

Feedback from the Centre for Research on Islamic and Malay Affairs of the Association of Muslim Professionals**Executive Summary of Report to BAC**

RIMA has hosted two focus group discussions (FGDs) regarding genetic testing and research. Among the participants of the discussions were professionals from the legal, teaching and biological industries. These participants were Malay/Muslims ranging from those in their early 20s to those in their early 50s. The report is not representative of the Malay/Muslim community. An appropriate way of describing the participants of the FGDs would be that they make up a cross section of the community. By virtue of this cross sectional representation, the results of the FGDs hold no authority in painting a cultural or religious background of the Malay/Muslim community.

Generally, the participants were unsure of the procedures and purposes of genetic testing and research. We undertook the task of informing them prior to gathering feedback through a listing of the break down of what genetic testing and research encompass. Subsequently, the participants became more comfortable in articulating their concerns surrounding genetic testing and research. Several of the concerns pivoted around the permissibility of some of the procedures in genetic testing and research being in line with Islamic principles. Others centred on more practical and ethical issues that reflect the concern of consumers at the receiving end of the practice of genetic testing and research in a clinical setting.

With respect to the 24 recommendations forwarded by the Bioethics Advisory Committee in its consultation paper “Ethical, Legal and Social Concerns in Genetic Testing and Research”, the participants were in general agreement that the interests of the consumers have been accounted for. The feedback they hence gave was intended to add value to the recommendations from the perspective of a cross-section of the Malay/Muslim community. Through this consultation process, the feedback is hoped to be of use in reflecting some concerns that may arise amongst the Malay/Muslim community. It has to be emphasized again though, that the report is by no means representative of the views of the Malay/Muslim community. The feedback holds no

formal authority on religious injunctions but is one which is gathered from enlightened professionals within the community.

Report

INTRODUCTION

As a prelude to the discussion of the “Ethical, Legal and Social Issues in Genetics Testing and Research”, our participants were given a brief description of how genetics testing and research are conducted and the purposes behind them. For a start, we identified 7 general phases in which genetics testing and research can be organized and understood. The general flow of process can be understood in phases as:

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|-----------------|---|
| Phase 1: | Pre- Test Counselling (R1, R2) |
| Phase 2: | Consent (R3, R9) |
| Phase 3: | Genetic Testing (R5, R6, R8, R10, R16, R17, R20) |
| Phase 4: | Genetic Information (R4, R7) |
| Phase 5: | Interpreting Genetic Information (R19, R21) |
| Phase 6: | Post- Test Counselling (R22, R23, R24) |
| Phase 7: | Application (R11, R12, R13, R14, R15, R18) |

Within these 7 phases that we have identified, the 24 recommendations can be accommodated. Recommendations which we feel may pertain more to a particular phase will be presented as a recommendation subsumed under that phase. Nevertheless, we encouraged participants to think about the recommendations beyond the framework that we presented them with. Some of the recommendations may pertain to more than one phase in genetic testing and research. The framework was meant to act as a means through which they may understand the concerns that surround genetics testing and research that result in the formulation of the particular recommendation.

With this framework established, we embarked on an exploratory reading of the recommendations to deliberate over its possible implications and meanings. In general, after the participants have been exposed to the 7-phased approach to genetic testing and research that we presented them with, there was a positive outlook towards genetic testing and research. The fears were naturally present, especially with regards to processes such as germline genetic modification and choosing the desired traits in offspring through pre-implantation genetic diagnosis. However, most of our participants were receptive to the development that is taking place in the realm of genetic testing and research. Their concern revolved around the protection of the individual privacy and the nature of consent. Consent can be obtained only when the individual has been made to understand the full implications, options and the possibility of future use of the specimen obtained. Also, the issue of applying genetic information was also a cause of worry among the participants, there was a view that if not regulated and monitored, genetic testing could result in unethical ends. The rest of the paper will provide an insight into the discussion that took place with regards to the 24 recommendations forwarded by the Bioethics Advisory Committee.

Recommendation 1 was generally agreed upon. The isolated concern surfaced was whether it is advisable to set the highest ethical standards. This view is operating on the premise that restrictive guidelines which characterize medical ethics may be debilitating for development in genetics research and testing. Nevertheless, the participants trust the discretion of the board to balance the needs of genetics research and the preservation on ethical, legal and social interests.

