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The Coming of Bioethics to Singapore

W Calvin Ho and Sylvia SN Lim

Bioethics as an institutional concern with focus on biomedical research involving or pertaining to human beings took root with the establishment of the Bioethics Advisory Committee (BAC) by the Cabinet in December 2000, to provide the government with advice on ethical, legal, and social issues that might arise from research. It broke fresh ground under the national Biomedical Sciences Initiative, announced by the government in June that year. This initiative meant that institutional bioethics would develop in tandem with various other policy initiatives directed at expanding the narrow base of the national economy.¹ In particular, investment in biomedical sciences, alongside electronics, engineering, and chemicals, was considered critical in broadening Singapore's secondary export-oriented industrialisation as increasing competition from the region² necessitated a re-shaping of the nation-state's relationship to the global economy and the domestic allocation of resources among industries and major social groups.³ However, the investment is not without its share of controversies given the uncertain nature of biomedical research, limited talent pool, and ethical conundra.⁴

¹Normile D. Can Money Turn Singapore Into a Biotech Juggernaut? *Science* **297**, 5586 (2002): 1470–1473.

²Lim and Gregory identify competitors for inward investment from established firms abroad and for the limited pool of talent to support the growth of the biotechnology sector as Malaysia, Australia, India, Hong Kong, and China. Lim LPL and Gregory MJ. Singapore's Biomedical Science Sector Development Strategy: Is it Sustainable? *Journal of Commercial Biotechnology* **10**, 4 (2004): 352–362, p. 361.

³This notion of development strategy is drawn from Gary Gereffi. See Gereffi G. Paths of Industrialization: An Overview, in *Manufacturing Miracles: Paths of Industrialization in Latin America and East Asia*, eds. G Gereffi and DL Wyman. Princeton, NJ: Princeton University Press, 1990, pp. 3–31, p. 23.

⁴Normile D. An Asian Tiger's Bold Experiment, *Science* **316**, 5821 (2007): 38–41, pp. 39 and 41. See also Cao C. Making Singapore a Research Hub, *Science* **316**, 5830 (2007): 1423–1424.

This chapter provides an account of the institutionalisation of biomedical research ethics in Singapore through the work of the BAC. It draws from interviews that have been conducted with past and present members of the BAC and its sub-committees and working group,⁵ as well as from the authors' personal experiences, having worked in the Secretariat of the BAC since 2001. The chapter further examines the incremental manner by which an ethical framework (based on five key principles) has been developed by the BAC. For some, this ethical framework has come to characterise bioethics in Singapore. It concludes with a discussion of the significance of bioethics for the public and for the biomedical research community.

The work of the BAC comes within the genre of public bioethics, as it addresses ethical conundra arising from biomedical research by recommending policies that are intended to apply to all members of society.⁶ It is not a body that debates foundational issues, such as the fundamental normative values of biomedical science and technology, nor is it concerned with clinical bioethics, although a number of its recommendations do affect clinical practice. Foundational bioethics and clinical bioethics are addressed by other ethical bodies in Singapore. The former lies within the broad remit of the Centre for Biomedical Ethics, which was established in 2005 in the Yong Loo Lin School of Medicine at the National University of Singapore (NUS). The Centre operates under the direction of Alastair Campbell, who is the Chen Su Lan Centennial Professor of Medical Ethics, a position established in honour of one of the nation's best known philanthropists, Dr Chen Su Lan. The BAC collaborates with the Centre on a variety of educational activities for members of ethics review committees or institutional review boards (IRBs), researchers, and the public. In December 2008, the NUS Centre published the inaugural issue of the journal *Asian Bioethics Review* jointly with the Hastings Center, which is one of the field's premier research bodies in the US. Clinical bioethics, on the other hand, has been a concern of the Ministry of Health (MOH), and its National Medical Ethics Committee (NMEC) in particular. Ong Yong Yau, a former Chair of the NMEC, said that the scope of the NMEC

⁵A list of past and present members of the BAC and its sub-committees and working group is set out in Annex A of this publication.

⁶Although the BAC is not focused on calling into question the expectations of scientists concerning particular science and/or technology (such as pharmacogenetics in Adam Hedgecoe's paper), it does moderate these expectations with those of the public. See Evans JH. Between Technocracy and Democratic Legitimation: A Proposed Compromise Position for Common Morality Public Bioethics, *Journal of Medicine and Philosophy* 31 (2006): 213–234; and Hedgecoe A. Bioethics and the Reinforcement of Socio-technical Expectations, *Social Studies of Science* 40, 2 (2010) 163–186.

is narrower than that of the BAC as it is only concerned with issues that arise from medical practice, such as organ donation, end of life issues, and apportionment of healthcare expenditures.⁷ Set up in June 1994, the purpose of the NMEC is to assist the medical profession in addressing ethical issues in medical practice and to ensure a high standard of ethical practice in Singapore. However, he indicated that there should be a close working relationship between the BAC and the NMEC as an increasing number of medical practitioners are involved in research, and biomedical research is finding application in clinical settings at a growing pace. The BAC's report on genetic testing and genetic research was in fact prepared in consultation with the NMEC.

Prior to the establishment of the BAC, formal ethics review of biomedical research was somewhat of a novelty, except in the well established procedures for the regulation of clinical drug trials. The BAC's Deputy Chair, Lee Hin Peng, recalled that he was responsible for setting up an *ad hoc* IRB at NUS when he was the Principal Investigator of a research study with American collaborators in 1992.⁸ This project-specific *ad hoc* IRB was established to satisfy a requirement of funding by the US National Cancer Institute, that research carried out in Singapore be reviewed by a local IRB. Subsequently, an IRB was set up by the National University Hospital, where he served as Deputy Chair. But it was not until 2003 that NUS established its own IRB with him as its Chair.

GOOD SCIENCE AND THE INSTITUTIONALISATION OF RESEARCH ETHICS IN SINGAPORE

From around the turn of the 21st century (and perhaps even before that), an important change occurred in the way that 'good science' has come to be understood, not only in scientifically advanced countries, but also internationally. In the context of global health, the observation of Maureen Kelley and her collaborators is especially pertinent:⁹

"Good science" now means more than rigorous application of scientific methods toward important scientific discoveries. Good

⁷Interview with Professor Ong Yong Yau, 29 April 2009.

⁸Interview with Professor Lee Hin Peng, 27 April 2009.

⁹Kelley M, Rubens CE and the GAPPS Review Group. Global Report on Preterm Birth and Stillbirth (6 of 7): Ethical Considerations, *BioMed Central Pregnancy and Childbirth* **10**, Suppl. 1, S6 (2010): 1–19, p. 1.

science has also come to mean a deliberate attempt to direct methodologically rigorous science toward the disease burden of the underserved across borders. With this move, the role for ethics in science is becoming more than an important constraint on scientific practice and unintended consequences of unbridled discovery. Ethics can also inform and shape the research agendas for institutions and stakeholders interested in improving the lives and alleviating suffering...

Ethics has a profound impact on how biomedical sciences are viewed by society. The legitimacy of biomedical sciences depends not only on methodological rigour, but also on the ethical acceptability of their goals and applications. Edison Liu captures the essence of this in his remark, "Science in the absence of humanity is not only irrelevant but dangerous".¹⁰ He explained that science must be consistent with the fundamental values of society as it can be a destructive force if misapplied. Patrick Tan made a similar point in his observation that 'good science' is also a matter of assessing how far scientific pursuit can be justified within an existing system of norms and values.¹¹ He considered a goal of science to be pushing against knowledge boundaries,¹² so that like 'good art', 'good science' must not only be unquestionable in terms of its intellectual base or rigour, its results and impact must also extend beyond the present. But where a scientific postulation has profound impact on social norms and values, most scientists tend to be wary about pushing too far.

Patrick Tan went on to observe that apart from broader society, scientists are also embedded within their own communities. Due to this and possibly also to the need for funding, scientists tend to be socially conservative by nature and mavericks are rare. 'Good science' emerges as 'spikes' out of the communal effort of smart people working together on an idea within a suitable milieu. Ethical values are important for scientists within their own community, and in their relationship with broader society. As Marilyn Strathern argues, ethics may be understood as 'personal' responsibilities, rights,

¹⁰Interview with Professor Edison Liu, 8 July 2009.

