



“Why me?” The universal question among cancer patients

THIRTEEN years ago, Associate Professor Freddy Sitas and Professor Valerie Beral established a study in South Africa to measure the relative importance of known and emerging risk factors on the leading cancers. Although this study is ongoing, it has already established an increased prevalence of Kaposi's sarcoma (a once-rare cancer that causes tumours to develop in the tissues below the skin surface or in the mucous membranes) among people who test positive for HIV and

herpes virus. And more recently, after looking at the effect of several other viruses, the study has shown up an unexpected association between human papillomavirus (HPV) and cancer of the oesophagus.

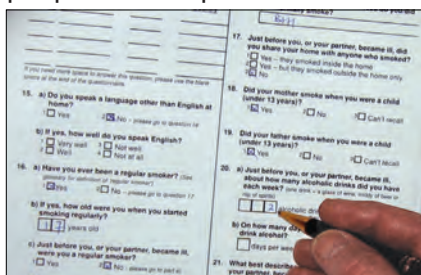
Through collaboration with the US National Cancer Institute, the German Cancer Research Centre, the International Agency for Research on Cancer, and colleagues from Iran, China and Australia these results are being re-tested in other large studies.

Based on that experience, Dr Sitas initiated the NSW CLEAR Study to provide the most comprehensive information to date on the lifestyle and genetic factors that influence cancer risk in the NSW population.

The plaintive cry, “Why me?” is a common appeal among patients

everywhere when they are diagnosed with cancer, and it is to provide helpful and constructive answers to that question that studies such as these have been set up. The researchers have found that systematically recording large numbers of cancer patients' past experiences in response to a detailed questionnaire, and storing their blood for future discovery, is the best way to discern patterns and to discover new agents. This approach yields important and sometimes unexpected findings for years to come.

If the causes of different cancers can be found then we can devise ways to remove them, and prevent it from occurring in future generations. Perhaps then the question “why me?” will be asked a lot less often. ■



Simply complete a questionnaire

Is this the face of a young tall poppy?

DR KAREN CANFELL has been nominated for one of this year's 'Young Tall Poppy Science Awards'.

Karen is the Sydney Rotary Research Fellow in the Cancer Epidemiology Research Unit at the Cancer Council NSW. Her D.Phil. in Epidemiology was obtained from the University of Oxford and concerned the effect of environmental and hormonal co-factors on the development of cervical cancer. Her current research focuses on the evaluation of alternative strategies for cervical screening, and hormonal risk factors for cancers of the female reproductive system.

Karen is also an investigator and research coordinator of the NSW CLEAR study, a major cancer bio-bank initiative that will provide the infrastructure for investigating genetic and environmental causes of a number of major cancers in the future.

The goal is to quantify the impact of HPV vaccina-



Dr Karen Canfell

tion on cervical cancer in Australia and several other countries. This information will be essential for developing screening policy, in terms of the technology used, the time between screenings, and the age range of women screened.

The Australian and New Zealand governments are already using their methods, and her team are in the process of evaluating new prevention strategies in the People's Republic of China.

Karen brings to her task a passionate commitment to bridging the gap between research and public policy in women's health and to increasing public awareness of prevention strategies for cancer. ■

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“Some of these questions are weird!” by Kate Christian

WHEN YOU SIT down to complete the 90 odd questions in the NSW Cancer, Lifestyle and Evaluation of Risk (CLEAR) Study questionnaire it will surely cross your mind that some of the questions appear to be straying into areas that at first sight (or even second and third) don't appear to have any possible link with cancer risk. In fact, it sometimes feels more like you're responding to a nosy neighbour than a group of objective scientists!

Knowledge comes...

I mean... really... who needs to know if I had my first period earlier than my friends? Or, whether I ever had a tattoo? Or, if I ate brown bread in 1998, or sprinkled a little talcum powder over myself? And if so, where? Let alone some of the extraordinarily intimate questions that I wouldn't even tell my own mother. In fact, I definitely wouldn't tell my mother. Or you, come to that! Unless there's a very good reason.

...but wisdom lingers

There is a very good reason, of course. But it's kind of hard to explain because these researchers don't know what they are looking for until they find it, and even then it's not immediately obvious. It's not like solving clues to a puzzle. The scientists are operating where no one's been before and there are no guides. They don't know what is a clue and what isn't, or even if there is one lying around.

They have cleverly constructed a questionnaire that appears to occasionally stray into areas that seem irrelevant, but from their point of view your responses just may show up little patterns of light. Knowing

that you owned a pet doesn't just communicate information about exposure to animal infections, it could allude to your level of fitness (did you take it for regular walks?), or your emotional state (the unqualified love of a pet), or your need for social interaction, and so on. And each of these pieces of secondary information may be useful in discerning an important pattern.



