National Bioethics Council’s Role in Promoting Ethics in Research Excellence

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An advertisement in a Health Magazine:

“Fertility Clinic Mama offers embryo testing to improve the chances of a successful pregnancy”

- Advertisement directed at childless couple
- IVF (Test-Tube Baby): removing egg or eggs from the woman's ovaries and letting sperm fertilize (perhaps in a test-tube), in a laboratory
- “Embryo testing to improve the chances of a successful pregnancy”
- HOWEVER, embryo testing may also offer:
  - A chance to choose gender
  - A chance to perform other genetic tests in embryos? What if the tests point to susceptibility to a chronic disease? Will embryo be discarded?
  - Why stop at testing for disease? Why not see if she's going to be a pretty girl? Where will it stop?

- Bioethical issues in the use of technology (embryo testing)
Babies on their First Birthday

Mother already had 6 other children through IVF

Mother had no job

Mother had been filed for bankruptcy

Is there no limit in the number of embryos implanted in one womb?*

Why did she / doctors decide on the IVF? (Frozen embryos)*

*Bioethical issues

Mother unmarried [sperm donor]
Contents

- Definition:
- Scenarios of Bioethical Issues:
  - Medical (Reproductive Technology: Test-tube Babies, Multiple Births and Frozen Embryos)
  - Environmental
  - Agricultural
- National Bioethics Council and its Role
- Why should you care?
Ethics and Bioethics

- **Ethics**: Application of values and moral rules to human activities
- **Ethics** is understanding the issues of right and wrong
- **Bioethics**: A branch of ethics. Deals with moral problems in medicine and the life sciences
  - IVF (choosing genders)
  - Octuplets (frozen embryos; multiple births)
- **Bioethics and the Law**: In ethics, a wrong decision (may be morally wrong) but is (usually) not punishable by law.
Morality

- **Morality** is the day to day practice of *what is perceived to be “good”*. (Guidelines?)
- “Good behaviour” is variable across groups and societies
  - Culture
  - Religion
  Functions as *lenses* through which “good behaviour” is filtered

- In many *Bioethics Issues*, when a **choice must be made** and the **consequences are painful**, (whichever course of action is chosen) → **MORAL CONFLICT**
  - IVF (Genetic testing)
  - Nadya (Only for the rich?)
Moral Conflict

- A young woman suffers a massive stroke and can be kept breathing only with the assistance of a ventilator. The decision has to be made whether to shut off the ventilator.

- Medically and intellectually straightforward **BUT** emotional conflicts (young, autonomy, beneficence)
- To shut off ventilator or not shut it off. The final choice is influenced by **Values** and **Integrity** (honesty and truthfulness; consistency of actions; opposite of that is hypocrisy. “munafiq”)
- When values point towards opposing actions ➔ conflict and debate
- Debate:
  - within oneself
  - with others
  - with society at large
Who are the Bioethicists?

- People from many backgrounds should contribute to bioethical discussions (it begins with YOU)
  - medical doctors
  - researchers
  - lawyers
  - religious leaders
  - philosophers
  - media guys
- Council members within NBC have diverse backgrounds
Environmental Bioethics

- Ethical relationship between human beings and the natural environment

Diversity of Animal Life

Diversity of Plant Life
Biodiversity of Sarawak

Mulu - World Heritage
Environmental Bioethics (contd)

- Plants and animals should also be associated with our guiding principles as well as our moral and ethical values (the prostitute and the dog)
  - Industrial activities and pollution
  - Cutting down forests
- Human beings have duties towards our environment
Environmental Bioethics (contd)

KELANTAN FLOODS DECEMBER 2014
Diversity of Marine Life

- Shark
- Jackfish
- Nudibranch
- Turtle
- Lionfish
Rubbish in the Water!!

Vibrant Marine Life

Sharks Fin Soup!!

Dead Corals!!
Environmental Bioethics: Scenarios

- Malaria/Dengue control: Will genetic modification of mosquitoes provide a safe control method?
  - DDT cheap but health effects?
  - Genetically modified mosquitoes - Is it right and how do we test its safety and effectiveness?
Agricultural Biotechnology

- A posting in Facebook:

  “There will be a meeting tonight to discuss the promise and concerns in agricultural biotechnology, specifically in **functional foods and their role in nutrition**”

  - **Functional foods**: designed to improve health and bridge the gap between foods and medicine. Foods with added nutrition
    - Vitamin enhanced rice
    - Vegetables containing edible vaccines
  - “The meeting” should bring together
    - Academics, scientists, farmers, food industry representatives, policymakers
Use of Animals in Research

• Animal experimentation and testing (IKIM) – Other disease models? As effective?

• “--- virtually every medical achievement in the past century has been reliant on the use of animals in some way” – The Royal Society, 2004

Should animals be used in scientific experiments??
National Bioethics Council (NBC)  
[Majlis Bioetika Negara (MBN)]

- July 9, 2010: The Government of Malaysia agreed to establish the National Bioethics Council of Malaysia (Majlis Bioetika Negara), with its secretariat administered by the Ministry of Science, Technology and Innovation of Malaysia (MOSTI).

- Members of the council include those from various backgrounds that include ministries/agencies, academia, industries, social organisations, in order that there is close cooperation in carrying out various activities without much overlap.