¹¹Interview with Associate Professor Patrick Tan, 26 June 2009.

¹²Dr Lim Bing expressed a similar view. He felt that biomedical research is about "pushing against boundaries", although scientists in general value life. He himself considers all life to be valuable. Interview with Dr Lim Bing, 13 July 2009.

and liabilities which are drawn from more general social sensibilities embedded in all kinds of human interactions and moralities. Consequently, the ends of ethical conduct ensure that, as means, they meet certain criteria in themselves.¹³ Philosopher Nuyen Anh Tuan also observed scientists to be socially more conservative than he thought prior to his experience with the BAC.¹⁴ He was surprised to find that scientists in Singapore tended to avoid socially controversial research even if these controversies lacked ethical or philosophical basis. For instance, scientists have been concerned with the moral status of an embryo even though most philosophers do not regard an embryo as having moral status. Upon reflection, he felt that scientists may have been concerned with public backlash since public opinion was influenced by religious views on the subject. In addition, some scientists as members of society may believe in the sanctity of human personhood as beginning from the point of conception.

Lee Eng Hin, who was Dean of Singapore's only medical school at NUS in 2000, said that the government recognised how intricately biomedical sciences have become intertwined with ethics.¹⁵ Having considered a number of national ethics bodies in the English-speaking world, the BAC was appointed by the government to guide its policies on developing the nation's biomedical research capabilities within an ethical and social normative framework that is acceptable both locally and internationally. He indicated that there was some urgency in fully operationalising the BAC as biomedical research activities had increased exponentially and there was a need to establish clear ethical guidelines for such research especially in the controversial area of human embryonic stem cells. For Singapore's research findings to be accepted internationally it was extremely important for Singapore to have a robust ethical framework. Ethical direction and consistency are further important in sustaining the legitimacy of and commitment to an uncertain long-term venture taken up in the interest of the common good. Tan Chorh Chuan, who was Director of Medical Services (or Chief Medical Officer in some countries) at that time, indicated that the government also recognised that the public must be comfortable with the pace of progress in biomedical sciences, which

¹³Strathern M. Accountability . . . and Ethnography, in *Audit Cultures: Anthropological Studies in Accountability, Ethics and the Academy*, ed. M Strathern. London: Routledge, 2000, pp. 279–304, pp. 292–293.

¹⁴Interview with Associate Professor Nuyen Anh Tuan, 21 April 2009.

¹⁵Interview with Professor Lee Eng Hin, 9 April 2009.

would accelerate with the adoption of the Biomedical Sciences Initiative.¹⁶ Hence, the work of the BAC was not limited to advising the government, but also involved promoting public trust. In particular, the BAC had the critical task of facilitating public deliberation of bioethical issues through appropriate framing of such issues and the provision of accessible and factually accurate information which served as a starting point for discussion.

Since the time of its inception, the members of the BAC have been composed of men and women of high standing, capable of providing balanced views and with the expertise to address ethical, legal, or social challenges that biomedical research presents. Members were also chosen with a view to public engagement.¹⁷ Lim Pin, who has been the longest serving Vice-Chancellor (President) of NUS, from 1981 to 2000, was appointed the founding Chair of the BAC. He said that he was at first reluctant to take on this position as he wanted to focus on medicine (he being an endocrinologist by training) after many years of service to the University.¹⁸ However, he appreciated the importance of the government's Biomedical Sciences Initiative and recognised that the success of the initiative would also depend on a sound ethical basis upon which this enterprise was to be built. He described the role of the BAC as one of steering the development of the scientific enterprise based on understanding its temperament and characteristics through close interaction with interested stakeholders but without being directive or overbearing. The BAC does not possess a definite legal identity or statutory powers although it is mandated to formulate policies that, if accepted by the government, profoundly influence the course of biomedical research. This characteristic of the BAC is similar to the national bioethics bodies in a number of countries, such as the US. In 1996, members of the US National Bioethics Advisory Commission were appointed by President Bill Clinton,¹⁹ and such appointments have remained the practice through three different administrations since that time. The situation differs in the UK where, as Alastair Campbell observed,²⁰ membership positions to serve on ethical set-ups like the Nuffield Council on Bioethics and the Biobank Ethics and Governance Council are advertised

¹⁶Interview with Professor Tan Chorh Chuan, 4 May 2009.

¹⁷Interview with Ms Tricia Huang, 22 April 2010.

¹⁸Interview with Professor Lim Pin, 27 April 2009.

¹⁹For an evaluation of the work of the US National Bioethics Advisory Commission, see Eiseman E. *The National Bioethics Advisory Commission: Contributing to Public Policy*. Arlington, VA: RAND, 2003.

²⁰Interview with Professor Alastair Campbell, 15 April 2009.

in furtherance of the Nolan principles.²¹ However, he recognised that this approach may not be suitable for Singapore as the UK has a larger pool of expertise to draw on. In addition, there is a longer tradition of volunteerism in policy-related public service among very qualified people in the UK.²²

Since 2002, the BAC has provided recommendations to the Steering Committee on Life Sciences, which was constituted by the Cabinet in June 2000 as the Life Sciences Ministerial Committee. The Steering Committee is responsible for fostering the development of biomedical sciences through various policy measures, including the coordination of activities of government ministries such as the Ministry of Trade and Industry, the Ministry of Education, and the Ministry of Health. As we have seen, the establishment of the BAC is a proactive initiative by the government to ensure that biomedical research in Singapore is conducted under standards of ethical governance that are acceptable both locally and internationally.

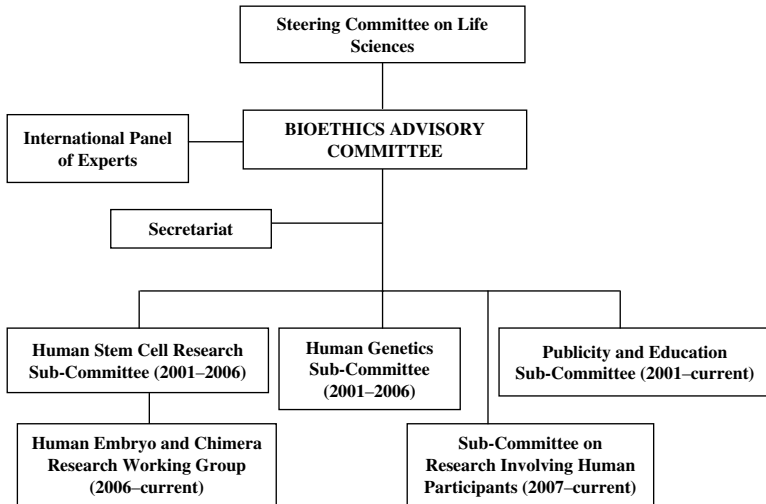
From the time of its inception, the BAC has constituted four sub-committees and a working group (see Fig. 1) to assist it in examining specific issues in more detail. The Human Stem Cell Research Sub-Committee (HSCRS), the Human Genetics Sub-Committee (HGS), and the Publicity and Education Sub-Committee (PES) were formed in 2001. The HSCRS and the HGS concluded their term in 2006. A working group on Human Embryo and Chimera Research (HECR) was formed in 2006 and the Sub-Committee on Research Involving Human Participants was formed in 2007. Their work is still ongoing, as is the work of the PES. Between 2002 to 2008, six sets of recommendations were published by the BAC, and they relate broadly to the subjects of human embryonic stem cell research and cloning, human tissue, research involving human subjects, and genetics.²³ All the recommendations have been prepared after detailed review of international ethical and regulatory norms, ethical and regulatory practices in key jurisdictions, and after public consultation. In addition, they have also been reviewed by the BAC's International Panel of Experts²⁴ and endorsed by the Biomedical Sciences International

²¹Committee on Standards in Public Life, UK, *The First Seven Reports: A Review of Progress*, September 2001. The seven principles of public life have been set out as selflessness, integrity, objectivity, accountability, openness, honesty and leadership.

²²Bill Bryson, ed. *Seeing Further: The Story of Sciences and the Royal Society*. London: Harper-Press, 2010.