Help us find every piece of the jigsaw

Look what we learned

Another example that has been thrown up by the survey is the relatively widespread belief that early vaccination of young girls against the Human Papillomavirus (HPV) is an effective protection against the possibility of contracting cervical cancer. Well, it is. So do it. But that doesn't mean you shouldn't be vaccinated if you are older or already sexually active, because the vaccine may still offer you some protection.

Human Papillomaviruses are a group of over 100 different viruses, some of which are more likely to lead to the development of cancer than others. It's estimated up to four out of five women will have HPV at some time in their lives, usually without knowing it.

The cervical cancer vaccine (Gardasil or Cervarix) protects against two of the types of HPV that have been found to cause cancer and these two are responsible for the majority of cervical cancers — between 70 and 80 per cent of cases in Australia and New Zealand.

While the vaccine is most effective if given to girls before the start of sexual activity (and therefore, to exposure to HPV), if you've already been sexually active you could potentially still benefit to some extent. This is because you don't know which types of HPV you have been exposed to, and so you can still be protected against the types you have not yet acquired.

However, whether you've been vaccinated or not, it's still critically important to have regular Pap tests. All women between the ages of 18 and 70 who have ever had sex should have a Pap test regularly, because this can detect any abnormal cell changes in the cervix brought about by strains of HPV not covered by the vaccine.

There's a reason for everything

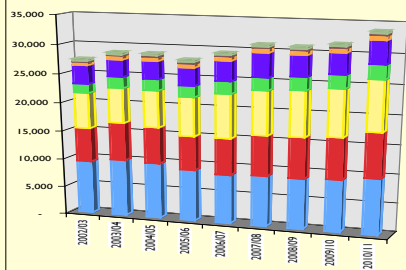
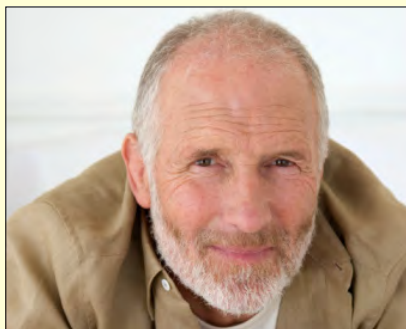
So, answer all the questions as honestly as you can. If you're concerned for your privacy, you are safe. Once the data is entered there is no way that the responses can be linked to you. And if you're concerned about answering questions that seem to be a little weird, don't be. Patterns may be found among the most surprising pieces of information, and cross referencing your responses with all the others in the study could lead to a breakthrough of blinding light or simply a faint pathway of blinking lights that lead the scientists a little further down the track in their pursuit of the killer. Weird but true.

Balding men have less hair!

AN EARLY AND astounding result from an analysis of the first 1,000 responses to the CLEAR study show that men who go bald have less hair than men who retain their hair. This has huge implications for the hairdressing and comb manufacturing industries.

The responsibility for this phenomenon has not, as yet, been sheeted home to a virus, and neither has this non-existent virus made any claims to be carcinogenic.

Obviously this is a load of rubbish but it fills up the space that I have allocated to the story I am waiting on based on Alicia's basic demographic information from an early analysis of the first 1,000 respondents.



An odd-looking chart representing Alicia's statistics

Interview with a participant in the CLEAR study

I COULDN'T get hold of Lisa Fisher yesterday, so I will try again today. As you can see from the space left, there's probably only room for an interview with Lisa.

I intend to ask her questions along the lines of "Why did you agree to join the CLEAR study?", "Did you find it intrusive to be asked to enter the study when you were dealing with your cancer?", "What did you have to do for the study?", "Did they meet with you?", "Where did you have to go to give blood?", "Did the whole process take up a lot of your time?", "Was it a difficult or frustrating experience?"

Then "Tell me the story of Lisa and cancer?", "How were you diagnosed?", and "What is the prognosis?"

Finally, and more for your purposes than the story, "When do you think would be the best time to ask a cancer patient or their spouse to join the CLEAR study?", "What would be the best way to be asked?"

As must be obvious this could take up three pages, but I don't know what I'll get till I ask and it will then be savagely edited to an interesting and useful 250 word article!



Lisa Fisher

Are you eligible to join our CLEAR study?

