



Institute for
Research &
Development

Forum for Research & Development
Institute for Research & Development

Disaster Research & Ethics



Ethics: A Friend of Research



Forum for Research & Development
Institute for Research & Development
No. 762/04B, Pannipitiya Road
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IJME

**Forum for Research & Development
Institute for Research & Development**

Disaster Research & Ethics

Consensus Generating Meeting
January 15-16, 2007

Ethics: A Friend of Research

Basic Course in Bioethics
January 13-14 & February 03-04, 2007

Advanced Course in Bioethics
January 13-14, 2007

Inaugural Session for Both Events

January 13, 2007

Our mission

To bring together Sri Lankan scholars, academics & professionals from diverse disciplines, living anywhere in the world to create a research culture in Sri Lanka, and to foster evidence based informed decision-making which is crucial for the sustainable development of the country.

www.ird.lk
www.forum4research.org

Index

Messages	02
Resource Persons	10
Programme of the opening day	18
Programme of the closed meeting	19
Time table	20
List of recommended reading	30
About rules, regulations & declarations	36
Important codes of ethics	37

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No. 762/04B, Pannipitiya Road

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Sri Lanka.

Telephone : +94 11 2884431/ +94 11 2419782

Fax : +94 11 2419782

Email : projects@sysnet.lk

Printed by: PrintWave (Pvt) Ltd,

95/28, Rajagiriya Road, Rajagiriya.

Tel : +94 11 2 888 750

**Messages for the Occasion of Disaster Research and
Ethics Consensus Generation Meeting,
January 13, 2007, Colombo, Sri Lanka**

Message from the Chairman of Forum for Research and Development

It is with a deep pride that I comment on the international conference on 'Disaster Research and Ethics; a consensus generation meeting' organized by the Forum for Research and Development (Institute for Research and Development) because it gives me an immense satisfaction to see that we have taken the initiative to discuss disaster ethics on an international level in Sri Lanka.

From the time of conception, FRD (IRD) had a vision to support an overarching research culture in Sri Lanka. From the early stages bioethics was one of our main objectives to develop among others like the Sri Lanka Twin Registry (SLTR) and mental health research. In this regard we have in a short time developed ethical guidelines and taken steps to increase the mass of professionals formally trained in bioethics. Our basic course in bioethics was an outstanding success.

After Sri Lanka experienced the devastating 'tsunami' we were engaged in rescue, relief, and rehabilitation and during this process we had the opportunity to foresee the critical need of discussing ethical issues of disaster research.

We received support and encouragement from local and international academics and organizations to take this initiative forward. It is my view that our work will make a significant contribution towards building an ethical research culture in Sri Lanka and disaster affected developing countries. I would like to thank everyone who contributed to make this important event a success.

Dr. Nihal Abeyasinghe
Chairman
Forum for Research & Development
Institute for Research & Development

**Message from the Honorable Minister of Disaster Management
and Human Rights**

It gives me immense pleasure in congratulating the Forum for Research and development (Institute for Research and Development) for organizing an international conference on 'Disaster Research and Ethics; a consensus generation meeting' for the first time in Sri Lanka.

After the 2004 'Tsunami', the great tragedy that befell on our nation, we saw a marked increase of academic interest in studying disaster aftermath. Our own academics as well as many foreign academics flocked around the disaster affected communities in order to conduct research. However, there were no boundaries or parameters set, ethical or otherwise. It is of paramount importance to adhere to ethical guidelines when any form of research is conducted.

It is therefore with great satisfaction, that I look upon this initiative taken by the FRD (IRD) to organize an international conference on disaster related research ethics. I am pleased to see that FRD (IRD) has recognized the need to inform academia in order to enhance their knowledge on research ethics related to disaster.

The basic and advanced courses in bioethics will also enhance the bioethics capacity in researchers, and benefit science.

The Institute of Research & Development is already involved actively in disaster management in Sri Lanka, doing policy level work with the Ministry of Disaster Management and Human Rights in various fields to establish services needed for the country.

I take this opportunity to wish all those involved in this endeavor all success and my Ministry's cooperation for the continuation of such important initiatives.

Honorable Mahinda Samarasinghe
Minister of Disaster Management and Human Rights
Sri Lanka

Message from Institute of Psychiatry, King's College, London

Sri Lanka experienced the Tsunami, worst natural disaster to hit its shores that devastated and destroyed valuable human life and property. In the disaster aftermath, Sri Lanka and its tsunami-hit community became a hotbed for research activities. Researchers from all over the world were keen to use this valuable opportunity. But, the question was whether that research was conducted safeguarding the autonomy, dignity and rights of research participants and was it beneficial to the humankind.

Forum for Research and Development (Institute of Research and Development) should be commended for recognizing this problem in a timely manner and organizing an international conference on Disaster Research & Ethics which seeks to address the need of ethical and research governance of disaster research.

The basic and advanced courses in bioethics organized by the FRD (IRD) will make an important contribution to capacity building. This will eventually help to establish a research culture.

I wish to extend warm wishes to FRD (IRD) and all those involved in this event personally from me and also from Institute of Psychiatry, King's College, London which is one of the main partners in this event.

Professor Martin J Prince MD MSc MRCPsych
Professor of Epidemiological Psychiatry
Chair, Division of Psychological Medicine MPhil and PhD Committee
Vice Chair, IoP Postgraduate Research Committee
Honorary Consultant Psychiatrist, King's College Hospital

Message from the Centre of Biomedical Ethics and Culture SIUT, Pakistan

'Disaster Research and Ethics; a consensus generation meeting' organized by the Forum for Research and Development in Colombo addresses an important issue in the domain of research ethics, especially in the context of the developing world. Natural disasters know no boundaries. The shores of Sri Lanka have recently suffered the devastation of the tsunami in 2004 and the earthquake in October 2005 brought death and devastation to hundreds of thousands in Pakistan and India. The massive and sudden scale of destruction required mobilization of international support to augment indigenous efforts at rescue, rehabilitation and then rebuilding operations. Such unforeseen events mandate empirical research to develop a better understanding into the various aspects of situations created by such disasters so that human and material responses could be optimally utilized for the benefit of those effected, and to improve management and care of future victims facing similar situations.