Recommendation 2 has been deemed to be rather vague. There were views that for Genetic Testing to be done in adherence to ethical guidelines, individuals undergoing the tests have to be informed adequately. This information has to be presented in simple terms to facilitate understanding among the common man. The full implications of the test have to be related to the individual to prepare him in every way possible. Methods of relaying information to individuals too need to be sensitive towards the patients'

backgrounds. There was also a general sentiment of dissatisfaction with the approach of counselling to be that of a “one size-fits-all formula”

Recommendation 3 was presented as being subsumed under the second phase of genetics testing and research. The obtaining of consent ought to come after sufficient genetic counselling, informing individuals of the risks involved in the process of the tests and research. The participants were particularly concerned as to the manner in which the consent is obtained. The time frame given for the consent to be given ought to be sufficient for the individuals to deliberate sufficiently the costs and benefits of the genetic test. Also, there ought to be enough time for the individuals to seek a second or even a third opinion with regards to the impending genetic test. It was generally agreed that consent was to be obtained specifically for different tests, taking into account the duration in which the consent remains valid.

Recommendation 4 was categorized under the phase in which genetic information is obtained. The prompt information delivery clause that was included in the recommendation was well accepted by the participants. However, there were contentions with regards to the inclusion of the phrase “treatable conditions” in the recommendation. Some of the participants felt that even for untreatable conditions, the test results still ought to be disclosed. This is so that proper care and management of the affected individual can be achieved. Also, there were suggestions of an “opt-out” clause in relaying the results of the genetic test to the individual. Everyone hence, except for those who chose to “opt-out”, would be informed of the test results, whether or not the disease is treatable.

Recommendation 5, categorized under genetic testing, was generally well accepted.

Recommendation 6 also came under the genetic testing category. With regards to this recommendation, there were concerns regarding the body of authority that will determine the importance and relevance of the research and test. There were views that

there ought to be an overarching body that governs the directions of researches along ethical guidelines.

Recommendation 7 was classified under the fourth phase where genetic information is handled. It was generally agreed upon that this was a vital recommendation as it deals with the issue of confidentiality of an individual's genetic information. There were views that there ought to be no exception for third parties whatsoever. Also, the exact process of disclosure is not outlined in the recommendation to give the participants an idea of how the disclosing of genetic information is achieved.

Recommendation 8 was explained in terms of the third phase, which is genetic testing itself. It was generally agreed upon that the test should take place through the intermediation of a healthcare professional. The contention came when the participants came across the statement regarding the advertising of genetic tests by manufacturers or suppliers. Some felt that the term "banned" should be used to replace "strongly discouraged". There were others, however, who felt that the advertising may in fact increase awareness and put people on their toes with regards to conducting genetic testing outside the healthcare realm. The concern revolved around the concern of what kind of advertisement would be allowed and on what grounds.

Recommendation 9 was categorized under the issue of consent. This recommendation received positive feedback.

Recommendation 10 again was dealt with under the phase of genetic testing itself. This recommendation was well received by the participants.

Recommendation 11 was discussed in the sphere of the last phase of genetic testing and research, the application phase. There was unanimous agreement on the participants' part that indeed, the use of preimplantation genetic diagnosis for sex selection and the selection of certain desired traits for non- medical reasons should be prohibited.

Recommendation 12 was also deliberated upon in terms of the application phase and was again, well received.

Recommendation 13, also discussed in the light of the last phase, received positive feedback.

Recommendation 14, pondered upon in relation to the last phase received generally positive feedback. The only concern, especially amongst the experienced mothers amongst the participants, was that counselling ought to be done at this stage by trained and professional counselors.

Recommendation 15 also came under the application phase. This recommendation was met with positive feedback in general.

Recommendation 16 was subsumed under the third phase, the process of genetic testing itself. There were concerns regarding the drawing up of ethical guidelines based on the objectives of the testing bodies. There was a general sentiment that there ought to be a standard set of guidelines and that these separate bodies be monitored by an overarching authority.

Recommendation 17, also categorized under the phase of genetic testing, was also generally agreed upon.

Recommendation 18 was deliberated in the light of the last phase, application. Similarly, this recommendation was also welcomed positively.

Recommendation 19 was discussed in terms of the fifth phase, which is interpreting genetic information. The participants felt that the clause “legally designated persons” ought to be applied to other aspects of genetic testing and research. It was agreed upon that, through out the entire process of genetic testing, the lack of ability on the

individuals' past to make decisions of comprehend the full information or implications of the process, there should be present, a "legally designated person".