²³See Annex C of this book for a list of reports published by the BAC between 2002 and 2008.

²⁴See Annex B of this book for information on members of the International Panel of Experts.



Terms of Reference

The BAC has two main roles:

1. Examine ethical, legal, and social issues arising from research on human biology and behaviour and its applications; and
2. Develop and recommend policies to the Steering Committee on Life Sciences on these issues.

The BAC has three priorities:

1. Protection of the rights and welfare of individuals;
2. Public education and a source of information on bioethical issues; and
3. Identification of broad principles to govern the ethical, legal, and social implications of human biomedical research.

Fig. 1. The Organisation Structure of the BAC and its Terms of Reference.

Advisory Council.²⁵ These recommendations have since been accepted by the government and all registered medical practitioners who are involved in biomedical research are required to observe the BAC's recommendations under a directive issued by the Director of Medical Services in 2006.²⁶ The work of the BAC and significant international and local events surrounding its work are listed in the table in Annex D of this book.

²⁵The Biomedical Sciences International Advisory Council is composed of eminent scientists and visionaries in the field of biomedical sciences. More information is available at: <http://www.a-star.edu.sg/AboutASTAR/BiomedicalResearchCouncil/BMSInitiative/BMSIAC/tabid/352/Default.aspx>.

²⁶Ministry of Health, Singapore, *Directive 1A/2006: BAC Recommendations for Biomedical Research*, 18 January 2006.

RECOMMENDATIONS IN RELATION TO HUMAN STEM CELL RESEARCH AND CLONING

The first set of recommendations on human stem cell research and cloning was prepared by the HSCRS and published by the BAC in June 2002.²⁷ Richard Magnus (then Senior District Judge), Chair of the HSCRS, explained that the BAC had decided to prioritise its deliberation on stem cell research and cloning because of local research interest in the field. There was also a need to clarify Singapore's position as political contention over the subject intensified.²⁸ Ng Soon Chye said that local researchers had been involved in IVF-related embryo research for some time. He himself was working with Ariff Bongso on embryo research, and was also interested in therapeutic cloning involving primates.²⁹ In 2000, the establishment of ES Cell International, which aimed to develop therapies from human embryonic stem cells, drew public attention to Singapore's engagement in this ethically contentious area of embryonic stem cell research. In the year that followed, the then US President George W Bush limited public funding to certain established embryonic stem cell lines and an international treaty to ban cloning was considered by the United Nations.³⁰ Not surprisingly, many past and present BAC members consider human embryonic stem cell research and cloning to have been the most ethically contentious subject that the BAC considered.

Among the documents considered by the BAC, the Warnock report³¹ and a report on the subject by the US National Bioethics Advisory Commission³² have been important resources. To counter any misperception that Singapore intended to lure stem cell researchers with lax regulatory policies, the BAC was careful not to deviate from the ethical and regulatory policies of major

²⁷Bioethics Advisory Committee, Singapore, *Ethical, Legal and Social Issues in Human Stem Cell Research, Reproductive and Therapeutic Cloning*, June 2002.

²⁸Interview with Mr Richard Magnus, 18 April 2009.

²⁹Interview with Professor Ng Soon Chye, 26 May 2009.

³⁰For a more detailed analysis of events surrounding the BAC's recommendations on human stem cell research and cloning, see Ho WC. Governing cloning: United Nations' Debates and the Institutional Context of Standards, in *Contested Cells: Global Perspectives on the Stem Cell Debates*, eds. B Capps and A Campbell. In press: World Scientific/Imperial College London, 2010.

³¹Warnock M, *Report of the Committee of Enquiry Into Human Fertilisation and Embryology*, UK Committee on Human Fertilisation and Embryology, 1984.

³²National Bioethics Advisory Commission, USA, *Ethical Issues in Human Stem Cell Research*, 1999.

scientific jurisdictions. The policies of the UK, US, Canada, and Australia were especially important due to historical factors and institutional affiliations, as well as broadly similar political cultures. As the Biomedical Sciences Initiative was understood from the start to be a long-term investment, it was critical for Singapore not to stand out as an apparent 'rogue state'. However, as Richard Magnus observed, a consequence of this approach is that the BAC's recommendations may come across as having a 'Western' character, even though there are distinctively 'local' features, such as the recommendation by the BAC for no one to be "under a duty to participate in any manner of research on human stem cells, which would be authorised or permitted by the law, to which he has a conscientious objection".³³

Another important development that was initiated from the first report of the BAC was the progressive promulgation of a set of ethical principles or 'goals' that should be the basis of ethical review of biomedical research in Singapore. This case-by-case development of the ethical framework resembles the approach of the UK Nuffield Council on Bioethics.³⁴ Five ethical principles (justice, sustainability, respect for individuals, reciprocity, and proportionality) have been restated in their entirety in the BAC's 2008 report on egg donation (2008 restatement).³⁵ They may arguably be viewed as representative of ethical thinking in Singapore, in much the same way as the Belmont principles (respect for persons, beneficence, and justice)³⁶ or the four ethical principles (respect for autonomy, beneficence, non-maleficence, and justice) of Beauchamp and Childress³⁷ have come to characterise American bioethics.

Two of the five ethical principles, 'just' and 'sustainable', were set out in the first report. However, the ethical content of 'just' and 'sustainable' set out in relation to stem cell research and cloning is broader than that

³³Bioethics Advisory Committee, Singapore, *Ethical, Legal and Social Issues in Human Stem Cell Research, Reproductive and Therapeutic cloning*, June 2002, p. 35, Recommendation 11.

³⁴The BAC is similar to the Nuffield Council on Bioethics in a number of ways. Like the Council, the BAC is also not bound by the values of particular schools of philosophy or approaches in bioethics. See Whittall H. A Closer Look at the Nuffield Council on Bioethics, *Clinical Ethics* 3 (2008): 199–204.

³⁵Bioethics Advisory Committee, Singapore, *Donation of Human Eggs for Research*, November 2008, p. 10, para 4.1.

³⁶The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, USA, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, 18 April 1979.

³⁷Beauchamp TL and Childress JF. *Principles of Biomedical Ethics*. New York: Oxford University Press, 2008 (6th ed).

of the restatement as they also relate to a policy orientation of the BAC. The principles of 'just' and 'sustainable' in the former context relates to fair representation and viable course of action. Sociologist Eddie Kuo observed that in Singapore, consensus may be difficult to arrive at given the diversity in religion, ethnicity, and culture that constitutes the Singaporean public. This challenge was similarly acknowledged by many of the past and present BAC members who were interviewed. Despite this, Tan Chorh Chuan indicated that as a diverse society, open consultation can be a constructive and inclusive platform for fair representation of different viewpoints in the interest of fostering better understanding of these perspectives and of building consensus.

The right to conscientious objection was adopted out of respect for persons and leaves some leeway for certain groups that are opposed to the research. BAC Chairman Lim Pin similarly observed that Singapore is a diverse society and hence an empathic, practical, and realistic approach is often necessary to avoid a standstill and social stagnation. On the stem cell debate, he recognised that those opposed to the research are sincere and not motivated by self-interest. However, as there is no single dominant view on the subject in Singapore, it was necessary for the BAC to craft a *sustainable* position even if not everyone will agree, provided that they have had a *fair* opportunity to express their views. In other words, the BAC has been a critical intermediary in bringing together views, in some cases irreconcilable, of different groups and communities. Hence, the principles of 'just' and 'sustainable' as presented in the context of stem cell research and cloning related to a public policy orientation of the BAC, whereas the 2008 restatement of these principles are directed more specifically at research, so that 'just' is concerned with the fair distribution of the benefits and burdens of research, whereas 'sustainable' is directed at the impact of research on future generations.³⁸

As it turned out, a 14-day limit on the development of embryos for research, coupled with regulatory control and the right to conscientious objection, constituted a plausible passage through an ethical impasse. The

³⁸Bioethics Advisory Committee, Singapore, *Donation of Human Eggs for Research*, November 2008, p. 10, para 4.1 (d) and (e). The ethical principles of 'just' and 'sustainable' thereby follow from the BAC's narrower reading of 'just' as allowing "research with tremendous potential therapeutic benefits to mankind" to proceed and 'sustainable' as producing research with "little biological or genetic impact on future generations". See Bioethics Advisory Committee, Singapore, *Ethical, Legal and Social Issues in Human Stem Cell Research, Reproductive and Therapeutic Cloning*, June 2002, p. 35, para 47.

