

Despite the stakes, public role in bioethics debate falls short

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At what point does human life begin and when does it end? Who is allowed to alter human genes and to what extent?

Discussing bioethics can be like an endless philosophical debate, one that many scientists and biotech firms would perhaps like to avoid. To them, bioethics can be the foe that hinders their progress.

According to Kyoto University law professor Ryuichi Ida, however, every member of society should regard bioethics as a basic universal principle that ensures technological development stays within bounds.

"The most important thing in bioethics is to hold a thorough public debate, reach a consensus on ethical principles and take the appropriate steps," said Ida, 55, who has been a member of the U.N. Educational, Scientific and Cultural Organization's bioethics body since 1996 and was chairman of the committee between 1998 and 2002.

A specialist on international law, Ida was appointed to take part in mapping out the 1997 U.N. Universal Declaration on the Human Genome and Human Rights through the International Bioethics Committee of UNESCO.

He is now working on an outline of the next universal U.N. ethical principles on biotechnology with the IBC.

As a jurist, Ida felt unfamiliar with biotechnology at first. But after joining the UNESCO team, he soon realized that ethical principles and legal systems have one thing in common -- both are established through people's contributions.

Having been involved in bioethics in the international arena, Ida believes Japan lacks understanding of the subject and thus ordinary people allow the debate to be monopolized by a handful of experts.

"Bioethics is an issue that affects all of us in the end," and thus the central government and scientists should be accountable to the public, he said.

In Japan, however, ethical problems are often ignored when new projects are started, Ida said, citing the gene data bank project that is to debut this month.

The five-year project, backed by the Education, Culture, Sports, Science and Technology Ministry, aims to establish a blood-sample genetic information database on **300,000 patients suffering 30 illnesses**, including cancer and diabetes.

Under the so-called biobank project, their blood is analyzed to enable researchers to study the relationship between genetic makeup and diseases.

This will mark a step forward in the effort to create drugs that can be tailor-made to each individual's genetic makeup so they are more effective and safe.

But despite the anticipated benefits, there are **concerns over the possible mishandling of personal genetic information**.

Ida said if the link between genes and diseases is identified, and if a person is found to be carrying a defective gene that is believed will trigger a specific illness in the future, that carrier could be subjected to **discrimination**.

The carrier might face a job rejection or be denied a life insurance policy, he warned.

But what worries Ida the most is that the project was quickly approved by the government without public debate.

"Britain, for instance, had a heated debate for four years before reaching an agreement" on whether to go ahead with a similar project and on what kind of measures to take to avoid risks, Ida said.

Ida believes scientists are more inclined to only talk about the bright side of biotechnology. But regardless of the benefits, they must remember there are always accompanying risks that could undermine human dignity.

"Humankind could lose its way if (such research proceeds) without ethical principles," he said.

Ida is also convinced that the teaching of bioethics should start at the junior high school level so that people can keep up with what is going on and agree on ethical principles.

Even though experts come up with research guidelines whenever new avenues of human biotechnology emerge, Ida said **the entire nation lacks a basic idea of how research should proceed**.

For instance, Japanese biologists who succeeded in producing the nation's first domestically made human embryonic stem cells were required to follow the science ministry's guideline on ES cells, but **the ministry has yet to establish a basic idea on how far embryos can be used for research purposes.**

ES cells are extracted from fertilized eggs left unused from fertility treatment and have the potential to grow into any form of tissue and organ.

Scientists believe ES cells hold promise for regenerative medicine and can help cure such serious diseases as Parkinson's.

The handling of ES cells raises the question of how to deal with those of unborn children. The general public, however, is largely left out of the discussion.

That is why education on bioethics is important, Ida stressed.

"The pursuit of bioethics basically depends on conscience," but that is not necessarily a given, he said. "Establishing ethical principles is only possible if people get involved."

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