compromise of privacy and confidentiality in a global sense; or whether privacy and confidentiality needs to be protected at all costs, most likely to the detriment of the health of the population and the of the individuals within it.
- With stringent controls under legislation and good systems of security in place for the protection and control of access to and dissemination of data, and with provisions for people to access and review their own data (under proper guidance from their own doctor, preferably), it is possible to maintain the highest levels of protection of privacy and confidentiality and still enable a high quality and useful health information system to be in place for the benefit of all. Without good information, the health system will fail.
- Registry operations should move towards more electronic forms of data capture from a variety of sources, perhaps adding required notification from some not currently included (such as medical practitioners, properly compensated for the notification).
- There should be more real-time electronic processing of data from sources, rather than paper-based, manual batch processes.
- Ideally, cancer registration should be integrated within a broad electronic health information system, which covers all aspects of disease prevention, health protection and healthcare in the community and it should be an important part of a well-considered and implemented cancer plan.
- However, for the foreseeable future, cancer registration needs to remain a separate specialised epidemiological operation, because it requires levels of ascertainment of cases

and accuracy of case definitions and specific cancer coding far in excess of the levels achieved currently in most clinical and administrative information systems.

- Most of the problems of identification of individuals and duplication of records would be overcome with an Australian universal unique personal health identification number. This would greatly improve healthcare quality and it should be introduced as soon as possible, obviously with high levels of protection of individual confidentiality and privacy.
- Whilst some very good computer data processing systems were seen in a number of places overseas, it is my judgment that no particular complete system is transferable directly to Australia without significant modifications to cater for local infrastructure differences.
- It is essential that the Cancer Registry must put out accurate, useful, information early and regularly so that it is available for timely use in practice, research and planning.
- De-identified datasets should be made available on the Internet to enable users to do their own analyses of the data.
- Finally, perhaps some attention should be given to whether the name "Cancer Registry" needs to be reconsidered. Perhaps the term "Cancer Information and Statistics Service" or "Cancer Epidemiology Service" might be more appealing?

## **DISSEMINATION AND IMPLEMENTING CHANGES**

In varying combinations, the opinions expressed above already have been disseminated to the following in terms of submissions, presentations, individual discussions, or group discussions:

- The Australian National Cancer Strategies group,
- The National Health and Medical Research Council Ethics Group - concerned with implementing guidelines for the impending National Privacy Principles legislation,
- The Australasian Faculty of Public Health Medicine, and
- Individuals in a number of other Australian Cancer registries via the Australasian Association of Cancer Registries network.
- Locally, these views have been put to managers and colleagues involved in public health, epidemiology and information systems for day-to-day work improvements and for implementation in a (hoped-for) redevelopment of the South Australian Cancer Registry.

In November 2001, I will be presenting a talk on my Winston Churchill Fellowship and my recommendations to the "Epidemiology Day" component of the "Clinical Oncological Society of Australia" (COSA) Conference in Brisbane. Also, in that same week, there will be the opportunity to discuss my findings in more detail with people face-to-face at the annual business meeting of the Australasian Association of Cancer Registries

I will continue to disseminate the findings, conclusions and recommendations from my Winston Churchill Fellowship in as many relevant forums as is possible. Opportunities for implementation are very fertile locally. We are at the early stages of planning for a complete redevelopment of the South Australian Cancer Registries systems. As I am heavily involved in that, I am in the position to put my views strongly and seek to have them implemented where appropriate.

**APPENDIX - DETAILS OF VISITS**

**DETAILS OF VISITS**

**ON THE**

**BOB AND JUNE PRICKETT WINSTON CHURCHILL FELLOWSHIP**

**TO STUDY APPLIED PUBLIC HEALTH PRACTICE CANCER EPIDEMIOLOGY, STATISTICS  
AND REGISTRATION SYSTEMS IN MAJOR WORLD CENTRES OF EXCELLENCE**

**BY**

**Dr WAYNE CLAPTON  
(B Comm, Dip Info Proc'g, MACS, BMBS, MPH, FAFPHM (RACP))  
(MEDICAL OFFICER (PUBLIC HEALTH PHYSICIAN))**

**OVER 11 WEEKS  
24<sup>th</sup> February 2001 to 12<sup>th</sup> May 2001**

**IN**

**FIVE COUNTRIES  
(CANADA, UNITED STATES OF AMERICA, UNITED KINGDOM, FRANCE, GERMANY)**

**WHERE**

**MORE THAN 160 PEOPLE WERE SEEN FORMALLY IN/FROM OVER 20 INSTITUTIONS**

**AND**

**A SUBSTANTIAL NUMBER OF ADDITIONAL PEOPLE WERE SEEN INFORMALLY  
(THOUGH NOT NECESSARILY LISTED HERE)**

**WEEK 1****VANCOUVER, CANADA****TUESDAY 27<sup>th</sup> FEBRUARY TO FRIDAY 2<sup>nd</sup> MARCH, 2001****VISITED:**

- British Columbia (BC) Cancer Agency and BC Cancer Registry  
Website: <http://www.bccancer.bc.ca/>
- Canadian Cancer Society (BC and Yukon Division)  
Website: <http://www.bc.cancer.ca>

**CONTACT:**

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 Scientific Director, BC Cancer Registry  
 Epidemiologist, Cancer Control Research Program  
 BC Cancer Agency  
 600 West 10th Avenue, Vancouver BC V5Z 4E6  
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 Email: [mmcbride@bccancer.bc.ca](mailto:mmcbride@bccancer.bc.ca)  
Website: <http://www.bccancer.bc.ca/>