recommendations of the BAC include proposals for stringent regulation of human embryonic stem cell research in Singapore and the legal prohibition of reproductive cloning, which was taken up by the legislature with the enactment of the *Human Cloning and other Prohibited Practices Act* in 2004.³⁹ For research that involves the creation of human embryos (such as therapeutic cloning), specific regulatory approval is required. In addition, the research must also be justified by strong scientific merit and potential medical benefit.⁴⁰

Following the publication of these recommendations, scientific developments in relation to cloning and induced pluripotent stem cell technologies necessitated a review of the recommendations. This was formally undertaken by the HECR Working Group in 2007, with a focus on the ethical, legal, and social issues arising from the procurement and use of human eggs for biomedical research, and on research involving human-animal combinations. Apart from scientific developments, review of these areas was considered necessary following the scandal involving unethical procurement of human eggs for research in South Korea⁴¹ and, more importantly, revisions to ethical policies and guidelines in the United States, Australia, Canada, and a number of European countries such as Britain and Denmark. This initiative was also undertaken by the BAC as part of its longer-term intention to consolidate its views and recommendations in the area of human embryonic stem cell research.⁴² It was apparent that there was increasing pressure to find a sustainable source of eggs for research, particularly for stem cell science, where the scarcity of human eggs is the limiting factor for therapeutic cloning. One solution is to use animal eggs, which became part of the public consultation on human-animal combinations conducted immediately following the closure of the consultation on egg donation.⁴³ Another alternative is to increase the number of eggs donated by women. One of the issues this raised was the possibility of offering incentives to donate for research purposes. This introduced

³⁹Singapore Statutes: *Human Cloning and Other Prohibited Practices Act* (Cap. 131B), Revised 2005.

⁴⁰Bioethics Advisory Committee, Singapore, *Ethical, Legal and Social Issues in Human Stem Cell Research, Reproductive and Therapeutic Cloning*, June 2002, pp. 27–29.

⁴¹Cyranoski D. Korea's Stem-Cell Stars Dogged by Suspicion of Ethical Breach, *Nature* **429**, 6987 (2004): 3.

⁴²Bioethics Advisory Committee, Singapore, Press Release, 7 November 2007, para 2.

⁴³Bioethics Advisory Committee, Singapore, Press Release, 8 January 2008. The late Anne McLaren indicated that human eggs are scarce and not usually available for research: McLaren A. Free-Range Eggs? *Science*, **316**, 5823 (2007): 339.

not only the issue of egg trading, but also the possibility of inducing women into a potentially risky and invasive procedure of ovarian stimulation and egg collection with no direct therapeutic benefit.⁴⁴

Recommendations relating to the donation of human eggs for biomedical research were published by the BAC at the end of 2008, after public feedback was received on various issues presented in a consultation paper⁴⁵ and at a public forum on 11 November 2007. In addressing the issue of egg donation, the BAC took the opportunity to clarify the scope of the 'non-commercialisation of the human body' requirement under the principle of respect for individuals. This principle was earlier applied in the context of donation of human tissue for research, where the BAC indicated that the donor should relinquish any property or property-like claims over the 'gifted' tissue.⁴⁶

Although a donor may make an outright gift of his or her tissue in the sense [that] he or she renounces any property rights to or in connection with the tissue, it is entirely open to the donor to stipulate or define the kind of research uses to which the tissue may be applied.

In its report on egg donation, the BAC recommended that women donating eggs for research should be reimbursed for expenses incurred and compensated for loss of time and earnings as a result of the procedures required to obtain the eggs.⁴⁷ Non-commercialisation of eggs was emphasised, as this was regarded as necessary to avoid putting women at risk of exploitation.⁴⁸ This is consistent with the BAC's goal of safeguarding the welfare of all research participants. Should an egg donor suffer from any medical complication as a direct and proximate result of the donation, she should be provided with prompt and full medical care. This provision gives effect to public feedback on the need to ensure that medical care is available for adverse

⁴⁴Bioethics Advisory Committee, Singapore, *Donation of Human Eggs for Research*, November 2008, p. 4, para 1.3.

⁴⁵Bioethics Advisory Committee, Singapore, *Donation of Human Eggs for Research: A Consultation Paper*, 7 November 2007.

⁴⁶Bioethics Advisory Committee, Singapore, *Human Tissue Research*, November 2002, p. 24, para 8.6.

⁴⁷Bioethics Advisory Committee, Singapore, *Donation of Human Eggs for Research*, November 2008, p. 3, Recommendation 6.

⁴⁸*Ibid.* pp. 16 and 17, paras 4.16–4.21.

health consequences arising from the egg donation procedure. Responsibility for this provision rests with the researchers and their institutions.⁴⁹

The BAC maintains that the ethical requirement for the donation of tissue (which includes embryos) for research to be outright gifts is not compromised so long as the contribution is not tainted by any inducement.⁵⁰ The giving of eggs for research is still altruistic if compensation that is directed at ensuring the financial neutrality of the contributor does not amount to an inducement. In other words, it is consistent with the principle of justice to allow compensation to be provided for loss of time and earnings that are consequential to the donation. In contrast, women should not be compensated for the donation of eggs for research when these are surplus to the treatment or obtained as a result of other medical treatments. No additional discomfort or inconvenience would have been assumed by these women as the risk, discomfort, and lost time are already an inherent part of the treatment.⁵¹ Hence, the BAC did not consider the 'compensated egg sharing' schemes adopted in the UK to be acceptable in Singapore.⁵²

The BAC took the view that respect for the human body is fundamental to ethical thinking and conduct in both medical practice and biomedical research.⁵³ Commercialisation of the human body, by treating it, or part of it, as a disposable economic asset is generally taken to be inconsistent with this principle. It noted that this view is not unchallenged, but insofar as it underpins current ethical thinking in Singapore, it supports a view that financial inducement to provide tissues or cells for research would amount to a form of commercialisation and is not acceptable.⁵⁴ This view found support among public institutions and the general public.⁵⁵

⁴⁹ *Ibid.* p. 3, Recommendation 5.

⁵⁰ *Ibid.* p. 16, para 4.18, reiterating the position taken in *Human Tissue Research*, November 2002, pp. 35–36, paras 13.1.8–13.1.10.

⁵¹ *Ibid.* p. 22, para 4.28.

⁵² *Ibid.* pp. 20–21, paras 4.23–4.24. On the position in the UK, see Capps B and Campbell A. Why (only some) Compensation for Oocyte Donation for Research Makes Ethical Sense, *Journal of International Biotechnology Law* 4 (2007): 89–102.

⁵³ Bioethics Advisory Committee, Singapore, *Donation of Human Eggs for Research*, November 2008, p. 16, para 4.16.

⁵⁴ Campbell AV. *The Body in Bioethics*. Oxford and New York: Routledge-Cavendish, 2009. See also Ho WC, Capps B and Voo TC. Stem Cell Science and its Public: The Case of Singapore, *East Asian Science, Technology and Society: an International Journal* 39, 1 (2010): (in press).

⁵⁵ See feedback from public consultation published with the report: Bioethics Advisory Committee, Singapore, *Donation of Human Eggs for Research*, November 2008, pp. C-2 to C-111. No respondent indicated support for the sale of human eggs.

In January 2008, a consultation paper on research involving human-animal combinations was distributed for public discussion and comment.⁵⁶ As with the consultation paper on egg donation, but unlike other consultation papers previously issued by the BAC, this paper did not propose any recommendations and thus had a more open-ended character. BAC member Nazirudin Mohd Nasir welcomed this approach as it presented the BAC as initiating consultation without committing to any ethical position.⁵⁷ HECR Working Group Chairman Richard Magnus⁵⁸ and member Eddie Kuo⁵⁹ were concerned that the subject of human-animal combinations is too broad and complex, thereby compounding the difficulty in assessing its ethical and social implications. Stem cell researcher and member of the HECR Working Group, Lim Bing,⁶⁰ further indicated that research involving human-animal combinations could be technically challenging even for IRB members. Hence, there may be a need for a specialist ethics body to be established for the review of such research at a national level. Although human-animal combinations is complicated and may not be a matter of public concern, Ng Soon Chye stated that it would not be sensible to delay consideration as human-animal combinations are increasingly commonplace constructs in biomedical research, and it is important that scientists know the ethical boundaries.⁶¹ Recommendations on this subject are still being debated and deliberated on by the HECR Working Group and the BAC.

