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.

“Large-scale studies valuable, but how to get subjects?” by Daryl Loo

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 Bipola for the forum, which was organized by the Biostatistics Advisory Committee to discuss its paper on the use of personal data.

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 experts, data on how research participants can seek redress if their personal data is linked to third parties.

Committee member Terry Kao of the National University of Singapore’s law faculty noted that while data has not been breached yet, action can and should be taken if personal data is compromised. “This is not a question of if but when,” he said.

The committee has submitted its draft proposal to 20 governmental and health-care groups and is seeking more public feedback before submitting its report to the Government later this year.

The consultation paper can be viewed on the website of the Singapore Medical Council. For more information, contact the Biostatistics Advisory Committee.