Recommendation 20 was subsumed under the third phase and was again, agreed upon in general.

Recommendation 21 was pondered upon in terms of the fifth phase, which is gathering genetic information. The participants felt that the guideline for this recommendation can be found in Recommendation 2 where there is emphasis on the "welfare, safety, religious and cultural perspectives and traditions of individuals" undergoing genetic testing. Also, many felt that it should be at this point where individuals making important decisions regarding genetic testing can be referred to counselors to help them make informed choices. The counsellors must be especially sensitive to the religious and cultural background of the individuals, keeping in mind their medical condition. The counsellors ought to act as a bridge between the individuals and healthcare professionals, who may tend to impose medical jargon on the common man. Therefore, it is imperative that the counsellors employ a simple and clear mode of communication along with being sensitive to the various backgrounds of individuals. This will, tie in very closely with Recommendation 22.

Recommendation 22 was agreed upon unanimously after being deliberated on in terms of the second last phase of genetic testing, which is the "post-test counselling" phase.

Recommendation 23, also subsumed under post-test counselling, was received positively with particular attention to the notion of counselling to be done in a "non-directive manner".

Recommendation 24 was also discussed under the last category of genetic testing, which is the application phase. This recommendation received amiable feedback in the light of having sensitive counsellors with a sound medical background.



College of Family Physicians Singapore

3rd Jun 2005

Associate Professor Terry Kaan
Chairman
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Honorary Editor

Dr Ng Joo Ming Matthew

Dear A/Prof Kaan

REQUEST FOR FEEDBACK ON CONSULTATION PAPER

The College 19th Council has discussed and noted that the consultation paper has comprehensively and extensively discussed the many ethical, legal and social issues involved in genetic testing and genetic research.

The proposed recommendations will put in place safeguards to prevent abuse without stifling opportunities for patients to benefit from advances in medical genetics.

Of particular relevance to family physicians is the point made in the paper that the relevant authorities should consider providing professional training in medical genetics and counselling to scientific and healthcare professional in this field.

It is foreseeable that family physicians will be consulted for advice on medical genetics by their patients or patients' families. Thus family physicians should be on the radar screen of the relevant authorities for professional training in medical genetics and counselling.

Properly empowered the family physicians have a significant role to play in genetic counselling.

In fact the College has taken the initiative to host the World WONCA Conference in July 2007 with the theme "The Human Genome".

With best regards.

Yours sincerely

A/Prof Cheong Pak Yean
President
19th Council (2003-2005)
College of Family Physicians Singapore

Faculty of Medicine
Dean's Office



Prof John Wong
Dean
Faculty of Medicine

June 7, 2005

Associate Professor Terry Kaan
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Bioethics Advisory Committee
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Dear *Terry*,

REQUEST FOR FEEDBACK ON CONSULATATION PAPER

Thank you for your letter of April 4, 2005, and allowing the Faculty of Medicine, NUS, the opportunity to comment on the consultation paper entitled "Ethical, Legal and Social issues in Genetic Testing and Genetic Research".

The Faculty generally thinks that the paper is well written and covers most key areas. However, the issue of genetic testing of already harvested or stored tissues and the consent issues behind this was not addressed in the paper. We are of the opinion that this should be explicitly addressed. The issue of whether a generic consent is sufficient for tissues obtained primarily for diagnostic or therapeutic purposes is a difficult one with vast implications for translational research. It has also become increasingly easy to obtain genetic information from stored tissue.

We hope that you would find the above feedback useful.

Yours sincerely

A handwritten signature in black ink, appearing to read 'John Wong', is positioned above the typed name.

Professor John Wong
Dean, Faculty of Medicine
National University of Singapore



**GLENEAGLES CRC PTE. LTD.
MEMORANDUM**

To : Biomethics Advisory Committee

From : Prof Jeremy Chapman

Cc :

Date : 09 May 2005

Re : Request for Feedback on Consultation Paper

Message

Please find our feedback for your perusal.

REQUEST FOR FEEDBACK ON CONSULTATION PAPER

BIOETHICS ADVISORY COMMITTEE

Professor Jeremy Chapman

The consultation paper: Ethical, Legal and Social Issues in Genetic Testing and Genetics Research

The International Scientific Advisory Panel of Gleneagles CRC has reviewed this paper and has the following comments:

The paper provides an excellent approach to the majority of issues involved in genetics testing. Two areas of current genetic testing seem not to have been considered specifically, or are mentioned but not identified as significant.