The Cancer Council NSW is urging patients and partners of patients (if applicable) who have been diagnosed in the past eighteen months to participate in this large-scale epidemiology study. We are actively recruiting participants at the following hospitals in NSW:

St Vincent's Public Hospital,
Darlinghurst Road, Darlinghurst.
Tel: 1234 5678

Royal Hospital for Women,
Easy Street (off Barker Street),
Randwick. Tel: 1234 5678

**Royal Prince Alfred Hospital
– Sydney Cancer Centre,**
Missenden Road, Camperdown.
Tel: 1234 5678

Liverpool Hospital,
Elizabeth Street, Liverpool.
Tel: 1234 5678

**SESAHS Clinical Cancer
Registry,**
Somewhere Street, Anywhere.
Tel: 1234 5678

Riverina Cancer Centre,
Meurant Avenue, Wagga.
Tel: 1234 5678

SSWAHS Clinical Cancer Registry,
Anywhere Road, Somewhere.
Tel: 1234 5678.



Please call

1800 500 894

to register, or for more information and we will send you out the questionnaire and make arrangements to take a blood sample.

This research study is a CLEAR winner!

by Dr Joyce Smith

THE CANCER COUNCIL has two main areas of research: clinical trials that test the effectiveness and safety of new drugs, and the investigation of the causes and patterns of disease.

The key part of our investigative research is the collection of large amounts of information about a particular cancer, which is then divided into 'subsets' of the population for comparison. These 'subsets' may be as simple as men or women, under or over 45, migrants or Australian-born people, indigenous or non-indigenous. These groups will show different patterns, and we investigate those patterns and see how they relate to the development of disease.

We know that viruses cause about 20% of cancers — for instance, the human papilloma (HPV) virus causes cervical cancer. Recently an HPV vaccine was developed in Australia, and the work done by one of the groups at Cancer Council helped us to show the Australian government that vaccination of all girls between 16 and 26 will assist in completely wiping out cervical cancer. In just 50 years, cervical cancer will be an historical disease, like polio and smallpox.

Viruses are suspected of causing other cancers as well, and we are busy investigating these by studying viruses in blood samples taken from people with cancer.

We focus on genes and lifestyle

It is generally accepted that cancer is caused by a combination of your genes and lifestyle. An individual's genetic profile might increase their chance of getting cancer, or it might protect them. That same individual

will then influence their genetic risk by making lifestyle decisions — such as smoking, or drinking an excess of alcohol.

If genes are something we're born with why do we analyse them? What can we do about it? Is there any point in knowing our genetic profile?

The answer is yes. A gene is a map for a protein. And we are at the forefront of developing a special new class of drugs that are tailored to a specific genetic profile. Herceptin is one of these drugs and it has had great success in the treatment of women who carry a protein called HER2.

Some cancers are known to have a genetic link, so we are also using genetic information to investigate

the risk of a family member developing a particular sort of cancer. Genetic

tests can be used to test risks in the sons, daughters, brothers or sisters of a cancer patient.

How do we do our investigative research?

The main part of our work is investigating the causes of various cancers. This can be retrospective or prospective.

In retrospective investigation, we look at people with cancer and look for what caused it.

However, the best science comes from prospective studies. These gather information over long periods of time from large numbers of people. By their nature, they take a

long time to complete and are very expensive to run.

One of these studies, the '45 & Up Study', aims to collect information on 250,000 participants, aged 45 and over. We will gather information about lifestyle and health for these people, and follow them as they are aging.

A case-control study explained

Our other flagship study is the **CLEAR Study** that investigates lifestyle and evaluates risk. For this we are seeking people who are:

- aged between 18 and 79
- have any type of cancer
- have been diagnosed within the past 18 months
- and have been diagnosed with cancer for the first time

The special thing about this study is that it is a case-control study (these are studies that use patients who already have a disease – *cases* – and compare them with subjects who don't have the disease but are otherwise similar – *controls*). We are seeking exactly the same information from the patients as we are from their domestic partners so that we can compare information from people with cancer and from people without cancer.

Generally, these couples will have a different genetic makeup, but they will live in the same house and probably share the same diet as well as many aspects of their lifestyle. We can then pick apart the similarities and differences for people with and without cancer.

Over time, the results from the CLEAR study will be invaluable for tracing patterns of risk — a CLEAR winner in the ongoing war on cancer.



Genes...