The aftermath of natural or man made disasters is liable to change the whole perspective of the study participants. From an independent and fully capable being, they may find their capacity reduced in many respects. Their displaced predisposition, their exposure to the elements, the psychological impact of the trauma or having lost their life belongings in a matter of a few moments, not to mention any physical injury sustained by them, rendered them in a state that is significantly different from the ordinary research subject encountered during the course of a routine research project. Hence there is a need for a set of ethical guiding principles to help researchers conduct themselves in such situations. This is what this group will attempt to do during the course of this meeting and I hope that we will be able to produce a consensus statement that will help in formulating such a document.

The Centre of Biomedical Ethics and Culture, SIUT Pakistan is pleased to be working in partnership with other institutions in conducting this meeting.

Dr. Aamir Jafarey
Centre of Biomedical Ethics and Culture
SIUT, Pakistan.

Message from University of the Philippines

Warm greetings to the organizers and participants at the 2007 'Disaster Research and Ethics; a consensus generation meeting' in Colombo. on behalf of the University of the Philippines, I am pleased to contribute to this event, which is a great opportunity to express solidarity among disaster-prone Asian countries, and people who have varying cultures and experiences. I look forward to a rewarding and successful meeting.

Leonardo D. De Castro, PhD
Director
Bioethics Initiative and Professor of Philosophy
University of the Philippines

Message from Chairman, University Grants Commission

It is with great pleasure that I accept the invitation of the Forum for Research & Development to issue a message at the inauguration of the Consensus Generation Meeting on 'Disaster Research and Ethics' of the developing world and basic & advanced courses in Bioethics.

Both developed & developing countries face disasters. Research after a disaster has become an essential part for proper addressing of issues relating to the disasters and traumatism. The need to find productive ways to conduct research in complex situations has been identified as a concern of the majority of researchers in this field. A consensus generation meeting on disaster related research ethics of the developing word is indeed fulfilling a need of the hour.

Bioethics is a growing academic area of inquiry. Hence, introducing Basic and Advance courses in Bioethics is a novel feature in the field of higher learning and will be a demanding study stream because of its wide coverage of important and sensitive areas of law, medicine and social sciences.

I take this opportunity to congratulate the organizers of the Consensus Generation meeting and the Inaugural Ceremony of the Basic and Advanced courses in Bioethics for their dedication demonstrated to see the successful completion of this task and I wish the meeting and the course every success.

Prof. Gamini Samaranayake
Chairman
University Grants Commission
Sri Lanka

Message from University of Sri Jayewardenepura

The forum for research and development, a group of Sri Lankan scientists and intellectuals has played an active role in disseminating a culture of critical thinking and scientific enquiry amongst the indigenous intelligentsia. In doing so it has laid a special emphasis on social relevance and ethical conduct. It has also complemented the role of universities and research institutions in capacity building in research. On this occasion they have organised this workshop on ethics of disaster research in the developing world, a globally relevant and topical subject. They have attracted a galaxy of internationally renowned experts for this purpose. I wish the participants an intellectually stimulating and productive workshop. I have no doubt that the final report of this workshop will provide material based on which internationally acceptable guidelines for the conduct of such research in the future could be drawn up.

Prof. Narada Warnasuriya
Vice Chancellor
University of Sri Jayewardenepura
Sri Lanka

Message from the Chairperson of National Science Foundation

I extend warm congratulations to Forum for Research and Development (Institute for Research and Development) for organizing an international conference on 'Disaster Research & Ethics'; a consensus generation meeting.

FRD (IRD) has taken a very positive initiative in organizing this event, which I am sure, will help to promote an ethics-based research culture in Sri Lanka.

The international participation and collaboration for this event will ensure sharing of knowledge with international academia where, Sri Lanka's science stands to gain immensely.

As the chairperson of NSF, I see the great potential of basic and advanced bioethics courses to be conducted by the FRD (IRD), which will help to produce a new generation of ethical researchers in our country.

I wish everyone involved in this important event success.

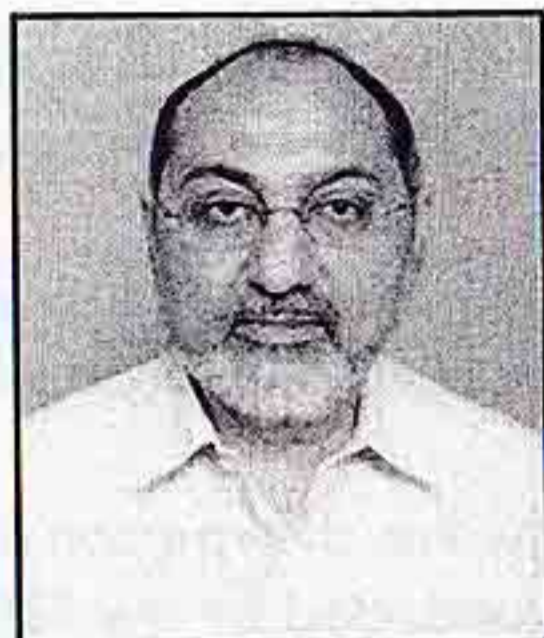
Prof. Sirimali Fernando
Chairperson
National Science Foundation



International Resource Persons

Aasim Ahmad; MBBS, FCPS

Aasim passed his MBBS from Sindh Medical College in 1983 and joined JPMC as a registrar. In 1990 he joined Aga Khan University as an instructor and rose to the rank of associate professor. He spent a year at Guys hospital as a renal registrar. Aasim is an examiner in nephrology for The College of Physicians and Surgeons, Pakistan. He has to his credits many publications in peer reviewed journals and chapters in two text books; he is a reviewer for the Journal of Pakistan Medical Association, Journal of College of Physician and Surgeons, Pakistan and the Pakistan Journal of Medical Sciences. He is a member of the international advisory board, Indian Journal of Medical Ethics. In 2003 he pursued his interest in Bioethics and completed his masters from university of Toronto. He is the chairperson of bioethics group and a member of ethics review committee of Aga Khan university. He is also a member of ethical review board of Médecins Sans Frontières (doctors without borders). In April 2004, he joined the kidney centre post graduate training institute, Karachi as a professor and head of department of Nephrology, where he is still working.