RECOMMENDATIONS IN RELATION TO RESEARCH INVOLVING HUMAN SUBJECTS AND GENETICS

The HGS was responsible for a series of recommendations which served to systematise ethical governance of research using human tissue, research involving human subjects, and genetics research. These recommendations were published in four reports. HGS Chairman Terry Kaan⁶² said that the topics considered were drawn from a broad review of ethical, policy, and regulatory debates around the world, and in consultation with the local medical and research communities. The need for a set of national guidelines on

⁵⁶Bioethics Advisory Committee, Singapore, *Human-Animal Combinations for Biomedical Research: A Consultation Paper*, 8 January 2008.

⁵⁷Interview with Mr Nazirudin Mohd Nasir, 1 April 2010.

⁵⁸Interview with Mr Richard Magnus, 18 April 2009.

⁵⁹Interview with Professor Eddie Kuo, 28 April 2009.

⁶⁰Interview with Dr Lim Bing, 13 July 2009.

⁶¹Interview with Professor Ng Soon Chye, 26 May 2009.

⁶²Interview with Associate Professor Terry Kaan, 16 June 2009.

the ethical derivation and use of human tissue was a pressing concern at that time as human tissue is a fundamental resource for most biomedical research. Fortunately, the HGS did not have to 're-invent the wheel' as many medical practitioners and researchers, especially those with some level of training in leading scientific jurisdictions, would already be familiar with ethical requirements. In many instances, the HGS focused on developing a set of ethical practices that was best suited to local conditions by drawing from the best ethical practices in key jurisdictions. The task was no less challenging as it was not always easy to decide which of the available ethical best practices is most suitable, particularly if the immediate objectives of medical practitioners and researchers do not converge.

The report on human tissue research, published in November 2002, provides a set of national ethical guidelines to be applied uniformly to all persons involved in human tissue banking and research using human tissue in Singapore. The ethical principles (referred to as governing ethical principles) embodied in the guidelines have been set out as the primacy of the welfare of tissue donors, the need for informed consent, confidentiality and ethics review, respect for the human body, and sensitivity towards the religious and cultural perspectives and traditions of tissue donors.⁶³ As earlier considered, the ethical requirement of non-commercialisation follows from the principles of respect for the human body and the primacy of the welfare of tissue donors. All the governing ethical principles are in turn encapsulated within the principle of respect for individuals under the 2008 restatement of the BAC's general ethical principles. Kaan said that once a set of ethical guidelines for human tissue research was developed, it then became necessary to consider how bioethical oversight was to be carried out. An ideal ethics governance structure should be enabling, so that researchers and their IRBs can work through differences.

In November 2004, a set of guidelines for IRBs on research involving human subjects was published to formalise the requirement for all human biomedical research in Singapore, including research involving human tissue or medical information, to be subject to ethics review. These guidelines built on the existing system of regulations for pharmaceutical trials and human biomedical research conducted by hospitals, private clinics, and other healthcare establishments under the supervision of the MOH. The NMEC's

⁶³Bioethics Advisory Committee, Singapore, *Human Tissue Research*, November 2002, pp. 33–36, para 13.1.

guidelines on research involving human subjects⁶⁴ and the Singapore Guideline for Good Clinical Practice⁶⁵ were the most influential. The BAC's IRB guidelines⁶⁶ set out the constitution, accreditation, and operation of IRBs, as well as the roles and responsibilities of IRBs, research institutions, and individual researchers. The normative justification for the structure of ethical governance is in turn grounded in internationally accepted values promulgated in documents such as the *Declaration of Helsinki*, the *Nuremberg Code*, the *Belmont Report*, and UNESCO's *Universal Declaration on the Human Genome and Human Rights*.⁶⁷ In the main, the ethical principles⁶⁸ that underlie the structure of ethical governance entailed in the IRB Guidelines (and in addition to those already specified by the NMEC) are captured by the principle of respect for individuals under the 2008 restatement. Also implicit in the structure is the principle of proportionality, most evidently reflected in the different levels of ethics review (exempted, expedited, or full review). All human biomedical research, which "involves any direct interference or interaction with the physical body of a human subject, and that involves a concomitant risk of physical injury or harm, however remote or minor"⁶⁹ should be "... [fully] reviewed and approved by a properly constituted ethics committee or IRB".⁷⁰ However, research using established commercially available cell lines or commercially available and anonymised human material or research involving the analysis of patients' information but without any interaction with patients may be exempted from ethics review or qualify for expedited review.⁷¹

The principles of reciprocity and proportionality are explicitly set out and explained in the BAC's deliberations on genetic research. Ethical governance

⁶⁴National Medical Ethics Committee, Singapore, *Ethical Guidelines on Research Involving Human Subjects*, August 1997.

⁶⁵Ministry of Health, Singapore, *Singapore Guideline for Good Clinical Practice*, 1998, Revised 1999. This document has the regulatory effect under Section 21 of the *Medicines (Clinical Trials) (Amendment) Regulations*, 2000 Revised Edition.

⁶⁶Bioethics Advisory Committee, Singapore, *Research Involving Human Subjects: Guidelines for IRBs*, November 2004.

⁶⁷*Ibid.* p. 25, para 4.8.

⁶⁸*Ibid.* p. 27, para 4.17. These ethical principles are respect for the human body, welfare and safety, and for religious and cultural perspectives and traditions of human subjects, respect for free and informed consent, respect for privacy and confidentiality, respect for vulnerable persons, and avoidance of conflicts of interest or the appearance of conflicts of interest.

⁶⁹*Ibid.* p. 17, para 3.7 (a).

⁷⁰*Ibid.* p. 18, para 3.9.

⁷¹*Ibid.* p. 19, para 3.15 (c), and p. 20, para 3.18 (c).

of genetic research was formulated to apply at two different junctures: at the point where genetic information is derived through various means of testing, and in the management and use of the information itself. The report on genetic testing and genetic research served to operationalise a number of internationally recognised ethical considerations in the local context. These ethical considerations relate essentially to the principle of respect for individuals, as they require respect for the welfare, safety, and religious and cultural perspectives and traditions of individuals; informed consent; respect for vulnerable persons; and privacy and confidentiality of genetic information.⁷² Specific ethical considerations have also been set out by the BAC in relation to five types of genetic testing and it further recommended that non-consensual or deceitful taking of human tissue for the purpose of genetic testing be prohibited by law.⁷³

There are at least two features that point to a less individualistic (and perhaps more communitarian) approach to decision-making for genetic testing. First, genetic testing is by and large regarded as a medical procedure. Consequently, genetic information is seen effectively as medical information even though its accessibility to certain third parties (such as insurers and employers) may be more limited than general medical information.⁷⁴ Second, the BAC agrees with the World Health Organization that pre-symptomatic or susceptibility testing of children and adolescents should be carried out only if there are potential medical benefits to them.⁷⁵ However, in a specific application of carrier testing, the BAC recognises that it would be ethical for such testing to be done if the family concerned could benefit from this knowledge:

We recognise that as a matter of principle, carrier testing in asymptomatic children should generally be deferred until the child is mature or required to make reproductive decisions. This is because to do otherwise is to risk pre-empting a later decision by the child, when adult, not to know his or her own genetic status or have it made known to others . . . However, the defence of this right

⁷²Bioethics Advisory Committee, Singapore, *Genetic Testing and Genetic Research*, November 2005, p. 23, para 4.1.

⁷³*Ibid.* pp. 30–41, and p. 9, Recommendation 4.

⁷⁴*Ibid.* p. 22, Recommendation 1.