**PEOPLE SEEN:**

- Ann Kelly, MPH, Director, Vancouver Information Centre, Cancer Information Service, Canadian Cancer Society (BC and Yukon Division),  
Website: <http://www.bc.cancer.ca>
- Dr Mary McBride
- Richard Doll, MSW, MSc, Provincial Leader, Cancer Rehabilitation and Behavioural Research, BC Cancer Agency
- Wendy Robb, Data Analyst -- Data and Evaluation Unit, Cancer Control and Strategy, BC Cancer Agency
- Donna Thomson, Supervisor Health Information, BC Cancer Agency
- Dr Susan O'Reilly, MB, FRCPC, Provincial Program Leader, Systemic Therapy and Chair, Division of Medical Oncology, BC Cancer agency
- Fran Caruth, Vice-President of Planning, BC Cancer Agency
- Dr T. Greg Hislop, Senior Epidemiologist, Cancer Control Research Program, BC Cancer Agency
- Chris Bajdik, Statistician, Cancer Control Research Program, BC Cancer Agency
- Don Henkelman, Provincial Information Technology Leader, BC Cancer Agency
- Keith Duncan, Programmer/Analyst, Information Systems, BC Cancer Agency
- Andrew J. Coldman, PhD, Provincial Cancer Control Strategy Leader, BC Cancer Agency
- Norm Phillips, Statistician, Cancer Control Strategy, BC Cancer Agency
- Cindy Brice, CCHRA(C), Regional Process Leader, Patient Information Management Services, BC Cancer Agency
- Mary-Anne Hiatt, Chief Health Record Administrator, BC Cancer Agency



- David Noble, BSc, BLS, Cancer Information Centre Leader, BC Cancer Agency
- Nhu D. Le, PhD, Research Scientist, Cancer Control Research Program, BC Cancer Agency
- Lisa Kan, Screening Program Evaluator, Cancer Control Strategy Program, BC Cancer Agency
- Emily Fowler, Secretary, Cancer Control Research Program, BC Cancer Agency
  
- Kimberlyn McGrail, Project Director, Centre for Health Services and Policy Research, University of British Columbia, (Health Link Study)  
Website: <http://www.chspr.ubc.ca>

**WEEK 2****SPRINGFIELD, ILLINOIS, USA****AFTERNOON, TUESDAY 6<sup>th</sup> MARCH AND AFTERNOON, WEDNESDAY 7<sup>th</sup> MARCH 2001****VISITED:**

- Illinois State Cancer Registry, Division of Epidemiologic Studies, Illinois Department of Public Health, Springfield, IL.  
Website(s): <http://www.idph.state.il.us/about/epi/index.htm>  
<http://www.idph.state.il.us/about/epi/cancer.htm>  
<http://www.idph.state.il.us/home.htm>

**CONTACTS:**

Dr Tiefu Shen MD PhD, Director,  
(also Division Chief, Division of Epidemiologic Studies)  
Ms Jan Snodgrass CTR, Manager,  
Lori Havener, Head of the Registry Operation Unit,  
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**PEOPLE SEEN:**

- Dr Tiefu Shen
- Ms Jan Snodgrass CTR, Manager,
- Lori Havener, Head of the Registry Operation Unit
- Larry Hebert, IT and Registry Operations
- Virginia Cook, Quality Assurance – Re-abstracting Study
- Pam Parrish, Auditing and Quality Assurance

**MORNING, WEDNESDAY 7<sup>th</sup> MARCH 2001****VISITED:**

- North American Association of Central Cancer Registries (NAACCR) Executive Office  
Website: <http://www.naacr.org>

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CHICAGO, ILLINOIS, USA

**THURSDAY 8<sup>TH</sup> MARCH AND FRIDAY 9<sup>TH</sup> MARCH, 2001**

VISITED:

- National Cancer Data Base, Commission on Cancer, American College of Surgeons  
Website(s): <http://www.facs.org/>  
<http://www.facs.org/dept/cancer/index.html>  
<http://www.facs.org/dept/cancer/ncdb/index.html>

CONTACT:

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Web site: <http://www.facs.org>

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Greg Wynn	202-5500	<a href="mailto:gwynn@facs.org">gwynn@facs.org</a>

IMPORTANT REPORT OBTAINED HERE:

- Hewitt, Maria and Simone, Joseph V. (eds), National Cancer Policy Board, Institute of Medicine and Commission on Life Sciences, National Research Council, "Enhancing Data Systems to Improve the Quality of Cancer Care" (National Academy Press, Washington DC, 2000) ISBN: 0-309-07191-7 Website for report full text:  
<http://www.nap.edu> (Home Page National Academy Press)  
<http://www.nap.edu/catalog/9970.html> (Direct to this book)  
[http://bob.nap.edu/html/enhancing\\_data\\_systems/](http://bob.nap.edu/html/enhancing_data_systems/) (PDF Format)

(Institute of Medicine Home Page: <http://www.iom.edu> )

**WEEK 3**

**WASHINGTON, DC / BETHESDA, MARYLAND, USA**

**TUESDAY 13<sup>th</sup> MARCH TO FRIDAY 16<sup>th</sup> MARCH, 2001**

**VISITED:**

- Surveillance Epidemiology and End Results (SEER) program at the National Cancer Institute, Bethesda, Maryland  
Website: <http://www.seer.cancer.gov>

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00001500

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Statistician  
[gs136m@nih.gov](mailto:gs136m@nih.gov)

(301) 402-5331

(301) 496-9949

**Elliott Ware**  
Medical Record Librarian  
[ew63a@nih.gov](mailto:ew63a@nih.gov)

(301) 496-8510

(301) 496-9949

[ALSO SEEN \(as he was visiting SEER at the time\):](#)

[Steven Roffers, PA, CTR, Clinical Instructor, Emory University,  
Rollins School of Public Health - GCCS](#)