Leonardo D. de Castro; PhD

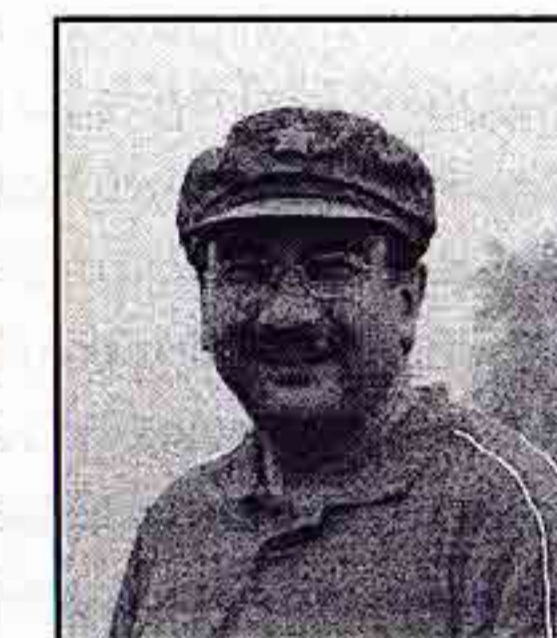
He is a professor of philosophy at the university of the Philippines, where he served as department chair for 9 years. He is vice chair of UNESCO's international bioethics committee and secretary of international association of bioethics. He directs the university of the Philippines - Fogarty international center curriculum development and intensive training project in research ethics. A member of the national ethics committee of the Philippines since 1996, Leonardo also sits on the national transplant advisory board and chairs the medical city research Ethics committee. Leonardo has published 4 books on ethical theory and bioethics. He sits on editorial boards of 6 international academic journals. His published articles reflect his current interest in research on ethical issues arising in organ donation and health research. Awards won by Leonardo include the Takashi Fujii prize for research given by the international federation of social science organizations, National Book Award from the manila critics circle, Outstanding Publication Award from chancellor of university of the Philippines, Outstanding Monograph Award from national academy of science and technology, and six international publication awards from president of university of the Philippines. He wrote on sanctity and quality of life for his doctorate of philosophy at the university of Wales.



Aamir M Jafarey; FRCS

Aamir is currently assistant professor at the Centre of Biomedical Ethics and Culture (CBEC), SIUT which he joined in October 2004 after training in bioethics as a Fogarty fellow at the Harvard School of Public Health, Boston Ma USA. He is also a consultant general surgeon, practicing and teaching at the Aga Khan university hospital Karachi since 1997. He has organized several national and international bioethics conferences and workshops at CBEC on different themes. He has regularly been publishing his research work in peerreviewed journals and is the editor of Bioethics Links, his Center's newsletter. He has been an invited speaker at several conferences across the world. He is currently involved in offering a postgraduate diploma program in biomedical ethics to health professionals through his Centre, which is the only one of its kind in Pakistan.

E-mail: aamirjafarey@gmail.com



Nandini K Kumar; MBBS, DCP

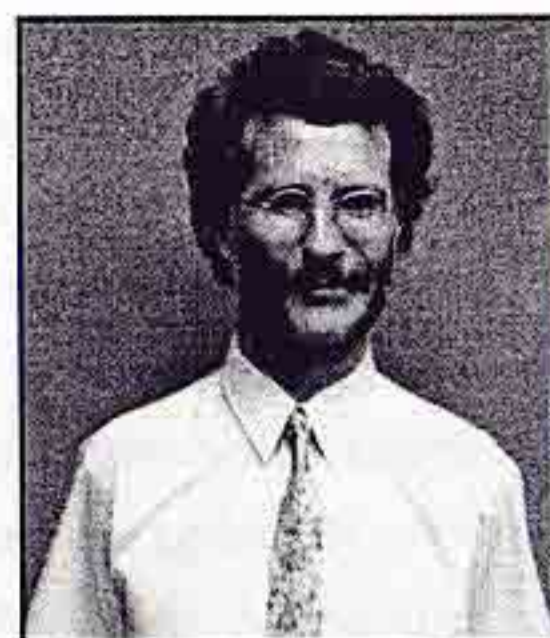
She graduated and did post graduate studies in clinical pathology from Trivandrum Medical College. She worked at various capacities as a researcher in gastroenterology department, Thiruvananthapuram and Institute of Medicine at Madras Medical College, Chennai where she was also in-charge of liver clinic at General Hospital, Chennai. She is presently program officer for traditional medicine research and bioethics. She had been closely involved in the finalisation of revised ethical guidelines of ICMR of 2000 and 2006, and in drafting guidelines for stem cell research and therapy and bio-banking. She is a member of several working groups of ICMR in traditional medicine and national and international bioethics groups. She is Fogarty fellow graduate in Bioethics, from university of Toronto and is a recipient of grants from Genome Canada and Fogarty International Centre, NIH, USA. she also works as a member of steering committee of "Forum for Ethics Committee in India" (FERCI), co-convenor and convenor of several international agency sponsored workshops on ethical issues involving biomedical research. She is presently involved in preparation of curriculum for biomedical ethics and social sciences research related to health.

