

Do it for science, not cash

13-member panel lays out the dos and don'ts of genetic research

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IF YOU'RE banking on choosing the gender of your kid, or picking some of your best traits to pass down to your next generation, you can't do it in Singapore.

But if you want to donate human tissue to do your part for scientific research, you can go ahead. However, expecting payment or coercing someone to do it against their will is out of the question.

These are some of the guidelines laid out in a 53-page report put together by a 13-member Bioethics Advisory Committee on "standard practices" in genetic testing and research.

While the committee has written three previous reports since 2002 on genetic research topics, the current document "puts into one place" all the various ethical guidelines that are already "widely accepted" in Singapore.

Playing a dual role as a member of the committee and chair of the Human Genetics Subcommittee, Associate Professor Terry Kaan Sheung-Hung, Faculty of Law, National University of Singapore, said the document deals with the

"here and now".

"Genetic research is already happening. So we want to send a signal to clinicians and researchers that they should go ahead with their work, so long as the ethical guidelines are there."

Concentrating more on genetic testing by researchers, the latest guidelines include the voluntary nature of genetic testing, the care-

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— Human Genetics Subcommittee chair Associate Prof Terry Kaan Sheung-Hung

ful use of vulnerable subjects like children and the confidentiality of genetic information.

The report was written after consultations that began nearly six months ago with over 100 professional bodies and religious groups, as well as feedback unit sessions with members of the public.

In some cases, said Associate Professor Kaan, the various parties "agreed to disagree".

The Islamic Religious Council

of Singapore noted that voluntary genetic testing which would affect decisions related to marriage, pregnancy and abortion "requires religious opinion from the Fatwa committee".

For example, prenatal genetic diagnosis is conducted on a foetus or a pregnant woman to identify a specific genetic disorder. Presymptomatic testing is available for "adults at risk", which the Council noted may have "religious and social implications".

To this, the committee clarified that people have the right to object.

The guidelines specifically state that genetic testing should be used to "empower an individual or family and for the management or prevention of disease".

A 12-member Institutional Review Board will act as a watchdog to make sure the standards are adhered to, with regular progress reports to monitor research.

If ethical guidelines are violated, funding can be withdrawn.

The board also has the responsibility to verify the authenticity of donations like eggs or human tissue for research.

The Ministry of Health's National Medical Ethics Committee will now be in charge of the implementation process, which the committee hopes will happen "as soon as possible".