**WEEK 4****ATLANTA, GEORGIA, USA****TUESDAY 20<sup>TH</sup> MARCH TO FRIDAY 23<sup>RD</sup> MARCH, 2001****VISITED:**

- Georgia State Cancer Registry and Georgia Center for Cancer Statistics, Emory University  
Website: <http://www.sph.emory.edu/GCCS/index.html>
- Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (including National Program of Cancer Registries)  
Websites: <http://www.cdc.gov/cancer/>  
<http://www.cdc.gov/cancer/npcr/index.htm>
- American Cancer Society, National Home Office  
Website: <http://www.cancer.org>

**CONTACTS:**

Drs John L.Young, DrPH, CTR  
Co-Director,  
Metropolitan Atlanta & Rural Georgia SEER Registry,  
Georgia Center for Cancer Statistics,  
Rollins School of Public Health of Emory University,  
1518 Clifton Road, N.E.,  
Atlanta, GA 30322 USA  
Phone: 404-727-8487  
E-mail: [jlyoung@sph.emory.edu](mailto:jlyoung@sph.emory.edu)

**Also:**

Jonathan M. Liff,  
Co-Director  
Phone: 404-727-8717  
[jliff@sph.emory.edu](mailto:jliff@sph.emory.edu)

Steven Roffers, PA, CTR  
Clinical Instructor  
Emory University  
Rollins School of Public Health - GCCS  
1462 Clifton Road, NE; Room 517  
Atlanta, Georgia 30322  
Phone: 404-727-4535  
Fax: 404-727-7261  
E-mail: [sroffer@sph.emory.edu](mailto:sroffer@sph.emory.edu)



## TUESDAY 20<sup>TH</sup> MARCH, 2001

### GEORGIA STATE CANCER REGISTRY AND GEORGIA CENTER FOR CANCER STATISTICS

Rollins School of Public Health of Emory University,  
1518 Clifton Road, N.E.,  
Atlanta, GA 30322 USA  
Website: <http://www.sph.emory.edu/GCCS/index.html>

#### PEOPLE SEEN:

- Jonathan M. Liff, Co-Director
- Drs John L.Young, DrPH, CTR Co-Director (seen 22<sup>nd</sup> March)
- Frances Michaud, BS, CTR Director of Registry Operations  
Ph: 404-727-4151 E-mail: [fmichau@sph.emory.edu](mailto:fmichau@sph.emory.edu)
- Kevin Ward, MPH Manager, Data Analysis and Quality Assurance  
Ph: 404-727-8455 E-mail: [kward@sph.emory.edu](mailto:kward@sph.emory.edu)
- Karen Ledford, RHIA, CTR Training Coordinator  
Ph: 404-727-8746 E-mail: [kledf01@sph.emory.edu](mailto:kledf01@sph.emory.edu)

## THURSDAY, 22<sup>ND</sup> MARCH, 2001

### CENTERS FOR DISEASE CONTROL, DIVISION OF CANCER PREVENTION AND CONTROL (DCPC), (Including National Program of Cancer Registries)

Koger Center, Davidson Building, Atlanta

Division of Cancer Prevention and Control  
National Center for Chronic Disease Prevention and Health Promotion  
Centers for Disease Control and Prevention  
4770 Buford Highway, NE, MS K-64  
Atlanta, GA 30341-3717  
Phone: (770) 488-4751 or Voice Information System (888) 842-6355  
Email: [cancerinfo@cdc.gov](mailto:cancerinfo@cdc.gov)  
Website: <http://www.cdc.gov/cancer/>

#### PEOPLE SEEN:

Mary Kaeser, MEd, Welcome and Introduction to DCPC  
Tom Richards, MD, MPH, Geographical Information Systems, DCPC  
Kathleen A. Carey, MS, Cancer Inquiry Specialist, DCPC  
Margaret Brome, MPH, National Breast and Cervical Cancer Early Detection Program

Corinne M. Graffunder, MPH	Chief, Section A, Comprehensive Cancer Control Program
Phyllis Wingo, PhD	Director, Cancer Surveillance Branch and NPCR
Louise Galaska, MPA	Deputy Director, DCPC
Kevin Brady, MPH	Associate Director, Office of Program and Policy Information
Nancy C. Lee, MD	Director, DCPC
Carol White, MPH	Cancer Surveillance Branch
Warren Williams, MPH	Cancer Surveillance Branch
Leah D. Simpson, MBA	Public Health Advisor, DCPC Cancer Surveillance Branch
Hannah Weir, PhD	Cancer Surveillance Branch
Phillip M. Talboy	Assistant Branch Chief, Cancer Surveillance Branch

**FRIDAY, MARCH 23, 2001**

VISITED:

Steven Roffers, PA, CTR  
Clinical Instructor  
Emory University  
Rollins School of Public Health - GCCS

VISITED:

AMERICAN CANCER SOCIETY,  
NATIONAL HOME OFFICE  
1599 Clifton Rd.  
Atlanta, GA 30329-4251  
Website: <http://www.cancer.org>

PEOPLE SEEN:

Michael F. Heron,	National Vice-President, Public Affairs Ph: (404) 329 7909 Fax: (404) 728 0133 e-mail: <a href="mailto:mheron@cancer.org">mheron@cancer.org</a>
Nathan Grey,	Director, Office of the Executive Officer Operations e-mail: <a href="mailto:ngrey@cancer.org">ngrey@cancer.org</a>
Ted Gansler, MD, MBA	Director, Health Content Ph: (404) 329 7690 Fax: (404) 325 2217 e-mail: <a href="mailto:tgansler@cancer.org">tgansler@cancer.org</a>
TJ Koerner, PhD, Tebbroek Smith	Director of Research Management Behavioural science research
Michael J. Thun, MD, MS	Vice-President, Epidemiology & Surveillance Research, Ph: (404) 329 5747 Fax: (404) 327 6450 e-mail: <a href="mailto:mthun@cancer.org">mthun@cancer.org</a>
Omar Shafey, MPH, PhD Derek Coombs,	Manager, International Tobacco and Surveillance Program, Research Analyst, International Tobacco and Surveillance Program