E-mail: nandkku@yahoo.com



Darryl R.J. Macer; PhD

Darryl is the regional advisor on social and human sciences in asia and the pacific, in RUSHSAP, UNESCO Bangkok, Thailand. He is also an affiliated professor in bioethics at United Nations University Institute of Advanced Studies since 2002; and director, Eubios Ethics Institute, Japan, New Zealand and Thailand (<http://www2.unescobkk.org/eubios/index.htm>), since 1990. He taught bioethics at the university of Tsukuba, Japan from 1990-2005. He is a member of the International Union of Biological Sciences (IUBS) bioethics committee, HUGO ethics committee, board member of International Association of Bioethics, and Secretary of Asian Bioethics Association. He is the editor, Eubios journal of asian and international bioethics since 1990, and has published 8 authored books, 12 edited books in English, 7 edited books in Japanese, 160+ academic papers. His books include a Cross Cultural Introduction to Bioethics; Bioethics is Love of Life; Bioethics for the People by the People. Born in 1962 in Christchurch, New Zealand, he has a B.Sc (Hons) in biochemistry from Lincoln College, university of Canterbury, 1983; PhD. in biochemistry at the MRC Laboratory of Molecular Biology, and Trinity College, university of Cambridge, U.K., 1987. He has since worked in UK, New Zealand, Italy, Japan and Thailand.



Email: d.macer@unescobkk.org

M. Omar Rahman; DSc

He is currently the pro-vice chancellor, director of the MPH program, professor of demography and executive director of the center for health, population and development at Independent University, Bangladesh. Prior to joining Independent University in 2003, professor Rahman was associate professor of epidemiology and demography at Harvard University, and research fellow in psychiatry at Harvard Medical School. He remains as an adjunct professor of demography at Harvard University and a fellow at Harvard Medical School, department of psychiatry. Omar completed his A.B. in biochemical sciences from Harvard University in 1979, followed by his MD from Northwestern University Medical School in 1983. Subsequently he received his MPH in health policy and management from Harvard University in 1986 and his D.Sc. in epidemiology and demography also from Harvard University in 1990. Omar trained in psychiatry at Harvard Medical School and is a US board certified psychiatrist. He is the author of multiple peer-reviewed articles on a variety of health and population related subjects, and has edited two books and several chapters. He has been the principal investigator on a number of large data collection and analysis projects funded by the US National Institute of Health, UNFPA and the Global Health Forum etc. His current scholarly and research interests are: Social and kin networks and their impact on health, gender differences in aging and development, health policy in the developing world, bio-ethics in the context of public health research and practice, and mental health research and policy in the developing world.



Sandhya Srinivasan; BA, MA (sociology), MPH

Sandhya is a freelance journalist and a consultant with master's degrees in sociology and public health. She writes on health and development for print publications and websites as well as for academic publications. She was a Panos reproductive health media fellow in 1998, writing on the infertility industry in India. She is a consultant on health and population for the development website www.infochangeindia.org. Sandhya writes for academic publications on research ethics in India. She is the executive editor of the Indian Journal of Medical Ethics, and a member of the editorial board of developing world bioethics and a member of institutional ethics review board of National Institute for Research in Reproductive Health and the Anusandhan Trust. In 2002, she was awarded an ashoka fellowship for work in medical ethics.

E-mail: sandhya_srinivasan@vsnl.com

Sleman Sutayo; PhD

Sleman is a consultant in paediatric hematology - oncology and also is the secretary of indonesian network on bioethics and health humanities. He is also active in teaching undergraduate students on medical ethics and professional conduct subjects. He is still active as professor at the paediatric department at Sarjito teaching hospital, director of biotechnology, Gadjah Mada University, Yogyakarta and also as a member of clinical ethics committee. He is also deeply involved in the management of disaster in Aceh and Yogyakarta Special Province, Indonesia. He published a book about hospital based disaster management with his fellows.



National Resource Persons

Sarath Nanda Arseculeratne; MBBS, D Phil, D Sc

He graduated from University of Ceylon in 1955, in medicine. He obtained his diploma in bacteriology from the university of Manchester in 1962 and a doctorate (DPhil) in bacteriology from the university of Oxford, UK in 1965. He was awarded an honorary DSc by the university of Ruhuna, Sri Lanka in 2000. His research has been on several microbial diseases in humans and animals and on traditional medicine, science, education and society, teaching of ethics in medicine; scientific literacy. His interest in science and government led to the chairmanship of the statutory committee on science policy research of National Science Council of Sri Lanka that produced the first and only official National Science & Technology Policy for Sri Lanka. He received the national award for scientific achievement. He serves(ed) on editorial boards of Indian Journal of Medical Microbiology, Asia-Pacific Journal of Allergy & Immunology and Ceylon Journal of Medical Sciences. He was a senior Fulbright fellow at Harvard University, Boston, USA, WHO-SEARO -visiting scientist at Mahidol University, Bangkok, Thailand and a DANIDA fellow at the University of Aarhus, Denmark. He was the professor of Microbiology, faculty of medicine, university of Peradeniya, 1971-1995 and is an emeritus professor of microbiology since then. He was a visiting professor of microbiology, Harvard University, Boston, Mass. USA and was the professor of medical microbiology & head of department, faculty of medicine, university of Kuala Lumpur, Malaysia. He served in the expert advisory panel on bacterial diseases, WHO-Geneva and was a consultant of water quality to the government of Malaysia.

Sriyakanthi Beneragama; MBBS, MD, MIRB

She is a consultant epidemiologist at the National STD and AIDS Control Programme, Sri Lanka. She has a MSc and a MD in community medicine and has also completed a masters degree in bioethics at Monash University in Australia. Currently she serves as a member of the ethical review committee of the faculty of medicine, Colombo.

Deepthi de Silva; MBChB, MRCP

She is currently working as a senior lecturer in the department of physiology, faculty of medicine, university of Kelaniya. She is a clinical geneticist with specialist registration as a consultant in clinical genetics in the General Medical Council, UK. Her interests are in ethics involved in practice of clinical genetics in developing countries with different social and cultural conditions from the west.