- 1 Genetic testing for the purpose of paternity testing (2.7a)
- 2 Genetic testing for matching of individuals for transplantation of cells and organs, especially for unrelated bone marrow transplantation

In addition to these two papers, genetic testing may be used extensively in the forensic medicine field and in criminal forensics. We presume that tests for these purposes are excluded from consideration under this auspice but the paper does not make this explicit. Indeed the definition: point 2.3 states "include, but are not limited to...", suggesting that any use of genetic information could be under consideration.



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17 May 2005

Associate Professor Terry Kaan
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Dear Prof Kaan

CONSULTATION PAPER ON ETHICAL, LEGAL AND SOCIAL ISSUES IN GENETIC TESTING AND GENETICS RESEARCH

Introduction

The Graduates' Christian Fellowship has been invited to give its comments to the paper on 'Ethical, Legal and Social Issues in Genetic Testing and Genetics Research',

We have divided our paper into two parts. The first segment outlines values and principles of our worldview and the outworking of these values and principles as they are translated into legislation. The second part sets out our specific recommendations to the paper and is based on the assumption that our basic premise is rejected and, therefore, seeks to preclude or mitigate the evil of certain aspects of genetic testing and genetics research.

Part I - Values and Principles

Human Dignity and Sanctity of Life—A bulwark of the Christian faith and that of many other religions is the respect for human life, the dignity of a human being and the sanctity of life.

Our perspective is derived from our belief that human beings are made in the image of the Almighty God.

So God created man in his own image, in the image of God he created him; male and female he created them. (Genesis 1:27).

Additionally, the Word of God makes it clear that life as we understand it begins at the time of conception and we say like the psalmist

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*“You formed my inward parts;
 You covered me in my mother’s womb.
 I will praise You, for I am
 Fearfully and wonderfully made;
 Your eyes saw my substance, being yet unformed
 And in Your book they all were written,
 The days fashioned for me,
 When as yet there were none of them.”*

So, the Holy Bible, directs our firm belief that all embryonic stem-cell experiments are forbidden as a destruction of life.

In addition, we reject the view of a dichotomous separation of the soul or spirit from the body. It is our view that as a human, we cannot separate the spirit from the body and from the soul or personhood.

*‘... the LORD God formed the man from the dust of the ground and
 breathed into his nostrils the breath of life, and the man became a living
 being.’ (Genesis 2:7)*

Man was created both matter and spirit in order to become a living being. As a human being, he or she is an integrated whole. We recognise that we do not live in a perfect world. There are some who among us were either born (perhaps now conceived, through natural or artificial means) or through debilitating illness or accidents, may seem less than human.

However, we cannot accept with good conscience attempts by those (based on the presupposition of a dualistic world view of the separation of the body and spirit) who seek to define personhood in terms of certain capacities. In exposing this presupposition, Gilbert Meilaender in his book titled ‘Bioethics’ writes,

*‘To be a person one must be conscious, self-aware, productive. The class
 of persons will widen or narrow depending on how many such criteria we
 include in our definition of personhood. But, in any case, the class of human
 beings will be wider than that of persons. Not all living human beings will
 qualify as persons on such a view – and, we must note, it is persons who
 are now regarded as bearers of rights, persons who can have interests that
 ought to be protected.’¹*

Such a definition of “personhood” based on criteria established by man arbitrarily, would eliminate human beings who do not satisfy these man-made criteria. These man-made criteria have, already, in many jurisdictions, eliminated the unborn who are voiceless and helpless and may if utilitarian views prevail eventually eliminate the sick, the old and hapless who are no longer economically productive.

It is our belief that the unborn, the helpless, the sick and the aged are fully human beings to be accorded value and dignity and who are loved by the creator God. They are no less valuable than those who are “conscious, self-aware” and “productive”.

