

**DIALOGUE SESSION WITH RELIGIOUS GROUPS**  
**4.00 PM, 17 MAY 2005**  
**SHERATON TOWERS HOTEL**

**Present:** Bioethics Advisory Committee (BAC)  
Professor Lim Pin  
Chairman

Senior District Judge Richard Magnus  
Deputy Chairman

Associate Professor Terry Kaan  
Chairman, Human Genetics Subcommittee

Associate Professor John Elliott  
Member

Mr Charles Lim  
Member

Participants

Fourteen representatives from the following religious groups:

1. Graduate Christian Fellowship
2. Inter-Religious Organisation, Singapore
3. Majlis Ugama Islam Singapura (Islamic Religious Council of Singapore)
4. National Council of Churches of Singapore
5. Singapore Buddhist Federation
6. The Catholic Medical Guild of Singapore
7. The Jewish Welfare Board
8. The Spiritual Assembly of the Baha'is of Singapore

**Report:**

The dialogue session was chaired by the BAC Chairman, Professor Lim Pin. Representatives from the religious organisations were invited to share their views and concerns on the issues discussed and the recommendations proposed in the Consultation Paper, *Ethical, Legal and Social Issues in Genetic Testing and Genetics Research*. The views of the participants centred on the following issues:

- Respect for the embryo and the concept of personhood;
- Preimplantation genetic testing;
- Prenatal genetic diagnosis;

- The importance of free and informed consent;
- Safeguards for privacy and confidentiality; and
- A conscientious objection provision for healthcare professionals.

Most of the views expressed had earlier been submitted in writing to the BAC. Additional comments are provided below.

- The Singapore Buddhist Federation's representative shared a guiding moral principle in Buddhism that as long as a deed, for example research, was beneficial to mankind or the world, it would generally be acceptable. In Buddhism, the morality of any deed is determined more by the intention of the one who performs the deed than the deed itself.
- The representative from the Jewish Welfare Board was concerned with voluntariness of 'consent'. In donating tissues for research, pressure should not be imposed on anyone to consent without being fully informed. The BAC's recommendation on the requirement for free and informed consent was welcomed.
- As the Inter-Religious Organisation comprised of members from various religions, there was a diversity of views on the issues considered by the BAC. The preference would be for the BAC to find a common ground in the ethical, legal and social issues that would help unite the communities in Singapore, and promote Singapore as a progressive nation with high ethical standards and moral values.
- Representatives from the Graduate Christian Fellowship, the National Council of Churches of Singapore and the Catholic Medical Guild reiterated at some length their continued difficulty in accepting research or medical procedures that entailed the sacrifice of embryos, for reasons set out in all their submissions to the BAC. The BAC Chairman and members felt that this intractable issue should not be reopened as different faiths took different views. Nevertheless the position of these organisations and their emphasis on the importance of effective conscientious objection provision were noted.

The BAC Chairman and members present agreed that the final recommendations on genetic testing and genetic research should include a provision to allow healthcare professionals to opt out of activities to which they have a conscientious objection.

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**DIALOGUE SESSION WITH MEDICAL PROFESSIONALS**  
**4.00 PM, 1 JUNE 2005**  
**BIOPOLIS**

**Present:** Bioethics Advisory Committee (BAC)  
Professor Lim Pin  
Chairman

Dr Denise Goh  
Member, Human Genetics Subcommittee (HGS)

Participants:

Nineteen representatives from the following healthcare institutions and *in vitro* fertilisation (IVF) service providers:

1. Centre for Assisted Reproduction Pte Ltd
2. Embryonics International
3. Christopher Chen Centre for Reproductive Medicine Pte Ltd
4. Institute of Mental Health
5. KK Women's and Children's Hospital
6. National Cancer Centre
7. National Neuroscience Institute
8. National University Hospital
9. O & G Partners Clinic for Women & Fertility Centre
10. Singapore General Hospital
11. Singapore National Eye Centre
12. Tan Tock Seng Hospital
13. The Heart Institute
14. Thomson Medical Centre

**Report:**

The dialogue session was chaired by Professor Lim Pin. Participants were invited to share their views and concerns on the issues discussed and the recommendations proposed in the Consultation Paper, *Ethical, Legal and Social Issues in Genetic Testing and Genetics Research*. The views of the participants centred on the following issues:

- Implementation and impact of the recommendations;
- The need for regular review of the guidelines;
- The stringency of guidelines for susceptibility testing and the use of preimplantation genetic diagnosis for sex selection;
- Treating genetic information as medical information;
- The practice of genetic counselling;
- More detailed guidance for researchers in genetic research; and
- Genetic testing of children.