Sarath Edirisinghe; PhD, MD

He is a consultant medical parasitologist and merit professor of faculty of medicine, University of Peradeniya Sri Lanka. Has 35 years of service as an academic staff member of the Peradeniya medical school. He was trained in medical education and educational technology at the universities of Southern California, New Mexico and Indiana, National University of Singapore, university of Malaya and Mahidol University, Thailand. He is also a committee member of the society for integration of science and human values (SISHVa) of the university of Peradeniya. Currently he is the director of Health Emergency Disaster Management Training Centre (HEDMaTC) of the faculty of medicine, university of Peradeniya. He has

special interest in medical education, curriculum development, self-learning, history of medicine and ethics. He has served in research and ethical review committee and research and higher degrees committee of university of Peradeniya for more than 20 years.

Varuni Ganepola; BA, MA, PhD

Won the prestigious Australian government scholarship and graduated with honors from Monash University in psychology. PhD was awarded to her from Swansea University to her study on internally displaced Sinhalese and Muslims living in Anuradhapura district due to forced migration.

Ravindra Lal Jayakody; MBBS, PhD

Professor of pharmacology at university of Colombo. He has taught ethics for undergraduate and postgraduate curricula for more than 15 years. Functioned as the secretary of ERC, Colombo Medical Faculty, member of ethics committees of SLMA, SLAAS, Ayurveda department etc. at various times. He also functioned as a resource person at WHO/SEARO on introducing ethics in medical curricula (SHEHAN project). He is a member of consultative group which drafted recent ethics in rational drug use document of WHO.

Chandrani Jayasekare; MBBS, MD, MIRB

Consultant community physician attached to National Institute of Health Sciences (NIHS), Kalutara, Sri Lanka. For last ten years she worked as the head of the family health teaching unit and now works as acting deputy director (training) at the same place. She has a MSc and a MD in community medicine and she has also completed a masters in research bioethics at Monash University in Australia during the year 2005. NIHS is the premier training institute for training of health cadres for primary health care program in Sri Lanka. Her training responsibilities include training of public health midwives, public health nurses, public health inspectors, community health orientation for medical officers of Health and for those who are studying for masters degrees in community medicine, medical laboratory technicians, pharmacists and other professionals on research methodology.

Nimal Kasturiarachchi; MBBS, MA, PhD

He was the director of medical education unit, university of Peradeniya. He was one of the key people involved in the activities of collaboration of medical ethics between Norway and Sri Lanka, funded by NORAD from 1992 - 1996. He visited and participated in the annual meeting of the European Society for Philosophy of Medicine and Health Care held in Norway in August 1993. Nimal visited Norway again in 1994 to take part in the activities at the center for medical ethics in Oslo, and spent two months at the center for clinical medical ethics at university of Chicago. He also participated in the "Megameeting" held in Pittsburgh of the four professional organizations in Medical Ethics in the US. He was also involved in developing research in cross-cultural medical ethics for this project. Nimal has been a WHO resource person for ethics coordinated, South East Asia Health Ethics Network (SEAHEN) and SEA regional database in health ethics for WHO. He has expertise and experience in curriculum development for ethics and also has international publications to his credit. Currently he is working as a consultant to World Bank funded health sector development project of the Ministry of Healthcare & Nutrition.

Susirith Mendis; MBBS, PhD

Senior professor of physiology, faculty of medicine, university of Ruhuna and the former dean. He is also the Head, Centre for the Development of Ethics in Medicine (CEDEM) university of Ruhuna, Sri Lanka. He is a WHO fellow on medical education, department of research in health education, university of Connecticut health center, USA, WHO fellow on medical education, centre for clinical bioethics, Georgetown university medical center, Washington DC, USA and department of medical education, College of Medicine, University of Illinois at Chicago, USA. He was the chairman, ethics committee, Sri Lanka Association for the Advancement of Science, and is the chairman of ethical review committee (ERC), faculty of medicine, university of Ruhuna, member of Sri Lanka Medical Council. He was a Member, National Health Research Council, Sri Lanka and the Ministry of Health Special Committee to draft Cabinet Paper to establish a 'National Centre for Ethics in Research on Human Subjects' (2000- 2001), resource person/visiting lecturer in "Professional Ethics", Sri Lanka Foundation Institute (SLFI) diploma course in counselling. He is the Chairman, board of management, Post Graduate Institute of Medicine, university of Colombo, Sri Lanka and a Member, standing committee on university education, National Education Commission (NEC) Sri Lanka.

Clifford Perera; MBBS, MD, MA, LLB

He is a senior lecturer in forensic medicine, at university of Ruhuna. He is involved in ethics training at undergraduate level. He is also qualified in law. He has been selected to attend the international ethics training course organized by the Indian Research Council (Feb 6 -10) in India.

Sisira Siribaddana; MBBS, MD

For training in endocrinology, he was in Brisbane, Australia where he was a clinical research fellow and was also a tutor & examiner in the new graduate programme for medicine at the university of Queensland. He was also a professional member of the endocrine society USA. He was a founder member and director of Sri Lankan Twin Registry which was supported by a grant from Wellcome Trust of UK. He and Dr. Athula Sumathipala has written "Research Ethics from a Developing World Perspective" (ISBN 955-8095--27-3). His own research is on diabetes, osteoporosis, obesity and medically unexplained symptoms. Sisira was involved in editing several evidence-based guidelines through consensus development for osteoporosis and diabetes. He also has published 48 publications in peer-reviewed journals. He is presently leading a large research study on common mental disorders, suicidal ideations and alcohol intake among twins and singletons which also involves development of a sophisticated molecular biology lab.

Athula Sumathipala; MBBS, DFM, MD, MRCPsych, PhD

Originally graduated and trained in Sri Lanka, obtained MBBS, Diploma in Family Medicine and a MD (by research) then re-qualified in UK, underwent postgraduate training in Psychiatry (MRCPsych) and also obtained Certificate of Completion of Specialist Training (CCST) in the UK (EU) and completed a PHD at University of London. He was attached to the Institute of Psychiatry, Kings College, University of London (Section of Epidemiology) but had been involved in research in Sri Lanka for the last 10 years. He has extensive experience in cross-cultural research and known internationally for his work on medically unexplained symptoms. Have carried out the only 2 controlled clinical trials using CBT in the developing world. Also co-founded Forum for Research and Development in Sri Lanka, which is, dedicated capacity

building and establishing an ethical research culture in Sri Lanka. He has also been known internationally for his strong background in ethics; research as well as expertise. He has been validated by the UNESCO as an expert in bioethics.