¹ Meilaender, Gilbert, Bioethics, 1996, Eerdmans, Grand Rapids

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Francis Crick, the Nobel Laureate and biophysicist, popularly known as the “father of DNA” has estimated that ‘the amount of information contained in the chromosomes of a single fertilized human egg is equivalent to about a thousand printed volumes of books, each as large as a volume of *Encyclopaedia Britannica*.’² Judge Robert H. Bork who referred to the point made by Francis Crick stated that ‘*Such a creature is not a blob of tissue or, as the Roe opinion so infelicitously puts it, a “potential life”. As someone has said, it is a life with potential*’³

Some would argue in favour of genetic testing in a search for cures to improve the ‘quality of life’ of the sick. It is imperative that we continue to find better treatments and alleviate as much as possible the pain and suffering of the sick. However, it is also imperative that the sanctity of life needs to be preserved. Otherwise, we may be trading one life for another. We subscribe to the statement made in the Lausanne Occasional Paper No. 58, ‘*Christians however maintain that all human lives are of equal worth, yet we recognise that modern medical decisions cannot avoid some ‘quality of life’ considerations. For example, judgments that the burden of a treatment outweighs its benefits for a particular patient involve an evaluation of the patient’s quality of life. There is no obligation to extend human life by the maximum amount of time, if the patient will die soon regardless of treatment and treatment will add burden to the dying process. Both ‘sanctity of life’ and ‘quality of life’ considerations are legitimate and important, with the proviso that for Christians, quality considerations cannot justify overriding the sanctity of human life.*’⁴

In a consumer society in which we live, trading or the commercialization of life often creeps in it unnoticed. The advancement of technology also brings with it a variety of options that bring hope of healing. The choice of an available option comes with responsibility for the consequences of the choice, for example, once a couple have decided to go ahead with a choice of natural or artificial procreation method, we are of the opinion that the human life henceforth conceived, is a vulnerable person and needs to be protected. We should not fall into a consumer mentality by disowning our own children, like picking a defective book off the shelf and subsequently casting it aside as having ‘no commercial value’. This plain disregard of human life runs against the grain of our belief. However, we find deep sympathy for victims of rape and incest and leave the matter as their conscience or faith guides them.

Stewardship – is another fundamental premise which Christians are to operate and practise in the world, on behalf of God. This call is not limited to just Christians but to the entire humankind.

‘God blessed them and said to them, “Be fruitful and increase in number; fill the earth and subdue it. Rule over the fish of the sea and the birds of the air and over every living creature that moves on the ground.” (Genesis 1:28)

This translates into an outworking for Christians to engage the world actively and positively in all dimensions of life. They include, helping the sick and needy, protecting human, animal life and the environment, good governance, ethical conduct.

² Doris Gordon, “Abortion and Rights: Applying Libertarian Principles correctly,” *Studies in Pro-life Feminism*, Spring 1995, pp. 121, 127

³ Bork, Robert H, *Slouching towards Gomorrah*, p.175

⁴ Chia, Roland et al, 2005, *Bioethics: Obstacle or Opportunity for the Gospel?* Lausanne Occasional Paper No. 58, Lausanne Committee for World Evangelization

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'He has showed you, O man, what is good. And what does the LORD require of you? To act justly and to love mercy and to walk humbly with your God.' (Micah 6:8)

In the health care industry, we continue to encourage and applaud professionals, practitioners and researchers (regardless of faith and creed) to develop new methods and cures. This include preventive medicine, antenatal and post-natal diagnosis and care for babies.

Preventive medicine is key in helping diagnosis and subsequently providing a cure before a medical condition occurs such as the use of vaccines. We also find it useful in antenatal diagnosis and cure or to cope with post birth procedures or care for the babies.

However as good and responsible stewards, the end does not justify the means. Neither should we presume to take the place of God rather than simply be good stewards. For the concept of steward or regent connotes that there is privilege in service to the world, but not ownership. As human beings and society, we need to come to terms with our limitations. Going beyond our limitations will only bring tragedy, which we have witnessed throughout history.

Pride – can be positive affirmation of achievements and efforts. A healthy dose of pride in our life, society and community is a good thing. However, we have seen all too often that pride is precedent to many a downfall. As a Chinese saying goes, 'jiao bing bi bai'⁵. In this information age, we can get information of almost anything. There arises much concern about security and the subsequent use of information.

We are glad to note the attempts to safeguard information derived from genetic testing and genetics research. We have in our comments sought to tighten the procedures. Thought should be given to the dangers of hacking and unscrupulous data mining. An engineering saying goes, 'fool proof systems only prove the existence of fools'. (Unattributable). We are of the opinion that unless it is absolutely necessary, and fully supported by recommendations of qualified professionals and medical evidence, information such as DNA should not even be documented, much less distributed.

We wish to emphasize that even having knowledge of a probability of contracting a certain illness through DNA testing, without a clearly defined cure or purpose is frivolous and should not be permitted. It only adds onto the burden of scarce medical resources and the expense of taxpayers' money. What is even more unthinkable is the possibility of insurance premia or medical resources pegged to such probabilities.