### ***Implementation and Impact of the Recommendations***

One participant pointed out that earlier reports had been published on the same issues as the BAC's Consultation Paper, for example, the *Ethical Guidelines for Gene Technology* produced by the National Medical Ethics Committee. He asked how the proposed measures in this Paper would affect current government policy or medical practice if they were to be implemented.

Another participant was in favour of broad guidelines for the protection of consumers while allowing flexibility in medical practice and for circumstances peculiar to individual patients. She enquired about the entity that would be responsible for monitoring compliance with the proposed regulations and details of the enforcement mechanisms.

Professor Lim explained that recommendations from the BAC would be translated into government policies when approved and hence would supercede previous guidelines. The present recommendations were prepared for the Life Sciences Ministerial Committee. If these recommendations were accepted, the measures to be taken would be the responsibility of the relevant authority, possibly the Ministry of Health (MOH). Therefore, BAC's recommendations would remain as guidelines unless superceded by legislation or regulations. The appropriate authority would eventually decide which recommendations ought to be made into law and which ones adopted as professional guidelines, practice directions or policies not requiring legislation.

### ***Future Review of the Recommendations***

There was concern that with the rapid and continuous evolution of science and medicine, the standards of benefit and harm might change accordingly and it was suggested that the BAC included a statement of intent to review its recommendations at a later time.

Another related concern was the possible inadequacy of policy if it lags too far behind science. The IVF guidelines were reviewed in 1993 and last in 1999. Since then, tremendous developments have taken place. Hence, it would be timely to review these guidelines.

Professor Lim felt that these were good points to note. He added that societal values and expectations would also change with time. For this reason, BAC's guidelines should never be cast in iron. Public feedback should be continually solicited and reviewed.

### ***Susceptibility Testing***

One participant felt that the requirement for “unequivocal empirical” evidence before a new susceptibility test could be introduced (Recommendation 18)<sup>1</sup> was not practical. Such a requirement was unrealistic as many genetic diseases were rare and it would take time for susceptibility tests to be developed. Moreover, as many people were unwilling to undergo susceptibility tests, the collection of data to support such tests posed a problem.

Dr Denise Goh agreed that data collection to validate susceptibility tests was not easy. But the intention of Recommendation 18 was to protect people from being subject to susceptibility testing when the basis for the test was very weak. Evidence-gathering testing should belong to the realm of research testing instead of clinical testing, until the evidence was sufficiently strong.

### ***Status of Genetic Information with Respect to Other Medical Information***

One participant suggested that genetic test results be clearly separated from other medical information and only be disclosed to insurers with specific consent and not the general consent which some patients might be asked to sign on the application forms without fully comprehending the implications. Treating genetic information separately from other medical information would help restrict the handling of genetic information to only qualified healthcare professionals.

Professor Lim clarified that genetic information should be treated like medical information as a matter of general practice. The BAC planned to provide recommendations for the access to genetic information in special situations, such as insurance and employment, in the next report which would deal with linked medical registries and genetic databases.

Dr Goh felt that attributing a higher level of confidentiality to genetic test result as opposed to other medical information might lead to impractical restrictions on common genetic tests and screenings. Furthermore, certain health conditions could not be exclusively classified into the genetic category. She felt that the better option would be to educate healthcare professionals, not so much on how to interpret genetic test results, but rather on the serious implications and the necessity to refer the patient to specialists, when indicated.

### ***Preimplantation Genetic Diagnosis (PGD)***

Two participants felt that certain circumstances, such as families yearning for a boy after having daughters in succession, might present a strong case for sex selection by

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<sup>1</sup> This recommendation stated that: “Susceptibility testing should not be applied clinically unless there is unequivocal empirical evidence of validity and utility.”

PGD. One of the participants enquired about the possibility of including an option for families to appeal to the regulator on a case-by-case basis for permission to select sex by PGD, instead of completely disallowing the procedure for non-medical reasons. People might wonder why they were denied their right to balance their family despite the availability of the technology.

Another participant added that foreigners had questioned why abortion was legal in Singapore while sex selection of the foetus was not. A fourth participant asked about the possibility of using alternative methods to PGD for selecting the sex of the embryo.

Professor Lim replied that at the ethical and moral level, sex selection for reasons other than medical ones were generally unacceptable. No major jurisdictions had approved the use of PGD for sex selection for non-medical reasons. He felt that the public would generally not accept such use of the technology. He explained that legalisation of abortion was brought about many years ago and the historical context of that time was very different from the present. Dr Goh added that if sex selection was allowed, there would be greater adverse public reactions. She clarified that in formulating policies, the principles underlying sex selection for medical reasons should be the focus and they should not be dependent on the means. The HGS felt that sex selection should only be allowed for medical reasons.