⁷⁵World Health Organization, *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services*, 1998, p. 9, Table 6.

must be weighed against the interests of other family members, the proper medical care of whom may depend on full and accurate information about a genetic condition in the family, as well as the wider public health interests of a given community. In Singapore, genetic screening programmes for at-risk groups aimed at lowering the incidence of lethal or disabling genetic conditions common in the local population, such as thalassaemia, are widely supported by both the medical profession and the public . . . Where compelling interests of other family members or public health exist, we are of the view that the physician should be able to decide, together with the parents, whether or not to determine the carrier status of the child . . . (emphasis added)⁷⁶

The social and ideological significance of communal interest was the basis for the principle of reciprocity in the BAC's report on personal information. This principle was explained as:

. . . the idea that accepting benefit from past medical research, inherent in the utilisation of medical services, carries some expectation of a willingness to participate in research for the common good or public interest. This is an especially important consideration in societies, including Singapore society, where individuals are seen as incurring obligations to others through their membership of and roles in society. In the wider public interest, therefore, we see the principles of autonomy and reciprocity as complementary.⁷⁷

Nuyen Anh Tuan explained⁷⁸ that reciprocity presupposes individuality in that each agent is seen as independent and autonomous. These agents will co-operate with one another if it serves their interests, on a "you scratch my back, I scratch yours" rationale. Hence, reciprocity is entailed in co-operation. In contrast, the principle of solidarity presupposes a community

⁷⁶Bioethics Advisory Committee, Singapore, *Genetic Testing and Genetic Research*, November 2005, p. 26, para 4.13.

⁷⁷Bioethics Advisory Committee, Singapore, *Personal Information in Biomedical Research*, May 2007, p. 27, para 5.19.

⁷⁸Interview with Associate Professor Nuyen Anh Tuan, 21 April 2009.

wherein agents have particular social roles based on their positions in the community. In this respect, solidarity is similar to Confucianism,⁷⁹ and cooperation is undertaken for the preservation of the community. Although reciprocity and solidarity are conceptually different, their net effect is the same in that the interests of a community are served.⁸⁰ Nuyen considered the BAC to have brought the notions of individualism (in reciprocity) closer to solidarity with its indication that reciprocity is not just an exercise of self-interest, but a duty to contribute a return to the community under a sense of continuity as involving future generations and having benefited from past generations.⁸¹ Ethical justification grounded in the principle of reciprocity was applied to the recommendation of the BAC to provide firm legal footing to disease registries that employ personal information in public health research.⁸² This recommendation contributed to the enactment of the *National Registry of Diseases Act* later that year.⁸³

Also explicated in its report on the use and management of personal information in biomedical research is the principle of proportionality *vis-à-vis* informed consent (or more generally, autonomy). It indicated that: “the process of obtaining consent should be detailed in proportion to the sensitivity of the research and the actual or perceived risk of harm to the individual concerned”.⁸⁴ It followed that general consent would suffice for research using de-identified information, but specific consent is required for the types of genetic research that may be of public concern, such as those relating to personality, behavioural characteristics, sexual orientation, and intelligence.⁸⁵ The application of this principle is further evident in the BAC’s discussion on

⁷⁹Nuyen AT. Moral Obligations and Moral Motivation in Confucian Role-Based Ethics, *Dao* 8 (2009): 1–11.

⁸⁰For a discussion on the ethical principles of reciprocity, solidarity, mutuality, citizenry, and universality, see Knoppers BM and Chadwick R. Human Genetics Research: Emerging Trends in Ethics, *Nature Reviews: Genetics* 6 (2005): 75–79.

⁸¹The BAC explained that “Existing patients are receiving the benefits of improved medical care through the use of medical information from past patients for research. There is little ethical justification for them to refuse a similar use of their medical information where their interests are not likely to be compromised.” See Bioethics Advisory Committee, Singapore, *Personal Information in Biomedical Research*, May 2007, p. 30, para 5.25.

⁸²*Ibid.* p. 33, Recommendation 3.

⁸³Singapore Statutes: *National Registry of Diseases Act* (Cap. 201B), Revised 2008.

⁸⁴Bioethics Advisory Committee, Singapore, *Personal Information in Biomedical Research*, May 2007, p. 25, para 5.13.

⁸⁵*Ibid.* p. 25, para 5.11.

de-identification and the accessibility of personal information by third parties such as employers and insurers.⁸⁶

THE VALUE OF BIOETHICS

The public has had a part to play in shaping the ethical framework put forward by the BAC. The BAC's recommendations are the outcome of professional and, in almost every case, extensive public feedback and suggestions. All public consultations have been widely publicised by the local media in order to encourage public deliberation and participation, and at least one public forum would be organised. In a number of cases, special meetings with religious group leaders and researchers were convened. The BAC has also worked closely with REACH (Reaching Everyone for Active Citizenry @ Home), the lead agency for engaging and connecting with citizens of Singapore. Previously known as the Feedback Unit, it has been tasked by the government to encourage and promote an active citizenry through citizen participation and involvement. Although the work of the BAC does not directly relate to government policies (such as tax, transportation, or education), Toh Yong Chuan and Lilian Ong of REACH said that it shares the BAC's interest in enabling the public to engage with bioethical issues and in gathering feedback on these issues.⁸⁷ In this connection, REACH has assisted the BAC in facilitating public discussion on bioethical issues and gathering public feedback. Although REACH has over 10,000 people on their contact list, including Singaporeans who are overseas, Toh and Ong indicated that bioethics is not a subject that many are naturally interested in. They added that when bioethical issues are presented to the public, it is important to be clear about the 'target audience', such as making a distinction between issues that affect the general public and those that are of interest only to researchers.

How much public interest in bioethics can we expect? Cheong Yip Seng, former Chair of the PES, said that it would be difficult to interest every member of society in bioethics given its technical nature. In addition, the 'man in the street' might not see the need to get involved as the Singaporean public has a high regard for science and especially learning.⁸⁸ There would not

⁸⁶ *Ibid.* pp. 20–22 (on de-identification) and pp. 38–41 (on access to medical information by employers and insurers).

⁸⁷ Interview with Mr Toh Yong Chuan and Ms Lilian Ong, 19 June 2009.

⁸⁸ Interview with Mr Cheong Yip Seng, 9 April 2009.

ordinarily be a need to question the way in which science and technology are managed in Singapore, much in the way that the general public would not be too concerned with how the Monetary Authority of Singapore manages the financial system. However, he felt it would still be important for the BAC to frame issues in a manner that could involve as much of the public as possible. He considered the BAC's website and the media to be important means by which the BAC could engage the public. This engagement is important because it gives legitimacy to the research and makes clear what the ethical expectations are for both the public and researchers. He added that when he was editor of *The Straits Times* (the main English language newspaper in Singapore), a science section was introduced to keep its readers informed of recent scientific advancements.

Han Fook Kwang, who took over from Cheong Yip Seng as Chair of the PES, shared a similar view.⁸⁹ He said that most Singaporeans have little knowledge of the BAC and its work, as it does not deal with 'bread-and-butter' issues. He added that Singaporeans are generally very practical and have to cope with "a very noisy world out there. Bioethics could get 30 seconds of fame with interesting personalities or issues, but it is not a daily news item." He also agreed with Mr Cheong that the public has a fairly positive view of the government and its ability, and hence may not see the need to get involved. However, public engagement is still important to ensure that the public understands (or does not misunderstand) the significance of investing in biomedical sciences.⁹⁰ He added that there has fortunately been no major issues so far but would not rule out a potential 'blow-up' if there was misunderstanding over a particular issue. He was not sure if it was meaningful for the BAC to try to engage the public in a general way over bioethical issues. The best approach was to do so when there are specific issues that need

⁸⁹Interview with Mr Han Fook Kwang, 31 August 2009.

⁹⁰See Skidelsky R. The Price of Clarity, *The Straits Times*, 24 May 2010, p. A24. Robert Skidelsky's remark, although made in relation to the financial crisis triggered by the US subprime mortgage situation, is apt here:

The greater the distance between the language of elites and ordinary people, the greater the risk of revolt. To the extent that complexity in finance or politics creates new opportunities to deceive or impedes understanding, we should aim to reduce it. To the extent that such problems reflect decreased ability to express oneself clearly, the remedy is to improve education. The price of clarity, like the price of liberty, is eternal vigilance, and the two are connected.

public understanding and support, and to canvass a wide range of views in these instances, including those from the non-English speaking public.