...Lifestyle



Cancer Council
153 Dowling Street
Woolloomooloo 2011
www.cancercouncil.com.au/CLEARstudy

INSIDE

THANK YOU for taking part in a Cancer Council study publico legero nos omnirios audentis tilaim cum

THE CLEAR STUDY nem re quam ciocciomurbi publico legero nos omnirios audentis tilaim cum

MENS HEALTH STUDY MOR nem re quam ciocciomurbi publico legero nos omnirios audentis tilaim cum

45 AND UP STUDY nem re quam ciocciomurbi publico legero nos omnirios audentis tilaim cum



Research report

Helping you care for people with cancer

cancercouncil.com.au

Winter 2009 | Issue 11

Thank you. Without you we would have nothing to study...

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 to thank you and explain what we are doing with your information, where we are up to, and why it matters.

The importance of involvement by the community is incalculable, 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; what exposure its victims have in common; how much the risk is increased through exposure; and how many cases of the disease could be avoided by eliminating the exposure.

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



12% of the community are already helping us out by participating as volunteers in one of the questionnaire-based research studies run by Cancer Council NSW

Disease	Associations
Lung cancer	Smoking
Liver cancer	Hepatitis B
Burkitts lymphoma, Epstein Barr virus	Malaria
Stomach cancer	Helibactor pylori
Kaposi sarcoma	Herpes virus
Cervical cancer	HPV
Breast cancer	HRT
Leukaemia	Radiation
Oesophagus cancer	Alcohol
Mesothelioma	Asbestos
Kidney cancer	BEX powders
Skin cancer	Sunlight UV

Cancer was generally considered incurable up to the late 19th century. However, by the 20th century clues were starting to be

found to some of its causes by observing the exposure of the population to tobacco, diet, environmental chemicals, and other external factors. With repeated confirmation of such associations, researchers began to entertain the possibility that cancer, like many other infectious diseases, might be prevented.

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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.



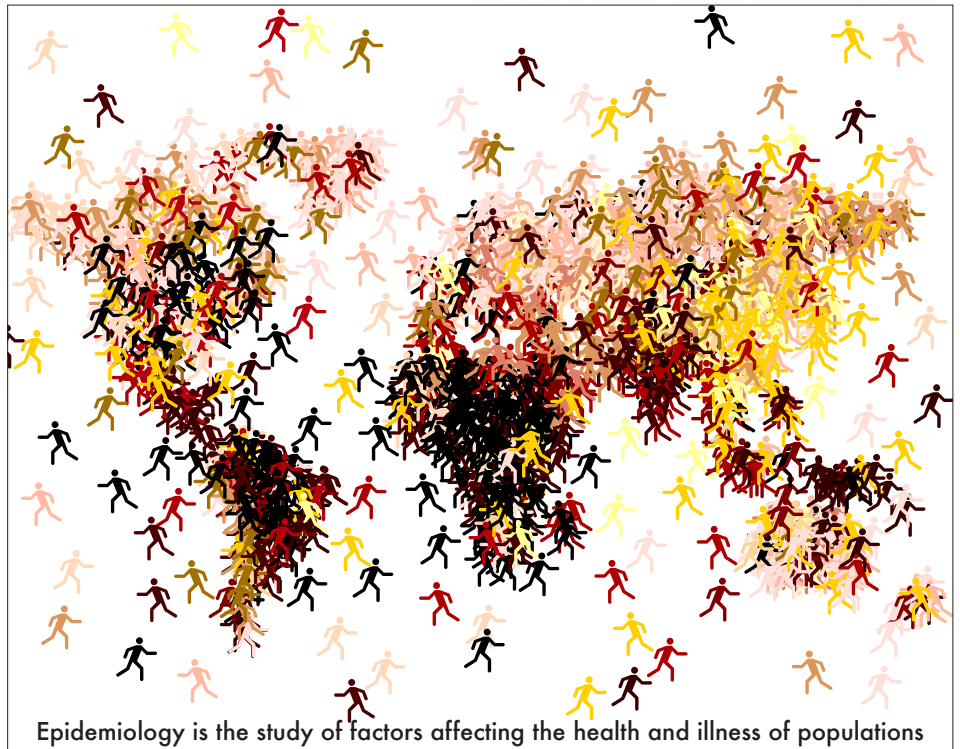
Since 1970, epidemiological studies have generated data that identifies risk factors for cancers at almost every body site. And they will undoubtedly continue contributing to cancer prevention by honing in on promising areas to identify specific factors that can be modified so as to reduce risk.

We need as many people as we can get to help with our research studies. Already in NSW, 12 in every hundred are involved but if we can move that to 20% or more we will speed up our rate of success. Most of our studies are questionnaire-based and only require you to set aside a little time.



And while time may be on your side it's not on everyone's. So please participate if you can...

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



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

STUDY REPORT: Could these studies affect you or someone you know?

