

Large-scale studies valuable, but how to get subjects?

In the third part of a series examining the promise and perils of using personal information in research, **Daryl Loo** looks at how cohort studies have shaped medicine in Singapore.

PROFESSOR Chia Kee Seng loves to tell the story of the late Sir Richard Doll, the British epidemiologist whose work proved that smoking causes lung and heart disease.

Back in 1954, Sir Richard rounded up a whopping 34,000 fellow doctors for the British Doctors Cohort Study, which eventually debunked the then conventional wisdom that lung cancer was caused by car fumes and the tarring of roads.

That study pointed to the usefulness of cohort studies in public health research, said Dr Chia, who is also an epidemiologist — a specialist in the study of illnesses in populations.

The director of the Centre for Molecular Epidemiology, he is the driving force behind the Singapore Consortium of Cohort Studies, which was formed this year with the lofty aim of ultimately recruiting 250,000 local subjects for a decades-long study

on how one's genes and environment interplay to cause common diseases.

While clinical research involves a small number of patients, epidemiological cohort studies track thousands of normal individuals over many years to examine the risk factors of certain illnesses.

More than 10 cohort studies are now ongoing in Singapore.

The consortium project nearly did not get started. Surveys from a year ago found that many Singaporeans were unwilling to take part in medical studies because they saw no benefit; some were also worried that taking part in these studies would uncover previously hidden health problems.

But Prof Chia happily told *The Straits Times* earlier this month that the consortium had managed to sign up about 4,000 subjects in the past six months, adding to the 6,400 it already



TRACKING THOUSANDS: Over 10 cohort studies are ongoing here.

had in hand as of the end of last year.

He said: "We had more publicity, and provided better public information to show that the project is part of a bigger health endeavour. I think that helped convince more people to sign on."

The study is well on its way to reaching its target of signing up 22,000 subjects by 2010.

The difficulty in getting

enough willing subjects is a real issue for researchers. Earlier this month, this newspaper reported that a study that aimed to sign up 5,000 pairs of twins aged 17 and below had to be scaled back because of this.

If getting people on board is a problem, keeping them on board is another. The National University of Singapore's Associate Professor Saw Seang Mei said drop-out rates tend to go up over the

years as the subjects' circumstances change.

Prof Saw, who began a study in 1999 on myopia among about 2,000 pupils, has since "lost" about 17 per cent of her subjects.

She said: "There's no magic number, but ideally, we would like to keep the size of the cohort at about 75 per cent of the original group for accurate results."

One way she has engaged the study subjects' interest is by keeping them updated on the progress of the study through a website, she said.

But it could get easier for these studies to be done soon, as the Bioethics Advisory Committee, Singapore's bioethics watchdog, has recommended laws to make it easier for "the use of personal information in registries, databases and medical records for epidemiological and public health research".

The committee said the information given out should not be traceable to individual patients, thus preserving the confidentiality of the data.

The changes "would definitely make it easier for our work", said Dr N.V. Ramani of the National Neuroscience Institute.

Dr Ramani is heading a study of 15,000 Singaporeans aged 50 and above on dementia, epilepsy, Parkinson's disease and stroke.

"The more data we have, the more accurate our conclusions," he said.

This is crucial, he added, because the results of a study can spin off further research into treatments for a disease.

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Doctors aided by cholesterol, eye research

ASSOCIATE Professor Saw Seang Mei has literally watched 2,000 primary schoolchildren grow up.

Her cohort study on the risk factors that make Singapore children nearsighted began in 1999 and involved pupils from Yio Chu Kang Primary School, Tao Nan School and Rulang Primary School. Many of her subjects have since gone on to secondary school.

Since 1999, they have returned once a year to their primary schools for their eye tests.

"It's also a sort of reunion for some of them," she said.

The study, jointly conducted by the Singapore Eye Research Institute (Seri) and the National University of Singapore, has unearthed startling trends: Singapore children not only get nearsighted at a younger age than children elsewhere, but their eyesight also worsens at a faster rate.

Researchers at Seri have moved on to look into new ways of treating myopia.

The results of cohort studies have also influenced how doctors work here.

For instance, the Health Ministry last month distributed to clinics and hospitals new guidelines on measuring cholesterol levels.

The guide was developed from two earlier cohort studies on cardiovascular and metabolic diseases.

The eyesight and cholesterol studies have since been absorbed into a consortium of cohort studies.

Epidemiologist John Potter of the Fred Hutchinson Cancer Research Centre in the United States said cohort studies have helped lower the incidence of disease by confirming their risk factors, and have led to the development of new drugs.

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Debate over data privacy

THE security of personal health data belonging to participants in biomedical research studies was raised at a recent public forum on the subject.

More than 100 students, medical workers and researchers turned up at the Biopolis for the forum, which was organised by the Bioethics Advisory Committee to discuss its paper on the use of personal information in research.

The paper makes a series of recommendations for ethical research practices, including that new laws be formulated to regulate the use of such personal data.

At the forum, which included presentations and a question-and-answer session with members of the committee, one participant asked whether research participants can seek redress if their private data is leaked to third parties.

Committee member Terry Kaan of the National University of Singapore's law faculty noted that while this has not happened here yet, action can, "in principle" be taken if the individual can prove that he suffered stress or damage as a result of the leak.

He added that if, for instance, a doctor doing research divulges someone's private data, a complaint can be lodged with the Singapore Medical Council. And if found to have been in the wrong, the doctor can be fined or struck off the register.

The committee has submitted its draft proposals to 70 religious, scientific and health-care groups and is seeking more public feedback before submitting them to the Government later this year.

The consultation paper can be viewed at www.bioethics-singapore.org; views can be sent to contactus@bioethics-singapore.org

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