Another participant expressed preference for an overall guideline to disallow social uses of PGD. She asked if the limitation of PGD to “serious medical conditions” would be specified by individual institutions, clinicians or by the MOH as guidelines. Another participant indicated that he would like to see clearer definitions for “serious medical conditions” and counselling requirements for mothers.

Dr Goh said that the MOH had recently approved a research trial for PGD to be used to diagnose beta-thalassaemia major. She believed that the MOH would specify the conditions for which PGD could be done, should PGD be accepted for clinical practice.

### *Genetic Counselling and General Comments*

Referring to the second line in Recommendation 21,<sup>2</sup> one participant recommended that the word “immediately” should be replaced with “as far as is practicable”, because there is usually a lot of preparation to be done by the genetic counsellor before counselling a patient. It might not be practicable for counselling to be provided immediately after the disclosure of the test result. He also added that genetic counselling was better described as a ‘sustained’ process, rather than a “time consuming” one, since genetic counselling might not necessarily be a one-off procedure, but may even last a lifetime.

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<sup>2</sup> This recommendation stated that: “...Genetic counselling should immediately follow the disclosure of the test result, particularly if the test result is not favourable.”

### ***Research Genetic Testing***

A participant cited a moral dilemma often encountered in research. He said that despite informing research participants that the outcome of the research programme could not be ascertained until more knowledge accrued and therefore the research findings would not be made known to them, many participants would still write to enquire about the research findings even after several years. He asked whether researchers were obligated to re-contact and inform the participants if the research were to yield findings of medical relevance to them, assuming it was possible to trace them. If such an obligation were to rest on the researcher, the researcher would be required to keep track of new information following new discoveries that may be of medical benefit to his research participants.

Dr Goh suggested that the IRB decides at the outset whether the researcher should or should not inform research participants of the research findings. An alternative solution proposed by the American Board of Medical Geneticists (ABMG) was for the researcher to inform research participants that they would not be provided with individual results, but might be provided with research findings based on the whole research group. However, the options would be different if the research involved testing a gene of established medical relevance (e.g. BRCA1 for breast cancer). The ABMG suggested that in such cases, a research participant screened positive for a well accepted disease gene be advised to seek a genetic consult and take a clinical test. The duty to re-contact research participants would place a great burden on researchers. Furthermore, researchers might not remain in the same field of research indefinitely and some research participants might not welcome the information.

### ***Genetic Testing in Children***

One participant stated that the basic guiding principle in the testing of children was the benefit to the child's health. She thought that the assessment should be based on whether there was a need to know the child's genetic status.

Another participant asked for further guidance for situations in which a child assessed to be mature had conflicting desire with his or her parents regarding genetic testing. He felt that BAC's recommendations were broad enough to allow the child's decision to take precedence if the child's decision was in line with the doctor's professional opinion. Otherwise, the child could not overrule the parents' decision.

The BAC Chairman noted all the views expressed and assured those present that their views would be considered in further discussions and preparation of the final report.

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## FOCUS GROUP DISCUSSIONS 14 May to 9 July 2005

As part of its public consultation process, the BAC organised a series of focus group discussions to understand public views and concerns regarding genetic testing and emerging reproductive technologies. The recommendations of the BAC in the Consultation Paper entitled *Ethical, Legal and Social Issues in Genetic Testing and Genetics Research*, address some of the concerns voiced at the focus group discussions.

The public was invited to participate in the discussions through the Feedback Unit of the Ministry of Community Development, Youth and Sports, the BAC website and announcements in local newspapers. Fourteen focus group discussions were conducted. Two groups comprised students from junior colleges and polytechnics. The discussions involving the public took place at the Tanjong Pagar Community Club on Saturday mornings, while the student groups were held at Biopolis during the school vacation in June. There were a total of 93 participants (55 Chinese, 13 Malays and 25 Indians) ranging from 17 years of age to those in their 60s. Forty-four participants were males, and 49 were females.

Each discussion group, divided according to age, gender and ethnicity, consisted of 4 to 11 participants and was led by one or two facilitators. Associate Professor Wong Mee Lian from the Department of Community, Occupational and Family Medicine, National University of Singapore, provided guidance to facilitators on conducting the discussions. The BAC is grateful to Associate Professor Wong and all the facilitators – Dr Hussaini bin Hafiz, Mr Calvin Ho, Dr Predeebha Kannan, Dr Patrick Kee, Mr Ahmad Khalis bin Abdul Ghani, Dr Lee Soo Chin, Dr Rathi Mahendran, Ms Airani Ramli, Ms Linda Tan, Dr T Thirumoorthy and Ms Sharon Wee – for their generous contributions.