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 life 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 control cancer in NSW.

The CLEAR Study

The CLEAR study (Cancer, Lifestyle, Evaluation of Risk Study) is designed to provide the most comprehensive information to date 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 exist amongst 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 the NSW population plus the fact that approximately 25% of the population is born overseas, means that there is an enormous medley of lifestyles 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 for cancers of the colon and rectum, prostate, breast and 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 2,500 participants,

Male cases	851
Male control	257
Total male	1,108
Female cases	1,116
Female control	263
Total Female	1,642
Breast Cancer	551
Prostate Cancer	307
Colorectal Cancer	276
Lung Cancer	89

In a recent development, the CLEAR section* of the Cancer Council web site is now set up so that participants may complete the appropriate forms and questionnaires online. This allows us to evaluate lifestyle and genetic influences on the incidence of cancer across a greater range of people with diverse ethnic backgrounds, as well as making the completion and analysis of the information easier and more efficient.

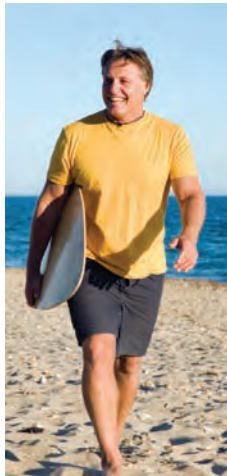
* <http://www.cancercouncil.com.au/editorial.asp?pageid=2482>



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 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:

- the 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.

'45 and Up' Study

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.



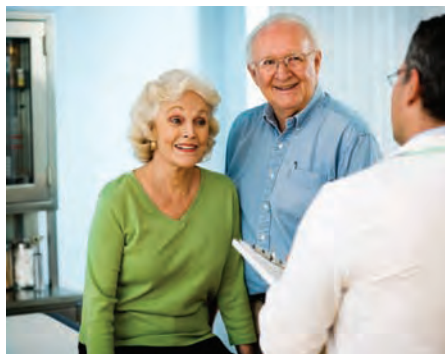
Information about health and lifestyle was collected from 250,000 men and women in NSW, aged 45 and over, to help us learn more about the factors which contribute to healthy or unhealthy aging.

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 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. In the future it is planned to collect biological samples from participants to help understand the relative contribution of environment and genes to healthy ageing.

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.

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 unknown. This study sets out to determine how patients have presented to doctors for their diagnosis, as well as exploring aspects of diet, family history, medication use, country of origin and the number of consultations preceding diagnosis.



Cervical Health Study

Cervical cancer is one of the leading causes of cancer death in women. The Cervical Health Study aims to understand the effect of lifestyle factors which lead some women infected with the HPV virus to develop pre-cancerous lesions.

Worldwide, it is estimated that approximately 500,000 women are diagnosed with invasive cervical cancer



each year, while in Australia only around 700 women are diagnosed with the disease each year (this is less than half the total we might expect, based on our population). The rates of cervical cancer in Australia are lower than in most other countries largely due to the success of the organised cervical screening program, which was introduced in the early 1990s.

A research team, based at Cancer Council NSW and led by Dr Karen Canfell has developed new models of cervical screening and human papilloma virus vaccination, which will be used to evaluate various cervical cancer prevention strategies in Australia and other countries.

Prostate Cancer Outcomes Study

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.

Our most respected and beloved leader, Dr Freddy Sitas

Associate Professor Freddy Sitas, is the Director of the Cancer Research & Registers Division at Cancer Council NSW.



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 2000, 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 the locals 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 virus and stomach cancer. It also confirmed the more holistic understanding that bugs and infections can cause cancer.

Currently Freddy is setting up new platforms to understand the inter-relationship between environment, lifestyle, genes and infectious agents, and how they react 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 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 (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.

In 2008, 1,360 survivors were recruited in NSW and Victoria. Each one completed a survey of their psycho-social wellbeing. This included a number of 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. 79% of 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 (more than 50%), worry about the cancer returning or getting worse (50%), and financial difficulties (33%).

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.



What really causes cancer? Is it lifestyle... genes...? Help us find the answer

Join one of our ground-breaking research projects.

How to participate?

Well, there are two ways to become involved:

- You can be included on our mailing list when we are recruiting for questionnaire-based research studies on people drawn from NSW.

Or,

- You can work as a volunteer clinical recruitment officer and help recruit participants to our studies (in this case it is desirable that you have a background in health)

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



Just complete the form below or register through our website at www.cancercouncil.org.au.

First name

Last name

Address

.....Post Code

Email address

Gender DOB

Tel: Mobile