As Harry Collins and Robert Evans observed, the concept of expertise has become so deeply woven into shared understanding that it would be difficult to arrive at particular goals without the benefit of expert input.⁹¹ The BAC has become a means by which bioethical issues are considered and addressed in Singapore. Charles Lim considered the deliberation of the BAC to comprise robust discussions by which different views were canvassed, debated, and distilled until a common ground was reached. Even then, this position might not necessarily be one of full consensus.⁹² Through the years, healthcare and research institutions, governmental entities, and professional and religious organisations have been in consultation with the BAC on its recommendations. Depending on the issue at hand, individual lay members of society (especially students) have also been engaged. The relationship between the BAC and the public has redefined itself in ways that could be limiting and enabling.⁹³ The notions of ‘public’ and ‘expertise’ are difficult to define, leading some to conclude that bioethics is not a distinct discipline, but a consortium of different expertise.⁹⁴

Even then, bioethics as a kind of ‘placeholder’ has social value.⁹⁵ Peter Singer argues that scientists (and bioethicists) do not have any greater access to ‘truth’, or otherwise any claim to special information or reasoning ability capable of devising a perfect and undisputed moral code.⁹⁶ However, he argues that thinking through an issue — especially by socially responsible people — and arriving at a “soundly based conclusion”⁹⁷ is difficult and time-consuming because it requires gathering detailed and reliable information, thorough analyses and assessment of the information within one’s moral

⁹¹ Collins HM and Evans R. The Third Wave of Science Studies: Studies of Expertise and Experience, in *The Philosophy of Expertise*, eds. E Selinger and RP Crease. New York: Columbia University Press, 2006, pp. 39–110. See also Jasanoff S. *Designs on Nature: Science and Democracy in Europe and the United States*. Princeton: Princeton University Press, 2005, p. 250.

⁹² Interview with Mr Charles Lim, 14 January 2008.

⁹³ Riles A. *The Network Inside Out*. Michigan: University of Michigan Press, 2001, pp. 58–59.

⁹⁴ O’Neill O. *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press, 2002, p. 1.

⁹⁵ Riles A. *Collateral Knowledge: Legal Reasoning in the Global Financial Markets*. In press, Chapter 5.

⁹⁶ Singer P. Moral Experts, in *The Philosophy of Expertise*, eds. E Selinger and RP Crease. New York: Columbia University Press, 2006, pp. 187–189.

⁹⁷ *Ibid.* p. 189.

views, while guarding against bias. Bioethics, as a form of moral (albeit collective) expertise, is better able to accomplish this task. Yap Hui Kim expressed a similar view.⁹⁸ She indicated that public bodies like the BAC need responsible people with views that are not skewed or self-interested. She accepted that a majority of the public would be apathetic but felt that the BAC must engage with individuals, groups, and institutions (like think tanks) who are able to invest the time and resources to think through and speak in the interest of the common good. It is also such engagement that provides a reason for some individuals and organisations to invest time and resources in understanding bioethical issues. Nazirudin Mohd Nasir indicated that his organisation (the Islamic Religious Council of Singapore) further built up its resources on bioethics as an outcome of its engagement with the BAC.⁹⁹ He agreed with Member of Parliament Zainul Abidin Rasheed that social institutions could adapt to technological changes, such as the reliance on astronomical calculations when the actual sighting of the moon is not possible, in the determination of when the fast of Ramadan (an important religious festival) begins.¹⁰⁰

Bioethics presents (and represents) the collective fabric of society and is a means of achieving what Zainul Abidin described as “secularism with a soul”.¹⁰¹ To varying degrees, bioethics reconciles science with religion on a normative platform, so that the agents of both enterprises are answerable to the collective. This observation of Fox and Swazey appears to support these views:

...“using biology and medicine as a metaphorical language and a symbolic medium, bioethics deals in public spheres and in more private domains with nothing less than beliefs, values, and norms that are basic to our society, its cultural tradition, and its collective conscience”...While recognizing the

⁹⁸Interview with Professor Yap Hui Kim, 20 April 2009. She indicated that it is important that there is fair representation and no single viewpoint should dominate. Public participation is an effective way to avoid hegemony.

⁹⁹Interview with Mr Nazirudin Mohd Nasir, 1 April 2010.

¹⁰⁰The use of astronomical calculations in the determination of when religious festivals begin is by no means a settled issue for Muslim communities in other parts of the world. See Shah ZA. *The Astronomical Calculations and Ramadan: A Fiqhi Discourse*. Washington and London: International Institute of Islamic Thought, 2009.

¹⁰¹Interview with Member of Parliament Mr Zainul Abidin Rasheed, 23 July 2009.

*basic interconnection of bioethics to advances in modern biology, medicine, and biotechnology, we have always been impressed by the degree to which “the value and belief questions with which [the field] has been preoccupied have run parallel to those with which the society has been grappling more broadly,” and by their wider “moral, social, and religious connotations” . . .*¹⁰²

To some extent, bioethics may appear to serve as a form of ‘public relations’ for researchers. The importance of public trust is generally recognised by the research community, as Lim Bing indicated,¹⁰³ and the public cannot be forced to accept scientific advances that it considers objectionable. However, Zainul Abidin indicated that the work of the BAC was not intended to be a public relations exercise. There has been genuine interest on the part of the BAC to engage meaningfully with the public in advancing the Biomedical Sciences Initiative. This initiative will be met with social resistance unless the public is genuinely convinced that the science is of value to society.¹⁰⁴ Alastair Campbell went further, indicating that bioethics has a more fundamental role in setting out ethical principles or values that all members of society are answerable to, whether researcher or otherwise. Hence, the BAC is not merely a public relations agency or a feedback unit. It steers (collaboratively with other bioethical bodies) the long-term course of the scientific enterprise through the definition of standards and norms (both local and international) as to the measure of ‘good science’.

A process by which the BAC derived its ethical principles was by achieving consensus through intermediation.¹⁰⁵ Richard Magnus (Chair of the HSCRS and the HECR Working Group)¹⁰⁶ and Terry Kaan (Chair of the HGS)¹⁰⁷ have both indicated that intermediation is akin to adjudication, or the manner

¹⁰²Fox RC and Swazey JP (with the assistance of Watkins JC). *Observing Bioethics*. New York: Oxford University Press, 2008, pp. 6–7.

¹⁰³Interview with Dr Lim Bing, 13 July 2009.

¹⁰⁴This is perhaps all the more so since the risk of the investment is borne by the population: Waldby C. Singapore Biopolis: Bare Life in the City-State, *East Asian Science, Technology and Society: An International Journal* 3 (2009): 367–383, pp. 381–382.

¹⁰⁵Pielke RA Jr. *The Honest Broker: Making Sense of Science in Policy and Politics*. Cambridge: Cambridge University Press, 2007. Pielke sets out different types of intermediation or ‘brokerage’ in a science policy environment.

¹⁰⁶Interview with Mr Richard Magnus, 18 April 2009.

¹⁰⁷Interview with Associate Professor Terry Kaan, 16 June 2009.

by which a court of law resolves competing claims.¹⁰⁸ Other legal experts on the BAC, Jeffrey Chan and Charles Lim,¹⁰⁹ indicate the range of possible outcomes from ethical deliberation to be significantly broader than adjudication. More importantly, all four legal experts have indicated that values such as independence, transparency, and balance that are critical to a sound judicial system are similarly vital to the BAC.¹¹⁰ An observation could be made here that although bioethics may lack a dominant methodology or discourse, it is not devoid of (at least in the case of a public bioethical body like the BAC) normative content. The extent of intermediation was not limited to differences between the public and the research community, but also included those between the research community and different expert or professional communities (such as scientific, medical, and regulatory), as well as within the research community. Jeffrey Chan observed that there were often differences of views between practitioners or researchers (who focused on outcomes and thus desired flexibility) and regulators (who sought to impose restrictions based on public policy). Mechanisms must be provided to balance these competing considerations. His preference was for scientific governance through clear legislative provisions rather than through ethical preferences of the moment. Clear laws make for a more certain and transparent system.¹¹¹

However, Edison Liu was concerned that too many legal provisions could burden research, especially if IRBs should operate in a legalistic manner (or if “ethics becomes law”).¹¹² Chia Kee Seng was similarly concerned.¹¹³ He indicated that if regulators or IRBs fear liability and adopt a “letter of the law” mentality (ie. applying ethical rules strictly and without flexibility in accommodating exceptional circumstances), research will be impeded. If society values research, there should be an authority or body that could speak up

¹⁰⁸Writing in relation to health care ethics committees in the US, Diane Hoffmann and Anita Tarzian indicate that these committees serve as a mechanism for dispute resolution for issues that arise out of medical practice in many states. See Hoffmann DE and Tarzian AJ. The Role and Legal Status of Health Care Ethics Committees in the United States, in *Legal Perspectives in Bioethics*, eds. AS Iltis, SH Johnson and BA Hinze. New York and London: Routledge, 2008, pp. 46–67, pp. 46–47.

