

Bioethics and life science in Asia

Asia is a force to be reckoned with when it comes to research in the life sciences. Asian countries play a major role both in shaping international research practices and in the formulation of bioethical research regulation in the field of biomedical research and research applications, including stem cell research, genetic testing and screening, reproductive technologies and the banking of biological materials. Not only wealthy welfare societies such as Japan and Singapore but also large developing countries such as China and India, are strong global competitors at the forefront of biomedical research and biotech applications. These new fields of research, on the one hand, promise to yield revolutionary technologies and biomedical knowledge that could enhance the health and welfare of large patient populations, including diabetes, muscular dystrophy, Parkinson's disease and Alzheimer's disease. On the other hand, bioethical concerns have come about due to the novel and global nature of research in the life sciences and the application of resultant technologies in some regions where even the most basic healthcare is a scarce good.

Margaret Sleeboom-Faulkner

IN MANY FIELDS HOWEVER, biomedical knowledge has indeed contributed to the ability of researchers and doctors to alleviate, what is regarded as, the genetic burden of population groups at risk of certain genetic syndromes including sickle cell disease and thalassaemia (see Patra p.22, Sui p.23). Furthermore, the ability to sample and store genetic data together with information on personal life style, disease history and environment, has contributed to new epidemiological insights into the aetiology of medical and genetic syndromes. Despite these benefits, the development of these new forms of research and its applications are accompanied by old and new social, financial, and political problems, some of which take on particular forms in Asia. These problems occur exactly as a result of using new diagnostic technologies and linking personal health data to people's genetic and biological make-up. Illustrative cases discussed in this special issue of the Newsletter relate to: the increasing need for therapies; social stigma; changing life values; the increased value of biological materials; the need for bioethical procedures; and international research collaboration.

The 'therapeutic gap'

The growing ability and practice of diagnosing and predicting diseases, such as Huntington's Disease and various forms of cancer, makes it a moral imperative to provide genetic counselling and, if possible, therapy to patients diagnosed positive. For instance, in the case of genetically inherited syndromes such as sickle cell disease and thalassaemia, diagnosis should ideally be followed by therapy or medication. Where there is no or little access to healthcare facilities post-diagnosis, we speak of the 'therapeutic gap'. The widespread existence of the therapeutic gap places a moral question mark behind the not-well-thought-through application of diagnostic technologies on carrier populations. Another problem also associated with careless diagnostic applications is that of social stigma, discussed in this special issue by [Prasanna Patra](#) in connection with sickle cell screening in India, by [Suli Sui](#) in relation to thalassaemia in China and by [Masae Kato](#) in connection with amniocentesis in Japan. When it becomes known that members of certain communities or families have a high prevalence of a certain genetic syndrome, varyingly associated with impurity, sin and uncouth behaviour,

entire households run the risk of becoming ostracised by the community. In such cases, the blaming of women for producing unworthy offspring is especially widespread.

When predictive testing leads to abortion, this can lead to a change in life values. This development is illustrated in Masae Kato's case study of the women's and handicapped people's movements in Japan, relating how groups of disabled people feel discriminated against when the abortion of fetuses with 'their' handicap becomes normalised. They experience this as a degradation of their lives. While women in Japan may believe they choose for abortion, [Jyotsna Gupta's](#) study on prenatal testing in India shows how, although the possibility of having an abortion empowers women, they may have no choice other than to have an abortion when opposition exists to raising a girl or an 'imperfect' child. Another issue related to the valuation of human life is exemplified by Suli Sui's case study of thalassaemia, which shows how parents of children with this disorder in China feel about giving birth to a 'saviour sibling'. Such dilemmas raise questions about what life people find worth supporting, a question also answered differently within Asia, with its rich cultural, political and religious variety.

Regulating bioethics

When life scientists started to collect, store and export biological materials from Asian countries on a large scale in the mid 1990s, including human tissues and DNA, the practice of taking people's samples became very controversial, after which its export has been regulated by Asian governments. At the same time, most Asian countries involved in the life sciences introduced bioethical regulation for sample taking to follow due ethical procedures, including informed consent. The taking and storing of biological materials, such as human DNA, reproductive materials, and umbilical cord blood, for the purpose of research or therapy, however, does not always take into account due procedure, as is shown by [Jan-Eerik Leppanen's](#) report of DNA sampling for the ethnic biobank in Kunming in Southwest China. An additional problem faced by developing countries, as shown by [Robert Simpson](#) et al's discussion of bioethical review in South Asia, is that the implementation

of bioethical procedures requires an institutional set up that can be expensive, labour intensive, and therefore hard to maintain.

The new developments of research and applications in the life sciences, then, are accompanied by a concern that new opportunities have come about for the exploitation of vulnerable people. This does not only refer to the use of or trade in human organs, genetic material, human tissues or information based on biomaterials, but also to the use of reproductive materials such as human ova, embryos and foetuses in human embryonic and foetal stem cell research. [Seyoung Hwang](#) and [Leo Kim](#) describe different aspects of the Hwang Woo-Suk scandal in South Korea that revealed how this well-known stem cell scientist used the ova of female laboratory assistants. Seyoung Hwang shows that the role of the public in discussions on bioethical regulation of stem cell science was hardly taken seriously in South Korea's quest to forge ahead in the field; and Leo Kim's account of a Parliamentary Life Science Research Forum illustrates how the 'global war' in stem cell science is emphasised over potential local harm.

Studies on bioethics in Asian societies indicate that life values are changing and vary from country to country. Together with the divergent ability of different countries to set up bioethics institutions, the variety in culture and development has far-reaching implications for the bioethical standards in international science collaborations, especially when countries with relatively permissive regulation become attractive to countries with relatively strict regulation. Contributing researchers of both the Socio-genetic Marginalisation in Asia Programme (SMAP), Leiden and the International Science and Bioethics Collaboration project (Cambridge, Durham and Sussex Universities) have tried to shed light on these implications, in the hope that bioethical problems will be duly acknowledged, recognised and addressed.

Margaret Sleeboom-Faulkner
Project Director, SMAP
University of Sussex, UK
m.sleeboom-faulkner@sussex.ac.uk

