



The Jamaica
National Commission
for UNESCO



THE NATIONAL BIOETHICS COMMITTEE OF JAMAICA
In collaboration with

THE JAMAICA NATIONAL COMMISSION FOR UNESCO,
PAHO/WHO & MINISTRY OF HEALTH

PRESENTS

**Health Information
Use & Protection
NBCJ 1st Consultation Meeting**

PROGRAMME

PAHO Conference Room, Gibraltar Road, Mona

19 February 2013
9:00 a.m.

Emed
Air Ambulance Jamaica

Guardian Life Ltd

UWI
Ethics Initiative

9.00a.m. –9.10 a.m. Welcome/Opening Remarks
Dr. Anthony Mullings, NBCJ Chairman

9:10a.m. – 9.30 a.m. Greetings:
Dr. Michael Coombs
Chief Medical Officer

Ms Margareta Skold
PAHO/WHO representative

Hon. Dr. Kenneth Baugh, M.P.
Opposition Spokesperson on Health

Dr. Jean Dixon
Permanent Secretary, MOH

9.30a.m – 10.10 a.m. HIPAA or not?, THE USA experience
Dr. Kenneth W. Goodman

10.10 am – 10.50a.m Health Information Privacy Legislation
-- Issues and Options, the Canadian experience
Carol Appathurai

10.50a.m—11.00am Q&A

11.00am – 11.15pm **Coffee Break**

11.15am – 12.00pm Data Protection, the UK experience
Dr. Mark Taylor

in Applied Ethics, Centre for Applied Ethics, Linköping University, Linköping, Sweden; and Utrecht University, Utrecht, Netherlands.

In 2010 he served on the HHS Special Emphasis Panel, FOA-OC-HIT-10-001: Health Information Technology, Special Emphasis Panel, Office of the National Coordinator for Health Information Technology, Curriculum Development Centers, 2010. Also, he was Associate Editor, *Acta Bioethica* (journal of the Pan American Health Organization)



Carol Appathurai is currently a Senior Health Privacy Consultant. Previously while working for several organisations including Ministry of Health, Ontario, Canada she was responsible for developing and implementing a privacy compliance strategy for the Ministry of Health and Long-Term Care, including policies and procedures, breach protocols, fee schedules for access to personal health information, and training materials.

She was responsible for leading the development of Ontario's Personal Health Information Protection Act, 2004 which has been cited as the "Gold Standard" for health privacy legislation by the Institute of Medicine in the USA. This involved:

- Identifying policy issues relating to the privacy of personal health information and developing solutions that balanced individual privacy with need for personal health information to flow for effective healthcare and planning and management of the system.

- Working collaboratively with a broad range of stakeholders including non-governmental organizations, health stakeholders, professional organizations, regulatory colleges, and consumer groups to ensure their needs were addressed.

- Preparation of legislative and regulatory submissions, and carriage of these submissions through government processes.

She was also involved in the Preliminary Privacy Impact Assessment to determine compliance with the federal Privacy Act and Treasury Board of Canada Directives and Guidelines, evaluate risk and provide recommendations for change as required.



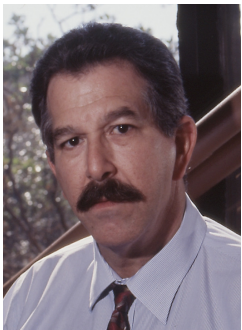


Dr. Mark Taylor is a lecturer at the School of Law since 2002 and is the Programme Director for the LLM in Biotechnology, Law and Ethics, Sheffield University. He is also actively involved in Research and Teaching Development and is responsible for the student-tutor programme in the School.

He studied law at the University of Hull, graduating with an LLB (Hons) in 1994. From Sheffield he has MA in Biotechnological Law and Ethics and also completed a PhD on the morality of regulating genetic discrimination.

He is a member of the Ethics and Confidentiality Committee of the National Information Governance Board (NIGB ECC) and is Deputy Director, Sheffield Institute of Biotechnology, Law and Ethics. He is the Establishing Chair, Confidentiality Advisory Group, Health Research Authority (2013-14) and Chair, National Information Governance Board's Ethics and Confidentiality Committee (2013). He is a member of the Health and Social Care Information Centre 'Code of Practice' Working party (2012-13)

He has significant experience in International Research leadership and publications in the areas of privacy in medical research especially genetic research.



Kenneth W. Goodman is Professor of Medicine and Philosophy; Director, Bioethics Program, University of Miami. He directs a WHO Collaborating Center in Ethics and Global Health Policy, one of six in the world and the first in the United States, and work on ethical issues on international health informatics.

