Six months down the track

The Cancer Survival Study

This year, the Centre for Health Research and Psycho-Oncology (CHeRP) completed the first phase of data collection in its Cancer Survival Study. Initial analysis gives a clear picture of how cancer survivors are faring 6 months after diagnosis — the problems they face, the positive and negative changes in their lives, how they are coping and the help they need.

3,060 survivors were recruited in NSW and are faring 6 months after diagnosis — the first phase of data collection in its Cancer Survival Study. The Centre for Health Research and Psycho-Oncology (CHeRP) completed the study in 1987, and a DPhil in Epidemiology by the University of the Witwatersrand. Freddy Sitas was hugely influenced by the 19th-century work of John Snow, who was a British physician and a leader in the adoption of anaesthesia and medical hygiene. Snow is considered to be one of the fathers of epidemiology, because of his work in tracing the source of a cholera outbreak in Soho, England, in 1854. Freddy enjoyed the detective work involved and discovered that he too was doing epidemiological research. Being influenced by the injustices in South Africa, he continued to work in the rural communities to empower these to create a better lifestyle for themselves.

The most common problems affecting cancer survivors six months after diagnosis are fatigue, pain and sleeping difficulties. Anxiety and depression are the most common; how much the risk is increased varies depending on the patient, their disease and their treatment. The importance of involvement by the community is inestimable, as it enables researchers to establish the risk factors for cancer in the community. These are known as epidemiological studies — epidemiology being the study of populations in order to determine the frequency and distribution of disease, and to measure risks.

Most diseases don’t occur randomly. They are related to the environment and to personal characteristics, both of which vary depending on the place, the time, and the subgroup of the population. By collecting, collating and mapping this information about disease it is then possible to determine who is prone to a particular disease, where risk of the disease is highest; when the disease is most likely to occur and its trends over time.

In NSW, 12% of the adult population is involved in a Cancer Council NSW study.

If you have been a participant in one of our studies, we would like you to thank you and explain what we are doing with your information, where we are up to, and why it matters.

The following table shows some of the human activities or illnesses that epidemiologists have established have a causal association with cancer.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Associations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer</td>
<td>Smoking</td>
</tr>
<tr>
<td>Liver cancer</td>
<td>Hepatitis B</td>
</tr>
<tr>
<td>Burkitt lymphoma</td>
<td>Melanoma, Epstein Barr virus</td>
</tr>
<tr>
<td>Stomach cancer</td>
<td>Helicobacter pylori</td>
</tr>
<tr>
<td>Kaposi sarcoma</td>
<td>Herpes virus - 8</td>
</tr>
<tr>
<td>Cervical cancer</td>
<td>HPV</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>HIV</td>
</tr>
<tr>
<td>Leukemia</td>
<td>Pneumonia</td>
</tr>
<tr>
<td>Oesophagus cancer</td>
<td>Alcohol, tobacco</td>
</tr>
<tr>
<td>Mesothelioma</td>
<td>Asbestos</td>
</tr>
<tr>
<td>Kidney cancer</td>
<td>Bux powders</td>
</tr>
<tr>
<td>Skin cancer</td>
<td>Sunlight UV</td>
</tr>
</tbody>
</table>

Research report

Thank you. Without you we would have nothing to study...
By the mid 20th century, the focus of much of epidemiology shifted from infectious diseases and heart disease to cancer. The first major breakthrough in identifying a cancer risk factor was the documentation of an association between tobacco smoking and lung cancer.

Since 1970, epidemiological studies have generated data that identifies risk factors for cancers at almost every body site. And they will undoubtedly continue contributing to cancer prevention by honing in on promising areas to identify specific factors that can be modified to reduce risk.

Our aim in the Cancer Research Division of Cancer Council NSW is to contribute to a reduction in the burden of the cancers we research. At present we have ten studies underway ranging from men’s health to cervical cancer. They are all at different stages of their study cycles, but as results become available they are released. Read them carefully because they may have implications for you or someone you know, or perhaps you could become a participant in the study and help defeat cancer in NSW.

Epidemiology is the study of factors affecting the health and illness of populations.

...because we can always do with more help.

The CLEAR Study

The CLEAR study (Cancer, Lifestyle, Evaluation of Risk Study) is designed to provide the most comprehensive and comprehensive information to data on the lifestyle and genetic factors that influence cancer risk in the NSW population.

CLEAR generates ongoing data on the effects of a wide range of lifestyle factors on the risk of developing cancer: factors such as migration, ethnicity, physical activity, alcohol consumption, smoking, reproductive history, occupation, and certain dietary patterns. It evaluates which factors are important, and the differences which cause Australians of various groups in our community. With the help of as many people with cancer as possible, an enormous research program is developing based on the CLEAR Study. The cultural diversity of NSW population plus the fact that approximately 25% of the population is born overseas, means that there is a range of lifestyle patterns that can be compared. From this data, meaningful answers about the causes of cancer are being uncovered.