**WEEKS 5, 6 AND 7****LONDON, UK****WEEK 5****MONDAY 26<sup>TH</sup> MARCH TO FRIDAY 30<sup>TH</sup> MARCH, 2001****COMPLETED THE SHORT COURSE:  
"CURRENT CONCEPTS IN CANCER EPIDEMIOLOGY"**

at the:

London School of Hygiene & Tropical Medicine (LSHTM),  
Keppel Street, London WC1E 7HT, UK.

Tel: +44 (0)20 7636 8636

Telex: 8953474

Fax: +44(0)20 7436 5389

Website: <http://www.lshtm.ac.uk/>**CONTACTS:****Professor Michel P Coleman, BA BM BCh MSc MFPHM,**

Professor of Epidemiology and Vital Statistics

Head of Cancer and Public Health Unit

London School of Hygiene and Tropical Medicine,

Keppel Street, GB-London, WC1E 7HT

Tel +44 207 927 2478;

Fax +44 207 436 4230;

Email: [Michel.Coleman@lshtm.ac.uk](mailto:Michel.Coleman@lshtm.ac.uk)Cancer survival research: <http://www.cancer-public-health.net>

Cancer epidemiology course 26-30 March 2001:

<http://www.lshtm.ac.uk/eph/ecph/short.htm>

and

Deputy Chief Medical Statistician

Office for National Statistics,

1 Drummond Gate, GB-London SW1V 2QQ

Tel: +44 207 533 5256;

Fax +44 207 533 5103;

Email: [michel.coleman@ons.gov.uk](mailto:michel.coleman@ons.gov.uk)

Miss Kelly Lawless

PA to Professor Michel P Coleman

Cancer and Public Health Unit Administrator

Department of Epidemiology &amp; Population Health

London School of Hygiene &amp; Tropical Medicine

Keppel Street

London WC1E 7HT

Tel: +44 (0)20 7612 7849

Fax: +44 (0)20 7436 4230

email: [kelly.lawless@lshtm.ac.uk](mailto:kelly.lawless@lshtm.ac.uk)Web: <http://www.lshtm.ac.uk/eph/ecph/short.htm>

Mrs Navkirat Dhami  
Registry Assistant  
50 Bedford Square, London WC1B 3DP  
Tel: +44(0)20 7299 4648  
Fax: +44(0)20 7323 0638  
E-mail: [navkirat.dhami@lshtm.ac.uk](mailto:navkirat.dhami@lshtm.ac.uk)  
[shortcourses@lshtm.ac.uk](mailto:shortcourses@lshtm.ac.uk)

## CURRENT CONCEPTS IN CANCER EPIDEMIOLOGY 2001 COURSE PROGRAMME

(All lectures will be held in the Manson Lecture Theatre, LSHTM)

### MONDAY 26 MARCH 2001

9:00-10:00		Registration
10:00-10:30		Introduction, content of the course and logistics Michel Coleman
10:30-11:00		Coffee
11:00-12:30	<b>Session 1</b>	<b>Overview of cancer epidemiology</b> Michel Coleman
12:30-14:00		Lunch
14:00-15:00	<b>Session 2</b>	<b>Epidemiological study designs</b> Isabel dos Santos Silva
15:00-15:30		Tea
15:30-17:00	<b>Session 3</b>	<b>Practical session</b>
17:00-17:30		<b>Review session I</b>
18:00		Welcome reception and buffet to be held in Room 5

### TUESDAY 27 MARCH 2001

9:30-10:30	<b>Session 4</b>	<b>Measuring the occurrence of cancer and other health-related events</b> Craig Higgins
10:30-11:00		Photograph
11:00-12:30	<b>Session 5</b>	<b>Interpretation of data from epidemiological studies</b> Isabel dos Santos Silva and Bianca De Stavola
12:30-14:00		Lunch
14:00-15:30	<b>Session 6</b>	<b>Practical session</b>
15:30-16:00		Tea
16:00-17:00	<b>Session 7</b>	<b>Integrating biomarkers into epidemiological study design</b> Chris Wild, Molecular Epidemiology Unit, University of Leeds
17:00-17:30		<b>Review session II</b>

**WEDNESDAY 28 MARCH 2001**

9:30-10:30	<b>Session 8</b>	<b>Cancer risk assessment</b> Henrik Møller
10:30-11:00		Coffee
11:00-12:30	<b>Session 9</b>	<b>The role of chemoprevention in cancer control</b> Klim McPherson
12:30-14:00		Lunch
14:00-15:30	<b>Session 10</b>	<b>Practical session</b>
15:30-16:00		Tea
16:00-17:00	<b>Session 11</b>	<b>The rationale for cancer screening</b> Klim McPherson
17:00-17:30		<b>Review session III</b>

**THURSDAY 29 MARCH 2001**

9:30-10:30	<b>Session 12</b>	<b>Cancer in immunocompromised patients</b> Chris Boshoff, Imperial Cancer Research Fund, London
10:30-11:00		Coffee
11:00-12:30	<b>Session 13</b>	<b>Cancer genetics: basic principles</b> Olivia Fletcher
12:30-14:00		Lunch
14:00-15:00	<b>Session 14</b>	<b>Cancer care: evaluating survival at a population level</b> Michel Coleman
15:00-15:30		Tea
15:30-17:00	<b>Session 15</b>	<b>Life-course cancer epidemiology</b> Isabel dos Santos Silva and Bianca De Stavola
17:00-17:30		<b>Review session IV</b>