¹⁰⁹Interview with Mr Jeffrey Chan Wah Teck SC, 13 April 2009; and Interview with Mr Charles Lim, 14 January 2008.

¹¹⁰Interestingly, these values have similarly been identified to be critical to national bioethics advisory bodies in the US: Briggles A. The Kass Council and the Politicization of Ethics Advice, *Social Studies of Science* 39, 2 (2009): 309–326.

¹¹¹Interview with Mr Jeffrey Chan Wah Teck SC, 13 April 2009.

¹¹²Interview with Professor Edison Liu, 8 July 2009.

¹¹³Interview with Professor Chia Kee Seng, 6 April 2009.

for researchers. It is inevitable — like collateral damage in war — that some researchers may stray into unethical territory from time to time. But any disciplinary action that follows must be edifying and not destructive. He allegorised this as mentoring a child. He emphasised the need to help researchers resolve ethical dilemmas in a constructive manner, a point that Yap Hui Kim also made.¹¹⁴ She said that there would be an increasing number of gray areas with rapid advances in biomedical sciences. A researcher might also be confused by different ethical standards that IRBs apply. She was concerned that one IRB may be more lax than another, hence some effort at harmonisation is necessary.¹¹⁵ Lim Bing expressed the same concern,¹¹⁶ indicating that the quality of ethics review differs among various IRBs in Singapore. An IRB composed of vocal members who are not well informed about science could hinder research, in addition to the burden of bureaucratic paperwork entailed in the ethics review process. Hence, the BAC has a role in harmonising the various current ethical practices based on the guidelines and practices of different leading jurisdictions — all acceptable to varying degrees and circumstances — that have been adopted by a diverse group of highly trained researchers, medical professionals, and IRB administrators. This role, as Terry Kaan indicated, was already taken up by the BAC when it deliberated on ethical practices for the use of human tissue in research, and will continue to be a critical function of the BAC.¹¹⁷

Aside from its 'active' role in engaging with and intermediating among many different levels and groups or segments of society, the BAC also has a more passive role that its Chairman Lim Pin described as akin to empathic listening.¹¹⁸ He said that listening is important as a form of empathy. From his experience, it took away a lot of anger and frustration. Ng Soon Chye, who has been involved in a number of public sessions organised by the BAC, said that some people attend these sessions or lectures not to learn, but to express

¹¹⁴Interview with Professor Yap Hui Kim, 20 April 2009.

¹¹⁵In the US, lack of homogeneity in structure and operation among health care ethics committees was attributed in part to the absence of federal regulation. Hence, the role and legal status of ethics committees in the US were regarded as "amorphous". See Hoffmann DE and Tarzian AJ. The Role and Legal Status of Health Care Ethics Committees in the United States, in *Legal Perspectives in Bioethics*, eds. AS Iltis, SH Johnson and BA Hinze. New York and London: Routledge, 2008, pp. 46–67, pp. 63.

¹¹⁶Interview with Dr Lim Bing, 13 July 2009.

¹¹⁷Interview with Associate Professor Terry Kaan, 16 June 2009.

¹¹⁸Interview with Professor Lim Pin, 22 April 2009.

their views.¹¹⁹ An important point to be noted here is that although public sessions or lectures are often viewed as a means of ‘public education’, or for the skeptics, ‘public indoctrination’, past experience suggests that these occasions have also been important for public expression. Public feedback, including views that are opposed to those of the BAC, has been published in the reports of the BAC. Hence, the BAC and its reports have been an avenue for public expression. Terry Kaan considered the BAC’s role in the production of these reports as “instrument of record” to be an important one.¹²⁰ John Elliott went further in proposing that the BAC take an additional step in providing specific responses to the views and comments (especially dissenting ones) expressed.¹²¹ Even if the BAC should adopt a different stance on an ethical issue, as inevitably occurs, clear explication of its position and ethical basis would reinforce the BAC’s role as an emphatic listener.

CONCLUSION

Since its founding in December 2000, the BAC has contributed to public policy (notably in legislative and regulatory changes) and developed an ethical framework for biomedical research in consultation with its network of consultation parties. The ethical principles that constitute the framework and give shape to ethical practices reflect international norms that define ‘good science’. As these principles also reflect local conditions and values, the BAC has been an important mediator or intermediary in the reception of bioethical norms in Singapore.

The BAC has been active in engaging with different segments and levels of society. For some, the BAC has been a source of information, a guide to resolving ethical dilemmas, or a ‘watchdog’ of some sort. For others, it has been a reason for them to devote time and resources to understanding bioethical issues. And for those whose position on a bioethical issue (such as whether a human embryo has the moral status of ‘personhood’) is settled, the BAC has been an avenue for expression and also a public agent of record. Public engagement has taken many forms and the above is but a sample of views as to how the work of the BAC could be perceived by the public. This diversity of forms suggests that to think only of the BAC’s role as ‘public relations’,

¹¹⁹Interview with Professor Ng Soon Chye, 26 May 2009.

¹²⁰Interview with Associate Professor Terry Kaan, 16 June 2009.

¹²¹Interview with Associate Professor John Elliott, 27 August 2009.

'feedback collector', 'rubber-stamper' of government pre-determined policies, 'indoctrinator' or the like is too simplistic. The relationship between the BAC and the public is complex, and one that is continuously re-defined. In July 2010, the BAC will be launching a bioethics exhibition (including related activities) developed in collaboration with the Science Centre Singapore and the NUS Centre for Biomedical Ethics. This is a commitment to align the ethical goals of science to the normative expectations of the general public through engagement.

In the initial years of the BAC, there was scepticism about whether bioethics would be a viable long-term enterprise. John Elliott said that such scepticism is unfounded, since the BAC's work will continue to be needed so long as a biomedical research sector is maintained as a national priority.¹²² A*STAR Chairman Lim Chuan Poh recently reiterated that the Biomedical Sciences Initiative that was taken up in 2000 is a long-term process.¹²³ Signs of progress are becoming apparent in the increased output for biomedical sciences from S\$6.3 billion in 2000 (3.9% of total manufacturing output) to S\$19 billion in 2008 (7.6% of total manufacturing output), more than doubling the number of jobs in research and development (R&D) between 2000 to 2008, and the publication of 1,927 papers in biomedical sciences between 2002 and 2008 by A*STAR's research institutes and filing of 216 primary patents by 2008.¹²⁴ The government's commitment to achieve a gross expenditure on R&D of 3.5% of gross domestic product by 2015 is likely to sustain the continued progress of the Biomedical Sciences Initiative.¹²⁵ In the light of this, there appears to be more work ahead for the BAC.

¹²² *Ibid.*

¹²³ Lim CP. Betting on Biomedical Science: The Nation's Economy Has Evolved Rapidly in Just a Few Decades from Labor-intensive Manufacturing to High-tech Production and Now to Corporate Management and World-class Research, *Issues in Science and Technology*, 22 March 2010.

¹²⁴ *Ibid.*

¹²⁵ This target is based on the recommendation of the Economic Strategies Committee. See Report of the Economic Strategies Committee, Singapore, *High-Skilled People, Innovative Economy, Distinctive Global City*, February 2010, p. 24.