In the first few years of the study, results show that cancer of the bowel, prostate, breast, lung, melanoma and non-Hodgkin lymphoma will be available. By the fifth year, enough information will be available to assess the effects of various genetic and lifestyle factors on the risk of developing liver, thyroid, ovarian and pancreatic cancers.

To date CLEAR has recruited nearly 2,700 participants

Men’s Health Study

Prostate cancer is the most commonly diagnosed cancer after non-melanocytic skin cancer, and the second most common cause of cancer death in Australian men. In 2006, prostate cancer accounted for 31% of all new cancer cases in males in NSW.

The Men’s Health Study was started in 2006 and completed data collection in late 2008. It is a unique population-based study of men living in NSW aged 50–84 years. It focused on three important but under-researched aspects of men’s participation in Prostate Specific Antigen (PSA) testing for the early detection of prostate cancer, namely:

- his decision-making process,
- psychological consequences, and
- patterns of care following an abnormal PSA test result.

It also collected valuable information about the general health of men in NSW, along with their attitudes and experiences with medical tests.

Cervical Health Study

Every year, many thousands of women in Australia are diagnosed with cervical abnormalities (changes to cells in their cervix). Unless they are treated, a small proportion of these women may develop cervical cancer, which is one of the leading causes of cancer death in women throughout the world.

Most women get infected with the human papilloma virus (HPV) during their lifetime. The Cervical Health Study aims to understand the effect of lifestyle factors which lead some women infected with HPV to develop pre-cancerous lesions.

How Thyroid Cancer is Diagnosed

The incidence of thyroid cancer has risen by 77% in females and 29% in males over the past decade. The reasons for this increase are as yet unknown and raise a number of questions, including whether there is a real increase in thyroid cancer risk (eg. due to increasing exposure to a risk factor such as ionizing radiation) or an artificial one (eg. occurring in response to improved and increased diagnosis).

45 and Up Study

Managed by The Sax Institute, the 45 and Up Study was established to gain insight and understanding into growing old, and why some people enjoy good health while others don’t, and why this occurs.

Information about health and lifestyle was collected from 250,000 men and women in NSW, aged 45 and over, to help us learn more about the factors which contribute to healthy or unhealthy aging.

We are investigating a huge variety of health issues. Participants are provided with a questionnaire regarding their background, lifestyle, health and their use of health services. Agreement has been granted to have their questionnaire information linked to health records, such as those held by Medicare Australia, and they have given permission to be approached for additional studies that will look more closely at the health of particular groups — such as people with diabetes, or those living in remote parts of NSW.

There are also plans to collect biological samples from participants to help understand the relative contribution of environment and genes to healthy aging.

In the first international publication from the study, the characteristics of people aged 50 years and over who do and do not use screening tests to check for bowel cancer were looked at. We found that smokers, as well as people who don’t eat fruit and vegetables and those who are physically inactive or obese, are all less likely to have a test for bowel cancer than their healthy counterparts. These results suggest that certain groups of people in NSW may need encouragement to seek bowel testing, especially if their lifestyle choices put them at risk.

Studying the impact of side effects on their quality of life.

Ultimately it aims to provide comprehensive information about side effects to men who have just been diagnosed and are facing treatment decisions, so that they can choose the treatment option that will work best for them.

When a man is diagnosed with prostate cancer he can be offered a range of treatments. These treatments may have long-term side effects that can affect his quality of life. The study follows men who have chosen each of the available treatment options and aims to assess the impact of side effects on their quality of life.

Ultimately it aims to provide comprehensive information about side effects to men who have just been diagnosed and are facing treatment decisions, so that they can choose the treatment option that will work best for them.

The study has now spoken to approximately 1,600 men five years after their initial diagnosis of prostate cancer. Early results from this study show that 75% of men treated for early prostate cancer, experience persistent “quality of life” side effects which in most cases is a major deterioration in sexual function.

The study also showed that not enough support is provided to men to help them deal with the changes in their sexual function, and that younger men in particular need more support in dealing with psychological issues after surviving prostate cancer.

Prostate Cancer Outcomes Study

Research report | Winter 2009 | Issue 11

This study, which is in the final stages of recruitment, is attempting to find out whether the observed increases in thyroid cancer incidence are real or artificial. By examining the pathways to the diagnosis of thyroid cancer for newly diagnosed thyroid cancer cases, and collecting some preliminary data on possible risk factors for thyroid cancer in NSW this study will provide invaluable information on this increasing problem.
By the mid-20th century, the focus of much of epidemiology shifted from infectious diseases and heart disease to cancer. The first major breakthrough in identifying a cancer risk factor was the documentation of an association between tobacco smoking and lung cancer.

Since 1970, epidemiological studies have generated data that identifies risk factors for cancers at almost every body site. And they will undoubtedly continue contributing to cancer prevention by honing in on promising areas to identify specific factors that can be modified so as to reduce risk.