**FRIDAY 30 MARCH 2001**

<b>8:30-17:30</b>	<b>Genetic Epidemiology of Cancer workshop</b> (see attached programme)
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**GENETIC EPIDEMIOLOGY OF CANCER WORKSHOP**

**FRIDAY 30 MARCH**

**HELD IN THE MANSON LECTURE THEATRE, LSHTM**

**8:30-9:15 Registration and coffee**

**9:15-9:30 Introduction**

**Professor Julian Peto**

**Cancer and Public Health Unit, LSHTM and Institute of Cancer Research, Sutton**

**9:30-10:30 Session 16 The cancer genome project**

**Dr Richard Wooster**

**Sanger Centre, Cambridge**

**10:30-11:30 Session 17 Inherited susceptibility to colorectal cancer**

**Professor Richard Houlston**

**Institute of Cancer Research, London**

**11:30-12:00 Coffee**

**12:00-13:00 Session 18 High-risk genes associated with cancer predisposition**

**Professor Tim Bishop**

**ICRF Genetic Epidemiology Laboratory, University of Leeds**

**13:00-13:30 Discussion**

**13:30-14:30 Lunch in the Jessel Room, Senate House**

**14:30-15:30 Session 19 Prospects for finding new cancer genes**

**Dr Doug Easton**

**CRC Genetic Epidemiology Unit, Strangeways Research Laboratory, Cambridge**

**15:30-16:30 Session 20 Breast cancer genetics**

**Professor Julian Peto**

**Cancer and Public Health Unit, LSHTM and Institute of Cancer Research, Sutton**

**16:30 Close**

**WEEK 6**

**MONDAY 2<sup>ND</sup> APRIL, 2001**

**VISITED:**

Cancer and Public Health Unit, London School of Hygiene & Tropical Medicine

- Professor Michel Coleman, Head of Cancer and Public Health Unit and Deputy Chief Medical Director, Office for National Statistics
- Dr Olivia Fletcher, Lecturer, Cancer and Public Health Unit

**ALSO:**

- Professor Tony McMichael, Co-director of the Centre on Globalisation, Environmental Change & Health, LSHTM.

**TUESDAY 3<sup>RD</sup> APRIL AND WEDNESDAY 4<sup>TH</sup> APRIL 2001**

**VISITED:**

Thames Cancer Registry  
Capital House, 1st Floor  
42 Weston Street  
London, SE1 3QD  
United Kingdom  
Tel: +44 (0)20 7378 7688  
Fax: +44 (0)20 7378 9510  
E-mail: [information@thames-cancer-reg.org.uk](mailto:information@thames-cancer-reg.org.uk)  
[tcr@kcl.ac.uk](mailto:tcr@kcl.ac.uk)  
Internet: <http://www.thames-cancer-reg.org.au>

**CONTACTS:**

Professor Henrik Møller  
[Professor of Cancer Epidemiology](#)  
[Cancer and Public Health Unit, LSHTM and](#)  
Director of Research, Thames Cancer Registry  
Division of Oncology  
Guy's, King's and St Thomas' School of Medicine  
King's College London  
1st Floor, Capital House  
42 Weston Street  
London SE1 3QD  
Tel: +44 (0)20 7378 7688  
Fax: +44 (0)20 7378 9510  
Email: [henrik.moller@kcl.ac.uk](mailto:henrik.moller@kcl.ac.uk)



Ms Gaye Nigro, PA to Professor Møller,  
 Tel: +44 (0) 20 7378 7688.  
 Fax: +44 (0) 20 7378 9510  
[tcr@kcl.ac.uk](mailto:tcr@kcl.ac.uk)  
[information@thames-cancer-reg.org.uk](mailto:information@thames-cancer-reg.org.uk)

PEOPLE SEEN:

<u>Name</u>	<u>Position</u>	<u>Email address</u>
Professor Henrik Møller	Acting Director	<a href="mailto:henrik.moller@kcl.ac.uk">henrik.moller@kcl.ac.uk</a>
Mr Chris Carrigan	Head of Computing	<a href="mailto:chris.carrigan@kcl.ac.uk">chris.carrigan@kcl.ac.uk</a>
Dr Janine Bell	Senior Researcher	<a href="mailto:janine.bell@kcl.ac.uk">janine.bell@kcl.ac.uk</a>
Mrs Shirley Bell	Data Manager	<a href="mailto:shirley.bell@kcl.ac.uk">shirley.bell@kcl.ac.uk</a>
Mr Vivian Mak	Information Analyst	<a href="mailto:vivian.mak@kcl.ac.uk">vivian.mak@kcl.ac.uk</a>

General: Tel: 020 7378 7688  
 Fax: 020 7378 9510  
 e-mail: [information@thames-cancer-reg.org.uk](mailto:information@thames-cancer-reg.org.uk)

Also: Pam Seworth, Data Management and Quality Assurance Supervisor

**THURSDAY 5<sup>TH</sup> APRIL, 2001:**

VISITED:

UK OFFICE FOR NATIONAL STATISTICS (now called "NATIONAL STATISTICS")

Website: <http://www.statistics.gov.uk>

CONTACT and PERSON SEEN:

Dr Mike Quinn,  
 Director,  
 National Cancer Registration Bureau,  
 Demography and Health Division,  
 Office for National Statistics,  
 (now "National Statistics")  
 B6/02 Bessborough Tower,  
 1 Drummond Gate,  
 GB-London SW1V 2QQ  
 United Kingdom.  
 Phone: +44 (0) 20 7533 5257  
 Email: [Mike.Quinn@ons.gov.uk](mailto:Mike.Quinn@ons.gov.uk)  
 Internet: <http://www.statistics.gov.uk>

Others whom I thought I might have seen; but they were not available on the day:

Dr Penny Babb,  
Epidemiologist,  
Phone: +44 (0)207 533 5266  
Email: [penny.babb@ons.gov.uk](mailto:penny.babb@ons.gov.uk)

Dr Peter Goldblatt, Director of Demography and Health Division

## **FRIDAY 6<sup>TH</sup> APRIL, 2001**

### VISITED

National Cancer Registration Office  
Segensworth Road,  
Titchfield,  
Fareham, PO15 5RR  
(Near Southampton)  
Switchboard: (01329) 842511

### CONTACT:

Ms Helen Booth      Tel:    01329 813759

Also talked with people in the Office of Registration of Births, Deaths and Marriages with respect to the receipt, checking, coding and recording of birth and death certificates. Outputs from the system were reviewed, eg mortality statistics and other vital and health statistics. (Margaret, Sue, Lynne Shane, Chris Bradbury)

**WEEK 7**

**MONDAY 9<sup>TH</sup> APRIL, 2001**

TELEPHONE CONVERSATION

(about 1 hour and 15 minutes) on the UK National Cancer Plan with:

Professor Mike Richards,  
UK National Cancer Director,  
c/- Dept of Palliative Medicine,  
Guys, Kings, St Thomas' Medical and Dental School,  
1<sup>st</sup> Floor, South Wing,  
St Thomas' Hospital,  
Lambeth Palace Road,  
London, SE1 7EH

Tel: +44 (0)20 7922 8009 (Direct)  
+44 (0)20 7922 9292 Ext 8009  
0589 486432 (Mobile)

Fax: +44 (0)20 7922 8253

E-mail per Secretary (Ann Sears): [Ann.Sears@gstt.sthames.nhs.uk](mailto:Ann.Sears@gstt.sthames.nhs.uk)

Websites: <http://www.doh.gov.uk/cancer> (NHS Cancer Plan)  
<http://www.nhs.uk/nhsplan> (NHS Plan)

VISITED:

National Office,  
Faculty of Public Health Medicine  
of the Royal Colleges of Physicians of the United Kingdom,  
4 St Andrew's Place,  
Regent's Park,  
London, NW1 4LB

Tel: +44 (0)20 7935 0243

Fax: +44 (0)20 7224 6973

Website: <http://www.fphm.org.uk>

Saw: Mr Paul Scourfield (Faculty Secretary) and met all others in the office briefly

Dr Ian Basnett,  
Deputy Director of Public Health,  
Camden and Islington,  
110 Hampstead Road,  
London, NW1

Tel: +44 (0)20 7853 5365

E-mail: [Ian.Basnett@cai-ha.nthames.nhs.uk](mailto:Ian.Basnett@cai-ha.nthames.nhs.uk)

**WEDNESDAY 11<sup>TH</sup> APRIL, 2001**

VISITED:

Mrs Helen Shirley-Quirk,  
Head of Cancer Policy Team,  
NHS Executive Headquarters,  
Department of Health,  
Wellington House,  
133-135 Waterloo Road,  
London, SE1 8UG

Tel: +44 (0)207972 4819

E-mail: [hshirley@doh.gov.au](mailto:hshirley@doh.gov.au)

Website(s): <http://www.doh.gov.uk>

<http://www.nhs.uk>

<http://www.doh.gov.uk/cancer> (NHS Cancer Plan)

<http://www.nhs.uk/nhsplan> (NHS Plan)

ALSO SAW:

Ms Jill Anderson,  
Cancer Information Systems Coordinator.

**NB: FRIDAY 13<sup>TH</sup> APRIL AND MONDAY 16<sup>TH</sup> APRIL WERE PUBLIC HOLIDAYS – EASTER LONG WEEKEND**

**WEEK 8**

**SHEFFIELD, UK**

**TUESDAY 17<sup>th</sup> APRIL TO FRIDAY 20<sup>th</sup> APRIL, 2001**

**VISITED:**

Trent Cancer Registry,  
6th Floor, Weston Park Hospital,  
Whitham Road,  
Sheffield, S10 2SJ,  
United Kingdom.  
Ph: 0114 226 5351  
Fax: 0114 226 5501  
E-mail: [trentcancer@sth.nhs.uk](mailto:trentcancer@sth.nhs.uk)  
Website: <http://www.trentcancer.prestel.co.uk/>

**CONTACTS:**

Dr Philip Needham,  
Deputy Director,  
Trent Cancer Registry,  
6th Floor, Weston Park Hospital,  
Whitham Road,  
Sheffield, S10 2SJ  
United Kingdom.  
Tel: 0114 226 5351 (Secretary)  
0114 226 5352 (Direct Line)  
Fax: 0114 226 5501  
Email: [Philip.Needham@WPH.TRENT.NHS.UK](mailto:Philip.Needham@WPH.TRENT.NHS.UK)

Dr Hannes Botha,  
Director,  
Trent Cancer Registry,  
6th Floor, Weston Park Hospital,  
Whitham Road,  
Sheffield, S10 2SJ  
United Kingdom.  
Tel: 0114 226 5351 (Secretary)  
Fax: 0114 226 5501  
Email: [Hannes.Botha@WPH.TRENT.NHS.UK](mailto:Hannes.Botha@WPH.TRENT.NHS.UK)