Dhananjaya Laksiri Waidyaratne; MD, DLM

Dananjaya went to Glasgow for his post graduate work, and as a consultant JMO he was involved in high profile Chemmani and Muttur excavations. He is the chairperson and a founder member of the ethics committee at Anuradhapura general hospital. He is a visiting lecturer and an examiner at Peradeniya medical faculty. His special interests are child abuse and teenagers in conflict with law.

Vasana Wickremasena; LLB, MA

He is the executive director of Centre for Integrated Communication Research and Advocacy in Sri Lanka. Vasana is a member of the International Media Lawyers Association based at Oxford University, and global working group on monitoring and evaluating media development, London. He is the secretary to code of ethics review committee of the editors' guild of Sri Lanka. He is also the course director of the certificate programme in journalism at the Open University of Sri Lanka and BBC world service trust trainer for Sri Lanka and the Maldives. Vasana is an attorney-at-law and holds an LLB from university of Colombo and an MA in journalism from Ateneo de Manila University, Philippines.

Disaster Ethics Workshop Programme

Venue: Sri Lanka Foundation Institute

13th to 16th January 2007

08.30am - 08.45am	Registration
08.45am - 09.00am	Ceremonial opening of the conference. Joint Chairs: Dr Nihal Abeysinghe (Chairman FRD) and Dr Athula Sumathipala (Director FRD) Lighting of the traditional oil lamp by guests
09.00am - 09.20am	Welcome address and presentation of the overall programme by Dr Athula Sumathipala, Director FRD
09.20am - 09.35am	"Disaster ethics policy implementation; Philippines' experience" by Prof Leonardo Castro, Director Bioethics initiative and Professor of Philosophy, University of the Philippines
09.35am - 09.45am	Address by the guest of honour: Prof Gamini Samaranayake, Chairman, University Grants Commission
09.45am - 09.55am	Address by the guest of honour: Prof Narada Warnasuriya, Vice Chancellor, University of Sri Jayewardenepura
09.55am - 10.05am	Address by the guest of honour: Prof Sirimali Fernando, Chairman, National Science Foundation
10.05am - 10.25am	Address by the chief guest: Hon. Mahinda Samarasinghe, Minister of Disaster Management and Human Rights.
10.25am - 10.35am	Address by Mr. J Arunasiri, Actg. Director, Sri Lanka Foundation Institute
10.35am - 10.50am	Tea
10.50am - 11.00am	Address by Dr Prasanna Cooray, Regional Public Health Manager and Country Coordinator, PANOS South Asia
11.00am - 11.15am	Theme lecture 1 by Dr Nandini Kumar, Deputy Director General, Indian Council for Medical Research
11.15am - 11.30am	Theme lecture 2 by Dr. Aamir Jafarey, Centre of Biomedical Ethics and Culture, SIUT, Karachi, Pakistan
11.30am - 11.45am	"Standards to Reality and Ensuring Human Security" by Dr. Darryl Macer, Regional Adviser in Social and Human Sciences for Asia and the Pacific, UNESCO
11.45am - 12.00noon	"Disaster Ethics and Health" by Prof. Sarath Edirisinghe, Emergency and Disaster Management Training Centre of the Faculty of Medicine, University of Peradeniya
12.00noon - 12.15pm	"Ethics and post-disaster media coverage: The Children of Tsunami experience" by Mr. Nalaka Gunawardene, Director and CEO, TVE Asia Pacific
12.15pm - 12.30pm	Closing address
12.30pm - 01.30pm	Lunch for workshop participants
From 01.30pm	Parallel sessions for basic and advanced courses

Closed meeting of invited resource persons with special interest or expertise in disaster related ethics

15th and 16th January 2007

Tasks

A. To be completed during the meeting

1. Develop draft of a statement/concept paper, from the developing world perspective addressing the ethical issues; research and clinical, in disaster situations.
2. Revisit the conclusions arrived at the meeting held in on January 13 and 14, 2003, The New York Academy of Medicine and the National Institute of Mental Health sponsored a meeting entitled "Ethical Issues Pertaining to Research in the Aftermath of Disaster.", in relation to the recent disasters in the developing world.

B. To be planned during the meeting to be completed within a time frame

1. Plan for a larger conference
 - a) Prepare a framework for holding an international conference in 2007 with a wider participation where specific issues such as exploitation, vulnerability, informed consent, ethical review process and other issues can be discussed further,
 - b) Identify national and international agencies and organizations who can act as potential partners and funding sources,
 - c) Identify individuals among the core group, who will lead specific defined tasks (e.g. Producing educational material, liaising with agencies, organizing the conference
2. Plan a mapping exercise of the existing literature on disaster related research with a view to identify the strengths and deficiencies, and designate the relevant tasks to core group participants - aim for a grant application in collaboration, to complete this work.
3. Plan to design a disaster related ethics module and a set of slides to be agreed by the core group so that this could be used by the group members with a uniform format and message for future events in their own countries or other meetings.
4. Plan for a consensus generation among international experts on what types of human subject research is acceptable to do after disasters and at what stages of disaster recovery process using Delphi technique and other qualitative approaches. (aim for a research grant application in collaboration).
5. Plan to establish a consensus framework for ethical approval procedures during a national disaster.
6. Identify potential future collaborations; training and research in disaster related ethical issues.