Our aim in the Cancer Research Division of Cancer Council NSW is to contribute to a reduction in the burden of the cancers we research. At present we have over ten studies underway ranging from men’s health to cervical cancer. They are all at different stages of their study cycles, but as results become available they are released. Read them carefully because they may have implications for you or someone you know, or perhaps you could become a participant in the study and help defeat cancer in NSW.

The CLEAR Study

Since 1998, the CLEAR Study has been collecting data about the health of about 1,000 men and 1,000 women aged 45–74 years. The study is continuing with a new cohort of 2,000 men and 2,000 women aged 45–74 years. The following results are from the first cohort of participants.

Cancer Types and Incidence

There were a total of 3,636 cancer cases identified in the cohort. The most frequently occurring cancer types were:

- 1,116 prostate cancers
- 276 lung cancers
- 307 female breast cancers
- 263 ovarian cancers
- 257 male breast cancers
- 251 bowel cancers

The incidence of bowel cancer in men is higher than in women. The incidence of prostate cancer is higher in men than in women. The incidence of ovarian cancer is higher in women than in men. The incidence of bowel cancer is higher in men than in women.

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Our leader, Associate Professor Freddy Sitas

Associate Professor Freddy Sitas is the Director of the Cancer Research Division at Cancer Council NSW which encompasses two areas, one focusing on epidemiology and one on psycho-oncology and behavioural research.

Freddy was born in Cyprus but moved to South Africa in 1970, where he obtained a BSc in 1981, and then an MSc/MED in 1987 from the University of the Witwatersrand (South Africa), an MSc in Epidemiology from the London School of Hygiene and Tropical Medicine in 1987, and a DPhil in Epidemiology from the University of Oxford in 1990. Part of his work showed for the first time that Helicobacter pylori is a cause of stomach cancer.

He returned to South Africa in 1990 to the position of Head of the National Cancer Registry and in 1999 was awarded a Directorship of the South African MRC Cancer Epidemiology Research Group. In 2002, he was awarded a Readership in Epidemiology by the University of the Witwatersrand.

Freddy Sitas was hugely influenced by the 19th century work of John Snow, who was a British physician and a leader in the adoption of anaesthesia and medical hygiene. Snow is considered to be one of the fathers of epidemiology, because of his work in tracing the source of a cholera outbreak in Soho, England, in 1854.

Freddy enjoyed the detective work involved and discovered that he too was doing epidemiological research. Being influenced by the injustices in South Africa he continued to work in the rural communities to empower these to create a better lifestyle for themselves. As a scientist working on the ability to understand influences he discovered that epidemiology was in fact a combination of maths and sociology — the building of models and the analysis of data to better understand trends and influences and impacts. Always looking at the bigger picture for answers.

At Oxford, the scholarship that funded his work allowed him to show the link between the Helicobacter bacterium and stomach cancer. It also confirmed the more holistic understanding that bugs and infections can cause cancers.

Currently Freddy is setting up large scale studies to understand the inter-relationship between environment, lifestyle, genes and infectious agents, and how they interact to cause cancer. In 2009, Freddy initiated an exciting project where a group of researchers from China, Iran, Germany, Brazil and Norway will combine all the data on cancer of the oesophagus to look at whether HPV can cause this cancer. 7,000 blood samples are being collected and the analysis will be conducted in Australia.

Six months down the track

The Cancer Survival Study

This year, the Centre for Health Research and Psycho-Oncology (CHeRPOP) completed the first phase of data collection in its Cancer Survival Study. Initial analysis gives a clear picture of how cancer survivors are faring 6 months after diagnosis — the problems they face, the positive and negative changes in their lives, how they are coping and the help they need.

1,360 survivors were recruited in NSW and Victoria. Each completed one survey about their psychosocial wellbeing. This included assessments of distress, anxiety, depression and supportive needs, as well as questions about lifestyle behaviour (such as, smoking, alcohol, sun, physical activity, cancer screening, complementary therapies), plus information about the patient, their disease and their treatment.

Results

Almost 25% reported symptoms of anxiety and almost 15% reported symptoms of depression. While this was lower than expected, there is a small but important group of survivors who need more support. The research suggests that for many, a cancer diagnosis results in an enhanced appreciation of life. Most participants agreed that since their cancer diagnosis they had realised how precious life was and were making the most of it.

The most common problems affecting cancer survivors six months after diagnosis are fatigue and sleeping difficulties. The most difficult story about the cancer returning or getting worse and financial difficulties.

These results highlight areas for improvement in cancer service delivery. Over the next 12 months, most participants will be invited to complete a third survey.

Make a difference. You can help with cancer research

Join one of our ground-breaking research projects.

☐ Please include me on my mailing list when you are recruiting for questionnaire-based research studies on people drawn from NSW.

☐ I would like to work as a volunteer recruitment officer and help recruit participants to your studies.

☐ Please send me more information about Cancer Council.

By helping us now, you can help us defeat cancer in the future.