## **Trent Cancer Registry**

### **Visit by Dr Wayne Clapton 17 - 20 April 2001**

### **Outline Programme**

#### **Tuesday 17 April**

**Morning**     ***Welcome and Introduction to Trent Cancer Registry***  
10.00         Dr Hannes Botha, Director

**Afternoon**   ***Clinical Audit & Monitoring Services***  
Philip Needham, Deputy Director  
Ingrid Ainsworth, Assistant Director (Registration and Audit)

***Registry Input to Clinical Audit & Cancer Service Monitoring***  
Philip Needham

#### **Wednesday 18 April**

**Morning**     ***Information Technology Issues***  
Alan Waterhouse, Assistant Director (IM&T)  
Teresa Turner, Computing Services Officer

**Afternoon**   ***Discussion with Director of Public Health***  
Dr John Radford, Director of Public Health, Doncaster HA

#### **Thursday 19 April**

**Morning**     ***Coding and Data Processing***  
Brenda Chattle, Registration Manager

**Afternoon**   ***Analytical & Reporting Systems***  
Dr Paul Silcocks, Assistant Director (Research & Intelligence)

***Information Uses***  
Dr Paul Silcocks

#### **Friday 20 April**

**Morning**     ***Dissemination of Information***  
Dr Hannes Botha

***Privacy, Confidentiality etc.***  
Dr Hannes Botha

**Afternoon**   ***General Discussion and Review***  
Dr Hannes Botha, Philip Needham  
Also: Presentation by me on “The South Australian Cancer Registry” to all staff at the Trent Cancer Registry.

**WEEK 9**

**OXFORD, UK**

**TUESDAY 24<sup>th</sup> APRIL TO FRIDAY 27<sup>th</sup> APRIL, 2001**

VISITED:

- Oxford Cancer Intelligence Unit (Cancer Registry) (Contact: Dr Monica Roche)  
Website: <http://www.phru.org.uk/ociu/index.htm>
- Unit of Health-Care Epidemiology (Contact: Dr Michael Goldacre)  
Website: <http://www.uhce.ox.ac.uk/>

BOTH AT THE:

Institute of Health Sciences,  
Old Road, Headington,  
Oxford OX3 7LF  
Main Switchboard: (+44) (0)1865 226666  
Website: <http://www.ihs.ox.ac.uk/index.htm>

CONTACTS:

Dr Monica Roche  
Medical Director  
Oxford Cancer Intelligence Unit  
Institute of Health Sciences  
Old Road  
Headington  
Oxford OX3 7LF  
Tel: 01865 226742  
Fax: 01865 226809  
Email: [monica.roche@phru.anglox.nhs.uk](mailto:monica.roche@phru.anglox.nhs.uk).  
X400: s=roche; g=monica;  
> o=nhs public health resource unit;  
> p=nhs a and o hn; a=nhs; c=gb;

General Contact for OCIU:

Oxford Cancer Intelligence Unit  
Institute of Health Sciences  
Old Road  
Headington  
Oxford, OX3 7LF

Tel: 01865 227040  
Fax: 01865 226809  
E-mail: [ociu.staff@phru.anglox.nhs.uk](mailto:ociu.staff@phru.anglox.nhs.uk)

[ociu@cix.co.uk](mailto:ociu@cix.co.uk)  
[ociu@phru.anglox.nhs.uk](mailto:ociu@phru.anglox.nhs.uk)

Dr Michael Goldacre,  
 Honorary Director,  
 Unit of Health-Care Epidemiology,  
 Institute of Health Science,  
 Division of Public Health,  
 University of Oxford,  
 Old Road,  
 Headington,  
 Oxford, OX3 7LF,  
 United Kingdom.

Telephone : (01865) 742277, Facsimile : (01865) 226993,  
 e-mail : [enquiries@uhce.ox.ac.uk](mailto:enquiries@uhce.ox.ac.uk)  
[michael.goldacre@public-health.oxford.ac.uk](mailto:michael.goldacre@public-health.oxford.ac.uk)

[pamela.evans@health-care-epidemiology.oxford.ac.uk](mailto:pamela.evans@health-care-epidemiology.oxford.ac.uk) (MG's secretary)  
[John.newton@public-health.oxford.ac.uk](mailto:John.newton@public-health.oxford.ac.uk)

## PEOPLE SEEN

(at the Public Health Resource Unit and the Oxford Cancer Intelligence Unit)

<b>Public Health Resource Unit</b>	<b>Fax : (01865) 227154</b>
<a href="#">Alison Hill, PHRU Director</a>	(01865) 226724
<b>Four Counties Public Health Medical Training Team</b>	<b>Fax : (01865) 226674</b>
<a href="#">Tony Bullock, IT Support Officer</a>	(01865) 226741
<a href="#">Rachel Dalby, Training &amp; Development</a>	(01865) 226776
<b>Oxford Cancer Intelligence Unit</b>	<b>Fax : (01865) 226809</b>
<a href="#">Pat Hall, Manager</a>	(01865) 226800
<a href="#">Neil Kennedy, IT Manager</a>	(01865) 226796
<a href="#">Julia Redburn, Deputy Director</a>	(01865) 227033
<a href="#">Monica Roche, Medical Director</a>	(01865) 226742

## ALSO SEEN:

- Dr Primila Webster (Coordinator of Training for the Faculty of Public Health Medicine in the Oxfordshire Area)
- Dr Etheline Enoch (Advanced Trainee in Public Health Medicine)
- Dr J.A. Muir Gray  
 Director, Institute of Health Sciences, University of Oxford and Director, Breast and Cervix Screening Programs



PEOPLE SEEN AT THE:

**UNIT OF HEALTH-CARE EPIDEMIOLOGY**  
**Division of Public Health**  
**University of Oxford**



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[\*enquiries@uhce.ox.ac.uk\*](mailto:enquiries@uhce.ox.ac.uk)