Part II - Comments on Recommendations

Genetic Information

Recommendation 1:

Genetic Information derived from Clinical Genetic Testing should be confined to a healthcare context, owing to its complex nature and need for professional input. Accordingly, it should

⁵ Jiao Bing Bi Bai – The proud army will certainly fall.

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be regarded as medical information and the highest ethical standard should be applied in its derivation, management and use.

Comment:

We agree and applaud the committees' recommendation that Genetic Information be limited to areas concerning of healthcare. In this regard, we are concerned that the information used will be harnessed for commercial, social engineering or discriminatory purposes. The context of healthcare should be further understood as primary relating to the individual. For example, where hereditary diseases are concerned the protection of the individual's right to privacy must be protected against the perceived social benefits of the society.

General Ethical Considerations

Recommendation 2:

Genetic Testing should be conducted in a manner that is respectful of the welfare, safety, religious and cultural perspectives and traditions of individuals.

Comment:

We agree and applaud the committees' recommendation that Genetic Testing be conducted in accordance with religious perspectives. The consequence of this recommendation must be to allow the individual equal access to the religious perspectives. A pragmatic viewpoint which may favour economic realities or self-actualisation should not be preferred to the religious perspective that considers the individuals relationship to His or Her God. The committee should, therefore, set guidelines that would allow equal access to counsellors who promote particular religious perspective, subject, of course to such counsellors being properly qualified and allow appropriate religious material to be available in hospitals and clinics throughout Singapore.

Recommendation 3:

Genetic Testing should be voluntary and conducted only after free and informed consent has been obtained. Consent must be based on sufficient information, which includes the nature, purpose, risks and implications of the test. Consent should also be obtained for future clinical and/or research use of tissue specimens.

Comment:

We agree with this recommendation.

Recommendation 4:

An individual should be informed of the test result without undue delay unless he or she has clearly indicated the wish not to know. However, the test results of newborn babies and children for treatable conditions should be disclosed. In research involving Genetic Testing, researchers should inform the individual prior to participation in the research, whether the Genetic Information so derived will be disclosed to him or her.

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Comment:

We agree with this recommendation.

The recommendations should take into account the possibility that treatment for a particular ailment may be developed in the future and allow doctors to inform potential clients that they may wish to come back for testing. If a test is positive but no treatment is available at the time, the regulation should allow patients to be informed when a new treatment has been developed.

Genetic Testing of Vulnerable Persons

Recommendation 5:

We do not recommend the broad use of Genetic Testing on children and adolescents. Confirmatory Testing and Predictive Testing for genetic conditions where preventive intervention or treatment is available and beneficial in childhood are recommended. Carrier Testing should generally be deferred till the child is mature or when required to make reproductive decisions. Predictive Testing should generally be deferred where there is no preventive intervention or treatment, or where intervention or treatment is only available and beneficial during adulthood. However, in exceptional circumstances, parents and the physician should have the discretion to decide regarding Carrier and Predictive Testing, and genetic counselling should be an intrinsic part of the testing process.

Comment:

We agree and applaud the committees' decision not recommend the broad use of Genetic Testing on children and adolescents. The decision as to discretion in exceptional circumstance should be made collectively by the parents, the physician and the child, where he or she is matured enough to understand the circumstance, after proper counselling.

Recommendation 6:

Genetic Testing involving vulnerable persons should be conducted only if appropriate free and informed consent has been obtained. In the case of persons in special relationships, extra care should be taken to ensure that the consent is freely given. Clinical Genetic Testing should only be conducted if it is medically beneficial. Genetic Testing for research should only be conducted if the research is considered of sufficient importance and there is no appropriate alternative test population.

Comment:

The determination of what is medically beneficial should be finally decided by the individual under the advise of the physician.

An independent committee should determine whether a particular form of research is sufficiently important to be pursued. These areas should be controlled by legislation and there should be a presumption against Genetic Testing unless it is pre-approved by the committee.

In the case of vulnerable persons, access to counselling for the guardians of these person should also be available, and recommended, in the same way as it is for the individual.

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Privacy and Public Access to Genetic Testing

Recommendation 7:

Genetic test results should not be disclosed to third parties, including employers and insurers, without the free and informed consent of the individual.

Comments:

We agree with this recommendation.