**Weekend 1 - First day 13th January 2007 (Saturday)
Inauguration ADVANCE & BASIC COURSE in parallel**

	Time	Title	Speakers
	08.30am - 12.30pm	Inauguration ceremony	See the Programme
12.30-1.30 Lunch at SLFI provided for participants and resource persons			
Basic Course - 13th January 2007 (Saturday) Venue: SLFI Auditorium			
Module / Task	Time	Lecture topic	Resource person
Introduction to the course basic and advanced	01.30pm - 02.00pm	Introduction to the course - 'Ethics a Friend of Research'	Dr. Athula Sumathipala
	02.00pm - 02.15pm	Discussion	
The two groups separate from this point, Basic course in room X and Advanced course room Y PROGRAMME FOR BASIC COURSE			
History, philosophy and principles of bioethics	02.15pm - 02.45pm	Basic principles of ethics	Prof. Leonardo de Castro
	02.45pm - 03.00pm	Discussion	
Tea 3.00 -3.15			
History, philosophy and principles of bioethics	03.15pm - 03.35pm	Culture and ethics (Islamic perspective)	Prof. Aasim Ahmad Prof. S N Arseculeratne
	03.35pm - 03.55pm	Culture and ethics (Buddhist perspective)	
	03.55pm - 04.10pm	Discussion	
	04.10pm - 04.30pm	What makes clinical research ethical	Dr. Nandini K. Kumar
04.30pm - 04.45pm	Discussion		

BASIC COURSE Weekend 1 - Second day - 14th January 2007 (Sunday)

Module / Task	Time	Lecture topic	Resource person
History, philosophy and principles of bioethics	09.00am - 09.30am	Social responsibility of a researcher	Ms. Sandya Srinivasan
	09.30am - 09.45am	Discussion	
	09.45am - 10.15am	Integrating ethics into to our professional work	Dr. Darryl Macer
10.15am - 10.30am	Discussion		
Tea 10.30am - 10.45am			
History, philosophy and principles of bioethics	10.45am- 11.30am	A career in bioethics? A panel Discussion	Prof. Aasim Ahmad Dr. Nandini K. Kumar
	11.30am - 12.00noon	Public health ethics	
	12.00noon -12.15pm	Discussion	Prof. Omar Rahman
Lunch 12.00noon - 01.00pm			
Group work and presentation (A & B) 01.00pm - 02.00pm Facilitator			
Group A - discusses the paper (01.00pm - 01.30pm) Alderson & Goodey. Theories of consent. BMJ; 1998;317: 1313-1315. Group A - Presentation 01.30pm - 01.45pm		Group B - discusses the paper (01.00pm - 01.30pm) Mitchell J. A fundamental problem of consent. BMJ 1995; 310:43-46 Group B - Presentation 01.45pm - 02.00pm	
	02.00pm-02.30pm		Discussion
Tea 2.30pm - 2.45pm			
Informed consent and developing countries	02.45pm - 03.15pm	Video presentation depicting informed consent, research in vulnerable and inducement for participation, and conflict of interest	Dr. Aamir Jafarey
	03.15pm - 03.45pm	Small group discussions on informed consent	
	03.45pm - 04.45pm	Discussion	
Closing sessions	04.45pm - 05.00pm	Closing remarks questions & feedback	Facilitator Dr. Athula Sumathipala

ADVANCED COURSE
Weekend 1 - First day - 13th January 2007 (Saturday)

	Time	Title	Speakers
	08.30am - 12.30pm	Inauguration ceremony	See the Programme
12.30pm - 01.30pm Lunch at SLFI provided for participants and resource persons			
INTENSIVE COURSE - 13th January 2007 (Saturday) Venue: SLFI Auditorium			
Module / Task	Time	Lecture topic	Resource person
Introduction to the course basic and advanced	01.30pm - 02.00pm	Introduction to the course - 'Ethics a Friend of Research'	Dr. Athula Sumathipala
	02.00pm - 02.15pm	Discussion	
The two groups separates from this point - Basic course in room X and Advanced course room Y PROGRAMME FOR ADVANCED COURSE			
History, philosophy and principles of bioethics	02.15pm - 02.45pm	Institutional Ethics Committees; management, role and responsibilities	Dr. Nandani K. Kumar
	02.45pm - 03.00pm	Discussion	
Tea 3.00pm - 3.15pm			
New genetics and technology	03.15pm - 03.45pm	Ethics of new technologies; genetics, genomics, ART, organ transplantation	Dr. Darryl Macer
	03.45pm - 04.00pm	Discussion	
History, philosophy and principles of bioethics	04.00pm - 04.30pm	International Collaborations, the issues they bring and quality of ethical review needed	Ms. Sandhya Sirinivasan
	04.30pm - 04.45pm	Discussion	

ADVANCED COURSE - Weekend 1 - Second day - 14th January 2007 (Sunday)

Module / Task	Time	Lecture topic	Resource person
International collaborations	09.00am - 09.30am	Standard of care - on going debate and issues	Prof. Aasim Ahmad
	09.30am - 09.45am	Discussion	
IRB	09.45am - 10.15am	Should research methodology be considered part of ethics review process in research	Prof. Omar Rahman
	10.15am - 10.30am	Discussion	
Tea 10.30am - 10.45am			
	10.45am - 11.15am	Research among children -vulnerability issue	Prof. Sleman Sutaryo
	11.15am - 12.00noon	Discussion	
Lunch 12.00noon - 01.00pm			
International collaborations	01.00pm - 01.30pm	Traumatized population as research partners	Prof. Leonardo de Castro
	01.30pm - 01.45pm	Discussion	
IRB	01.45pm - 02.15pm	Ethics in scientific publications	Prof. Sarath Edirisinghe
	02.15pm - 02.30pm	Discussion	
Tea 02.30pm - 02.45pm			
Informed Consent and developing countries	02.45pm - 03.15pm	Video presentation depicting, research in vulnerable and inducement for participation, and conflict of interest	Dr. Aamir Jafarey
	03.15pm - 03.45pm	Small group discussions on informed consent	
	03.45pm - 04.45pm	Discussion	
Closing sessions	04.45pm - 05.00pm	Closing remarks questions and feedback	Dr. Athula Sumathipala

BASIC COURSE
Weekend 2 - First day - 03rd February 2007 (Saturday)