A Fellow of the American College of Medical Informatics, he chairs the Ethics Committee for AMIA, and 10 years ago founded its Working Group on Ethical, Social and

Legal Issues.

He was elected (2008) Fellow, American College of Medical Informatics and was a visiting Scholar, Erasmus Mundus Programme

12.00pm – 12:45pm	"Current Status and Challenges in the Use and Protection of Personal Health Information in Jamaica" Dr. Michele Roofe, MOH
	Access to Information in Jamaica: Current status CITO
	Ethical concerns with personal health records Shereen Cox, NBCJ member
12:45- 1:00	Q&A
1.00 p.m. – 2:00 p.m.	Lunch
2.00pm – 3.00pm	Small group discussions on selected topics identified during the consultation
3.00 p.m – 3.30 pm	Report from Small Group discussions
3.30 pm. -3.50 p.m	Formation of Working Groups
3:50p.m – 4:00p.m	Closing



Rapporteur: Dr. Simon Clarke, Member, NBCJ

THE NATIONAL BIOETHICS COMMITTEE OF JAMAICA

The National Bioethics Committee of Jamaica (NBCJ) was established through the UNESCO’s Assisting Bioethics Committees (ABC) initiative. The initiative focused on the establishment and capacity-building of national bioethics committees across the world. The process of establishing a national bioethics committee in Jamaica commenced in June of 2007 under the auspices of the Jamaica National Commission for UNESCO (JNATCOM). JNATCOM is a governmental agency of UNESCO. The appointment of members was confirmed on September 27, 2008 and a formal launch ceremony was held on October 1, 2009. Jamaica is the first English-speaking Caribbean country to establish such a committee.

A National Bioethics Committee is defined as “an independent platform for public debate and policy advice in bioethics” (Ten Have, 2009). According to Article 19 of the *Universal Declaration on Bioethics and Human Rights*: , “Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to:

- Assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings;
- Provide advice on ethical problems in clinical settings;
- Assess scientific and technological developments, formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration;
- Foster debate, education and public awareness of, and engagement in, bioethics.” (UNESCO, 2005).

The National Bioethics Committee of Jamaica (NBCJ) defines bioethics as “a field of critical reflection on, and examination of, ethical issues of life and human existence”.

The committee has identified fields of importance to the Jamaican society which would be of relevance to a bioethics committee. The twenty-two fields identified included science and technology and health care, but also covered the humanities, information technology, education, the environment, law, and human rights. Having identified the fields to be covered, the challenge was the identification of the best process for selecting Committee members in order to ensure the broadest social representation possible. It was agreed that a committee of not less than 15 persons would be recommended and that persons would be selected not to represent an organization or an interest group. Although such entities would be asked to nominate persons for ratification by the relevant government authority, it was stipulated that once appointed, the member would be expected to act independently.

The Constitution and the rules of procedure of the NBCJ are designed to create the space for an independently functioning committee. They grant the Committee the rights to determine its own work agenda, to have its own secretariat, and to recall members for cause. They also set term limits on chairmanship and membership of the committee, and identify the process for electing members for the executive officers, as well as an evaluation process.

The JNATCOM nominated members of the preparatory committee based on their expertise and demonstrated interest, without considerations of political or ideological allegiance

Names	Positions	Profession
Dr. Anthony Mullings	Chairman	Obstetrician and Gynecologist, Senior Lecturer
Prof. Ayotunde Bewaji	Deputy Chair	Professor of Philosophy
Ms. Nancy Anderson	Secretary	Attorney at Law
Ms. Cheryl Brown	Inaugural member	Attorney at Law
Dr. Simon Clarke	member	Former UNESCO Director for the Caribbean
Dr. Michael Coombs	member	Medical Doctor, CMO, Ministry of Health
Mr. Cezar Cunningham	member	Architect and Musician
Mrs. Shereen Dawkins- Cox	Inaugural member	Bioethicist, Pharmacist
Rev. Oliver Daley	Member	Minister of Religion
Ms. Godiva Golding	member	Student
Rt. Rev. Dr. Howard Gregory	Inaugural member	Anglican Bishop
Mr. Everton Hannam	Inaugural member	Secretary General, JNATCOM, UNESCO
Lt. Col. Errol Johnson	member	Principal
Ms. Leisha Lyn-Cook	member	Teacher
Mrs. Donna McKoy	member	Nurse, Pharmacist, Administrator
Miss Gillian Mignott	member	Bioethicist, Medical Technologist, Lecturer
Mr. Simeon Mohansingh	member	Bioethicist, Lecturer
Prof. Ralph Robinson	Inaugural member	Scientist
Dr. Maria Smith	Inaugural member	Cultural Specialist & Administrator