- The National Bioethics Council of Malaysia play a role as an advisory panel that discusses and resolves bioethical issues that may have an impact concerning the environment, social, health, culture, laws and religions and Malaysian society in general.
1. **Kumpulan Pakar**
   UM, UiTM, USM, UPM

2. **Wakil Tetap Kementerian/Agensi**
   KPM, MOSTI, IKIM, ASM, Institut Integriti Malaysia, Badan Peguam Malaysia, KKM, Sumber Asli, Kewangan

3. **Wakil Silih Ganti Kementerian/Agensi**

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**Penyerahan Watikah Perlantikan oleh Menteri MOSTI Mei 2012**

**First Council Meeting 12th Jan 2012**
Majlis Bioetika Negara

Sekretariat (MOSTI)

Jawatankuasa Teras (Informasi dan Pendidikan)

Jawatankuasa Teras (Penyelidikan dan Pembangunan)

Jawatankuasa (Undang-undang dan Sosial)
# National Bioethics Council

## Thrust Areas and Members

### Research and Development
- **Prof. Dato’ Dr. Abu Bakar Abdul Majeed** (Universiti Teknologi Mara)
- **Prof. Madya Dr. Abdul Rahim Matalib** (Universiti Putra Malaysia)
- **Prof. Madya Dr. Latifah Amin** (Universiti Kebangsaan Malaysia)
- **Prof. Datin Paduka Dr. Khatijah Binti Mohd Yusof** (Universiti Putra Malaysia)
- **Dr. Shahnaz Binti Murad** (Kementerian Kesihatan)
- **Dr. Umi Kalsom Abu Bakar** (Kementerian Pertanian dan Industri Asas Tani)

### Law and Social Aspects
- **Prof. Madya Dr. Anisah Che Ngah** – Pengerusi (Universiti Kebangsaan Malaysia)
- **Prof. Datin Dr. Zahurin Mohamed** (Universiti Malaya)
- **Prof. Dato’ Dr. Khalid Yusoff** (UCSI University)
- **En. Letchumanan Ramatha** (Kementerian Sumber Asli dan Alam Sekitar)
- **Dr. M. Bala Tharmalingam** (Majlis Perundingan Agama Buddha, Kristian, Hindu, Sikh dan Tao)

### Information and Education
- **Tan Sri Dr. Salleh Mohd Nor** (Akademi Sains Malaysia)
- **Prof. Dr. Maude Elvira Phipps** (University of Monash Malaysia)
- **En. Goh Shook Ming** (Kementerian Pelajaran Malaysia)
- **Dr. Mohd Zaidi Bin Ismail** (Institut Kefahaman Islam Malaysia)
- **Pn. Azrina Sobian** (Institut Kefahaman Islam Malaysia)
Developments of Codes of Conduct and Guidelines

  - Association for Assessment and Accreditation of Laboratory Animal Care International, or AAALAC (UM)

  - Consensus Meeting 14th May 2015

- Code of Conduct for Biosecurity in the framework of Biological Weapons Convention [Science and Technology Research Institute for Defence] 1-4th June 2015
Awareness Programs & Training

- Website
- Inception Workshop (UNESCO). Assisting Bioethics Committee (ABC) UNESCO. May 2012
- Seminar Bioetika at UM. 6 Dec 2012
- Media appearance (IKIM)
- 2nd Training Workshop by UNESCO [25-28 November 2014]
- Public Engagement Activity on Issues of Genetics - jointly organised between NBC, MyHuman Variome Project and Genetics Society of Malaysia – 24th May 2015 at Sekolah Seri Puteri
Conclusion and Summary

- Generally, the efforts that have been undertaken by the National Bioethics Council are in line with the Council’s aim in mainstreaming bioethics among stakeholders such that research can attain world class standards.
Why should you care ----- ?
Bioethics and Society

Society needs to be engaged in Bioethics Issues
“I have better things to do rather than think about this bioethics thingy”

“ ---- if we decide that we do not have time to stop and think about right and wrong, then we do not have time to figure out right from wrong, which means that we do not have time to live according to our model of right and wrong, which means, simply put, that we don’t have time for lives of integrity --- “Stephen Carter
How to Create Awareness of Bioethics Issues ??

- Can be developed around real-life issues
- Schools and teachers and parents can play important roles:
  - eg Association between “Do Not Litter” and “Flash flood”
  - eg “Do you really need to print this?”
  - eg Earth Day (not just fun but has a purpose to it)
Bioethics awareness through Michael Crichton’s technothriller “Jurassic Park”

Genetically engineered dinosaurs which escape their confines and terrorize a group of scientists and children
Jurassic Park

- Entertaining while engaging food for thought.
- The book contains commentary on some of society’s most important scientific and ethical issues.
  - The ethics of cloning and genetic engineering, particularly as it relates to preserving endangered or even extinct species
  - Do humans control technology or does it, once created, ultimately control humanity?
  - The commercialization of science, corporate greed and profiteering from scientific research
Work in Progress ---

- Facilitate high-quality bioethics public engagement of individuals from a wide variety of perspectives, backgrounds
- Policy development around bioethics issues (eg Bioethics Act)
- Curriculum development: Law, Medical Curriculum --- school?
We need to address bioethics issues now while we still have time. Failure to do so would be a moral failure.

We should be prepared to ask difficult questions about what needs to be done.

We deserve good answers.

We ALL have important stake in those answers.
Conclusion

- Bioethical issues affect human life and the natural environment and touch on almost every area of human endeavour.
- National Bioethics Council plays an advisory role in issues of Bioethics while developing certain Codes of Conduct
- There is a need to encourage public engagement in issues in bioethics
- Practical approaches are required to bioethics education