We would urge the committee to propose legislation that would make it illegal to divulge such information to 3rd parties without consent of the individual. There should also be legislation that bans insurers and/or employers from requesting for genetic testing.

Recommendation 8:

Genetic Testing should be conducted through the intermediation of a qualified healthcare professional. Accordingly, the advertising of genetic tests by manufacturers or suppliers to the public is strongly discouraged. A comprehensive regulatory framework should be established for access to Genetic Testing services. Genetic tests that provide predictive health information should not be directly offered to the public.

Comments:

All Genetic Testing, without exception, should be conducted through the intermediation of a qualified healthcare professional. The conduct of Genetic Testing for matters other than related to healthcare should not be allowed and therefore the advertising of commercial genetic tests should be made illegal. Genetic Testing should not be available except in pre-approved facilities. The potential for misuse of Genetic data and Genetic profiling may give rise to a new form of discrimination. The use of Genetic Testing to satisfy human curiosity should not be permitted.

Recommendation 9:

The non-consensual or deceitful obtaining of body samples for the purpose of Genetic Testing should be legally prohibited.

Comment:

We agree with this recommendation.

Preimplantation Genetic Testing

Recommendation 10:

Preimplantation genetic diagnosis is permissible provided that it is subject to control by a relevant authority and limited to serious medical conditions. The relevant authority should license, monitor and assess preimplantation genetic diagnosis to ensure that it is employed within legal and ethical limits.

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Comment:

We believe that Preimplantation Genetic Testing should not be allowed. This process involves the testing the embryos for genetic defects prior to IVF and the determination as to what constitutes an acceptable genetic profile for a child may mean the destruction of embryos and a form of human genetic manipulation.

The consultation paper itself discusses the statement “the ideal that parental love should not be dependent on a child having characteristics that the parents hoped for, but rather as individuals in their own right. Allowing parents to exercise their preference in making such a ‘selection’ may introduce an element of control over the result of conception, thus making the “experience of parenthood very different from the present situation in which... parents are happy just to take their child as they find them”. We would like to propose that this argument is heeded on every level, including whether or not the child has a potential serious health condition.

If PGT is implemented, we feel it is also important for the Committee to prescribe what constitutes serious medical condition and who decides. The parents-to-be may consider a genetic condition serious where, for example, it requires extensive treatment or one or more corrective surgeries as a baby or adult. Whereas such a ‘serious’ medical condition does not discount the person from being able contribute to and thus benefit society as a whole.

According to the consultation paper more than 100 genetic conditions can be tested now. This number can only increase. The Committee should consider whether there should be a limit on the number of embryos that can be screened, or whether the limit will base on the financial and emotional strengths of the parents-to-be.

Furthermore, the Committee should consider that some embryos are carriers of a serious medical condition, but may not manifest the symptoms themselves. We would like the recommendation to ensure that embryos are not excluded from implantation on the basis that they are carriers of inherited diseases.

Recommendation 11:

Use of preimplantation genetic diagnosis for sex selection and the selection of certain desired traits for non-medical reasons should be prohibited.

Comment:

We agree with this recommendation.

Recommendation 12:

Preimplantation tissue typing, whether as the sole objective or in conjunction with preimplantation genetic diagnosis to avoid a serious genetic disorder, is permissible but should be licensed and evaluated on a case-by-case basis.

Comment:

We are of the view that Preimplantation tissue typing should not be allowed. The selection of embryos to bring the birth of a child who can provide a matching tissue donation should not be permitted even in circumstances where a sibling is seriously ill. Whenever possible,

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parents should be encouraged to conceive naturally even for the provision of matching tissue types

Germline Genetic Modification

Recommendation 13:

Clinical practice of germline genetic modification should not be allowed at this time.

Comment:

Germline Genetic modification should not be allowed at any time.

Recommendations 10-13 bring into focus the different religious beliefs concerning the IVF issue. We are of the view that that spiritual counselling for people of different faiths should be freely available and recommended before any IVF treatment is undertaken.

Prenatal Genetic Diagnosis

Recommendation 14:

Prenatal genetic diagnosis should be voluntary, conducted with informed consent and with appropriate pre- and post-test counselling. The prospective parents' choice of whether a genetic disorder warrants a prenatal genetic diagnosis or termination of the pregnancy should be respected.

Comment:

The process of counselling should include pastoral and spiritual for persons of different faiths. There should be recognition that informed consent requires education not just in areas of the physiological and psychological but must also involve the spiritual.