The discussions were focused on the following issues:

1. Genetic testing in general;
2. Predictive genetic testing in children;
3. Direct supply of genetic tests to the public;
4. Privacy and confidentiality of genetic information;
5. Access to and use of genetic information;
6. Preimplantation genetic diagnosis (PGD); and
7. Preimplantation tissue typing (PTT).

Participants were presented with two written scenarios and encouraged, through a series of open-ended questions, to share their personal views with the group:

- Scenario 1: a mother of two, with a strong family history of colon cancer considering genetic testing.
- Scenario 2: a couple who has a 5-year-old son with Duchenne Muscular Dystrophy considering PGD with the hope of conceiving a healthy child.

The discussions were lively and interesting as many participants freely shared their views and experiences. Most participants enjoyed the discussion and many expressed that they had greatly benefited from it. Generally, the BAC's views and recommendations correctly represented public views and concerns as expressed by these participants.

## **Opinions on Genetic Testing and Emerging Reproductive Genetic Technologies**

### ***Genetic testing***

We find the following to be the main factors that are likely to influence a person's decision to undergo genetic testing:

- (a) knowing that a genetic test is available;
- (b) the certainty or predictive value of the test result;
- (c) the nature of the disease concerned;
- (d) what can be done if the test result is positive;
- (e) the cost implications and follow-up options for a positive test result; and
- (f) privacy and confidentiality of the test result.

Most participants were aware of the risks and benefits in genetic testing and recognised the need to weigh individual interests against the interests of society when faced with conflict. It was generally agreed that the availability of or access to controversial technologies should not be completely barred, nor can such technologies be freely open to all. Clear rules and effective controls are needed to maintain public confidence.

Generally, participants valued the freedom of making decisions, although a certain level of regulatory control was desired to protect the welfare of individuals. The freedom of choice should be limited if its exercise would pose harm to wider societal interests.

### ***Predictive genetic testing in children***

Many participants felt that parents have the responsibility and right to decide for their children regarding genetic testing for a late-onset disease. Others felt that children not mature enough to make medical decisions should not be subjected to such tests.

### ***Direct supply of genetic tests to the public***

With increasing public availability of genetic testing services and at lower cost, several participants seemed prepared to try out such services procured overseas, via the Internet or over the counter, and without the mediation of a medical professional. Some of them thought that this would be the best way to ensure that their genetic test results were kept private. The majority, however, would consult a medical professional to confirm the diagnosis, especially for serious disease such as colon cancer, as they considered professional counselling to be beneficial.

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### ***Privacy and confidentiality of genetic information and access to and use of genetic information***

While no participants were willing to volunteer their genetic information to third parties like employers or insurers about a condition which they have not developed or might not even develop within their lifetime, the majority was willing to share the information with family members. The reasons were namely “social responsibility” on the part of the tested individual to inform genetic relatives of a hereditary condition and the sharing of financial, emotional and psychological burdens among family members.

### ***Preimplantation Genetic Testing***

The factors identified as important in preimplantation genetic testing were:

- (a) religious and personal values;
- (b) the probability of success balanced against the cost of the procedure;
- (c) the well-being of the existing sick child after the birth of a healthy sibling through PGD;
- (d) the well-being of the sibling who would be conceived through PGD or PTT; and
- (e) the physical and emotional stress on the woman undergoing the clinical procedure.

Participants weighed these factors differently because of differences in their beliefs and values, experiences and outlook in life, social and economic background and, to some extent, gender.

Most of the Christian participants would not consider PGD because of the destruction of surplus embryos or the belief that it is “God’s will” if their children were born with any genetic disorder. A few Muslim participants shared similar reservations towards PGD but the majority thought that PGD did not conflict with Islamic principles. Several Muslim participants suggested that Muslim patients be assisted by a Muslim counsellor or religious teacher before and/or after testing to ensure that their decisions and actions would not contravene Islamic law.

A great majority of the participants thought PGD and PTT appropriate if used to avoid a life-threatening disease. These participants differed in their opinions on what severity of disease should be allowed for the use of PGD and PTT, but they did not think that such technologies should be allowed for minor conditions such as myopia. None of the participants agreed to the use of PGD for selection of desirable traits. A majority of participants objected to applying PGD in selecting gender for social reasons. However, a few participants thought that use of PGD to balance the gender ratio in families might be permissible in extreme cases.

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