The Unit of Health-Care Epidemiology (UHCE), located at Headington, [Oxford](#) on the University of Oxford [Institute of Health Sciences'](#) site, is part of the [University of Oxford's](#) Department of Public Health and Primary Care. [Funded](#) by both the [NHS](#) and [academic](#) research grants, the Unit is able to keep actively involved in the current major issues affecting the NHS, as well as the broader academic areas of epidemiology, [health services and medical](#) research

*The direct line telephone number can be obtained by using 2 as a prefix to the extension number given*

*You can mail an individual from the unit directly using the links provided, send a message through the [unit](#), or, if not mentioned you can [search](#) for an e-mail address in the [University](#), or [elsewhere](#)*

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Evans Pamela Mrs	Unit Secretary	26994
<a href="#">Gill</a> Leicester Mr	Chief Computer Scientist	27017
<a href="#">Goldacre</a> Michael Dr	Honorary Director	26995
Mason Alastair Dr	Consultant Epidemiologist	26725
McGuinness Henry Mr	Research Officer/ Programmer Statistician	27021
<a href="#">Newton</a> John Dr	Consultant Epidemiologist	26991
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<a href="#">Seagroatt</a> Valerie Ms	Statistician/Uni Research Lect	26868
Vessey Martin Prof	Emeritus Prof of Public Health	27030
<a href="#">Yeates</a> David Dr	Computer Scientist	27007

**WEEK 10**

**LYON, FRANCE**

**MONDAY 30<sup>TH</sup> APRIL, 2001 TO FRIDAY 4<sup>TH</sup> MAY, 2001**

(NB: 1<sup>st</sup> May is a public holiday in UK and France)

**VISITED:**

International Agency for Research on Cancer (IARC),  
 150 cours Albert Thomas  
 F-69372 Lyon cedex 08,  
 France  
 Tel: +33 (0)4 72 73 84 85  
 Fax: +33 (0)4 72 73 85 75  
 Website: <http://www.iarc.fr/>

**CONTACT:**

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 Dr Rene Lambert  
 Dr Rengaswamy Sankaranarayanan  
 Mr Jacques Ferlay  
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 Mr Andy Cooke

Dr Silvina Arrossi  
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 Staff Scientist  
 Staff Scientist  
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 Staff Scientist  
 Staff Scientist

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Dr Robert A. Baan

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**WEEK 11****MAINZ, GERMANY**Website for Mainz City: <http://www.mainz.de>**TUESDAY 8<sup>th</sup> MAY TO FRIDAY 11<sup>th</sup> MAY, 2001****VISITED:**

- Cancer Registry of Rhineland-Palatinate  
(Krebsregister Rheinland-Pfalz)  
Websites:
  - (English) [http://info.imsd.uni-mainz.de/Krebsregister/engl/kr\\_start\\_e.html](http://info.imsd.uni-mainz.de/Krebsregister/engl/kr_start_e.html)
  - (German) [http://info.imsd.uni-mainz.de/Krebsregister/kr\\_start.html](http://info.imsd.uni-mainz.de/Krebsregister/kr_start.html)
- German Childhood Cancer Registry  
(Deutsches Kinderkrebsregister)  
Websites:
  - (English) <http://www.kinderkrebsregister.de/english/>
  - (German) <http://www.kinderkrebsregister.de/>

**CONTACTS:**

Univ.-Prof. Dr. med Jörg Michaelis,  
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Cancer Registry of Rhineland-Palatinate, and  
Register of Childhood Malignancies,  
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[http://info.imsd.uni-mainz.de/Krebsregister/engl/kr\\_start\\_e.html](http://info.imsd.uni-mainz.de/Krebsregister/engl/kr_start_e.html)  
<http://www.kinderkrebsregister.de/english/>

Frau Dipl.-Math. Irene Schmidtman  
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Dr Peter Kaatsch, PhD,  
 Deutsches Kinderkrebsregister (German Childhood Cancer Registry),  
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### **Krebsregister Rheinland-Pfalz**

**Finanzierung durch das Ministerium für Arbeit, Soziales und Gesundheit des Landes Rheinland-Pfalz**

## **ANSCHRIFTEN**

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<b>Koordination</b>	<b>Dr. Peter Kaatsch</b>
<b>Stellvertreter</b>	<b>Petra Enste</b>
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<b>Ansprechpartnerin</b>	Ulrike Knoll
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**Cancer Registry of Rhineland-Palatinate**

**Financial support by the Federal Ministry of Health and by the Ministry of Labour,  
Social Affairs and Health of Rhineland-Palatinate**

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Dr. med. Birthe Schmitt-Thomas, MPH (formerly at the Cancer Registry, now at the Anti-Cancer Foundation, Frankfurt)		

### German Childhood Cancer Registry (GCCR)

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- **Management :** Prof. Jörg Michaelis MD  
Peter Kaatsch PhD
- **Postal Address :** Deutsches Kinderkrebsregister am IMSD, D-55101 Mainz
- **Located at :** Institut für Medizinische Statistik und Dokumentation (IMSD),  
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Frau Lückel	Coding and Checking Program
Frau Bremensdorfer	Coding and Checking Program
Frau Kerenyi	Questionnaires for Case Control Studies
Dr Joachim Schüz	Handi Brain Study & Case Control Studies of the aetiology of Childhood Cancer
Frau Dr. Claudia Spix	German Neuroblastoma Screening Project
Frau Dr. Klein	Study of second malignancies after childhood Cancer

<b>THIS COMPLETES THE WINSTON CHURCHILL FELLOWSHIP VISITS</b>
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