Recommendation 15:

Prenatal genetic diagnosis should be limited to serious genetic diseases. The use of prenatal genetic diagnosis for gender selection, apart from sex-linked disorders is unacceptable. Similarly, it is unacceptable to use prenatal genetic diagnosis for the selection of any physical, social or psychological characteristics or normal physical variations.

Comment:

We agree that Prenatal genetic diagnosis should be limited to serious cases. In the case of sex-lined disorders Prenatal genetic diagnosis should be limited only to cases where there is an opportunity for medical cure on good medical grounds. All other areas of Prenatal genetic diagnosis should not be permitted. As we have outlined above, we ask the Committee to define what constitutes a "serious" case.

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Recommendation 16:

The appropriate professional bodies should prescribe detailed ethical guidelines on the practice of prenatal genetic diagnosis for their members.

Comment:

We are of strongly of the view that the recommendations outlined should be committed to legislation rather than left to be detailed in ethical guidelines.

Predictive Testing**Recommendation 17:**

Presymptomatic testing should be available for adults at risk who request it, even in the absence of treatment, after proper counselling and informed consent.

Comment:

We agree that Presymptomatic testing should not be available for healthy adults. We would urge the committee to focus on a clear and qualified definition of an “adult at risk” so as to limit the abuse of the definition to encompass non-critical illnesses.

Recommendation 18:

Susceptibility testing should not be applied clinically unless there is unequivocal empirical evidence of validity and utility.

Comment:

Susceptibility testing should be limited to areas where the information provided can be used to support post-birth care. We cannot agree to susceptibility testing where the purpose is to decide whether to abort the baby. In respect of being able to give informed consent, it should be mandatory for hospitals to provide persons of faith with access to religious guidance and information.

Genetic Screening**Recommendation 19:**

In genetic screening programmes, the appropriate free and informed consent should be obtained from the individual to be tested or parents (or legally designated persons) as the case may be. A confirmatory diagnostic test should be performed as soon as possible after a positive screening test, so as to minimise unnecessary anxiety or to enable measures for the prevention or treatment of the condition to be instituted without delay.

Comment:

We agree with this recommendation.

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Standards of Genetic Test Providers

Recommendation 20:

All laboratories conducting Clinical Genetic Tests should be accredited by an accreditation body designated by the relevant authority, based on standards it considers appropriate.

Comment:

We agree with this recommendation.

These laboratories should be monitored by the relevant authority to ensure that the procedures are followed and testing is carried out to the highest possible standard (ie minimising the possibility of false results).

An evaluation committee should be formed that will assess the value and use of new genetic tests as and when they are developed. When accredited tests are released for use in Singapore, then designated people from each accredited laboratory should be given a standard training to ensure the highest procedural standards are implemented.

Recommendation 21:

Interpretation of genetic test results should only be performed by healthcare professionals who are appropriately qualified or have sufficient experience. Genetic counselling should immediately follow the disclosure of the test result, particularly if the test result is not favourable.

Comment:

We agree with this recommendation.

Where possible, when the accuracy of the test is not assured then multiple types of testing (where available) should be recommended, especially for the serious medical conditions or in situations that are ethically controversial.

Genetic Counseling

Recommendation 22:

Genetic counselling should be offered to all individuals prior to and after they undergo Genetic Testing.

Comment:

We agree with this recommendation.

The costs of genetic counselling should be implemented in such a way that it can be readily claimed from medical insurance (ie to be considered a normal part of the treatment not an optional extra), so that people do not refuse the option of counselling based on possible financial constraints.

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The Committee should consider whether a help-line, or official on-line web site, is at all feasible. This would not be a substitute for genetic counselling but may be able to encourage individuals to pursue personal counselling. This resource could also include a list of contacts to counsellors, both medical and spiritual that are trained and authorised in this field.

Recommendation 23:

Genetic counselling should generally be conducted in a non-directive manner, and should provide sufficient information and appropriate support to the individual and his or her family members.

Comment:

We agree with this recommendation. We would further urge the committee to set criteria so that religious groups can train counsellors to attain the necessary qualifications to be certified as Genetic Counsellors.

Professional Development

Recommendation 24:

Individuals involved in genetic counselling should possess up-to-date knowledge of medical genetics and should be appropriately trained in both medical genetics and counselling.

Comment:

We agree with this recommendation.

Thank you.

Yours truly



for Timothy Goh
President, Graduates' Christian Fellowship

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