Module / Task	Time	Lecture topic	Resource person
New genetics and technology	09.00am - 09.30am	Issues of genetic testing and counseling	Dr. Deepthi de Silva
	09.30am - 09.45am	Discussion	
Human rights and justice	09.45am - 10.15am	Human rights and justice and health	Dr. Clifford Perera
	10.15am - 10.30am	Discussion	
Tea 10.30am - 10.45am			
International codes, law and intellectual property	10.45am - 11.15am	Ethics in national drug use	Prof. R L Jayakody
	11.15am - 11.30am	Discussion/questions and answers	
Conflict of interests	11.30am - 12.00noon	Relationship between industry and research	Prof. Susirith Mendis
	12.00noon - 12.15pm	Discussion	
Lunch 12.15noon - 01.00pm			
International collaborative research journal club	01.00pm - 02.00pm	Pappas & Hyder. Exploring ethical considerations for the use of biological and physiological markers in population-based surveys in less developed countries. (Globalization and Health 2005, 1:16 doi: 10.1186/1744-8603-1-16) Moderated by Dr. Athula Sumathipala	
	02.00pm - 02.30pm	Research fraud	Dr. Chandrani Jayasekera
	02.30pm - 02.45pm	Discussion	
	02.45pm - 03.15pm	Ethical evaluation of research proposals	Dr. Nimal Kasturiaratchi
	03.15pm - 03.30pm	Discussion	
Tea 03.30pm - 03.45pm			
Clinical ethics	03.45pm - 04.15pm	Ethics Committees	Dr. Nimal Kasturiaratchi
	04.15pm - 04.30pm	Discussion	

BASIC COURSE
Weekend 2 - Second day - 04th February 2007 (Sunday)

Module / Task	Time	Lecture topic	Resource person
New Genetics and technology	09.00am - 09.30am	Ethics in biotechnology and human biological material research	Dr. Sisira Siribaddana
	09.30am - 09.45am	Discussion	
	09.45am - 10.15am	Sending biological material abroad	Mr. Samantha Gunsekera
10.15am - 10.30am	Discussion		
Tea 10.30am - 10.45am			
International collaborations	10.45am - 11.15am	International collaborations	Dr. Athula Sumathipala
	11.15am - 11.30am	Discussion	
Media ethics	11.30am - 12.00noon	Ethical reporting a journalism perspective	Mr. Vasana Wickramasena
	12.00noon - 12.15pm	Discussion	
Lunch 12.15pm - 01.00pm			
	01.00pm - 01.30pm	Psychosocial approach when doing research	Dr. Varuni Ganepola
	01.30pm - 01.45pm	Discussion	
Case study IRB	01.45pm - 02.15pm	Presentation of case study - Mushrooming of ethics committees and inadequate capacity	Dr. D.L. Waidyaratne & Dr. Sisira Siribaddana
	02.15pm - 02.30pm	Discussion	
Tea 02.30pm - 02.45pm			
Closing sessions	02.45pm - 04.00pm	Closing remarks, questions and feedback	Dr. Athula Sumathipala

Day One 15th January 2007

First session (8.45-12.30)

Developing a concept paper

Chair/facilitators: Dr. Athula Sumathipala & Dr. Aamir Jafarey

Objective:

Develop draft of a statement/concept paper, from the developing world perspective addressing specifically the ethical issues in disaster situations

- 08.45am – 09.30am** Aims of the whole programme and the background to be presented by Dr. Athula Sumathipala and Dr. Aamir Jafarey
- 09.30am – 10.00am** Discussion and questions – tea/coffee provided
- 10.00am – 11.00am** Small groups (four groups) to discuss the draft of a concept paper
- 11.00am – 11.30am** Presentation and roundtable discussion
- 11.30am – 12.00noon** Final draft and consensus
- 12.00noon – 12.30pm** Strategies for dissemination of the draft and how to sell it

12.30pm – 01.30pm Lunch

Second session (01.30pm - 03.30pm)

Revisit the conclusions arrived about post disaster research ethics in developing world

Chair/facilitators: Prof. Susirith Mendis & Prof. R.L. Jayakody

Objective:

Revisit the conclusions arrived at the meeting held in on January 13 and 14, 2003, The New York Academy of Medicine and the National Institute of Mental Health sponsored meeting

- 01.30pm – 02.00pm** Presentation of the key points of the paper
- 02.00pm - 02.30pm** Discussion
- 02.30pm – 03.00pm** Develop a view point on the key issues of the papers in terms of agreement and disagreement

03.30pm – 03.45pm Tea break

Third session (03.45pm – 05.00pm)

Map the existing literature

Chair/facilitators: Prof. Omar Rahman & Prof. Aasim Ahmad

Objective:

Initiate the process of a mapping exercise of the existing literature on disaster related research with a view to identify the research carried out in post disaster situations, categorize them appropriately to type, geographical location, identify key issues including ethical issues.

Task of the meeting:

(i) Appoint a core group to lead it and to identify the tasks; ex. develop the protocol and obtain a grant.

- 03.45pm – 04.15pm** Presentation of the protocol/methodology of the mental health mapping project presentations Prof. Omar Rahaman and Dr Sisira Siribaddana
- 04.15pm – 05.15pm** Appoint the core group
Define the tasks
Set deadlines
Agree on a reporting system

Day Two 16th January 2007

Fourth session (09. 30am - 10.45am)

Plan for a larger conference

Chair/ Facilitators: Dr. Nandini K. Kumar & Dr. Sisira Siribadadana

Objective :

- A. Prepare a framework for holding an international conference in 2008/9 with a wider participation where specific issues such as exploitation, vulnerability, informed consent, ethical review process and other issues will be discussed further,
- B. Identify national and international agencies and organizations who can act as potential partners and funders,
- C. Identify among the core group, individuals who will lead specific defined tasks (e.g. Producing educational material, liaising with agencies, organizing the conference.

10.45am – 11.00am Tea break

Fifth session (11.00am – 12.30pm)

Plan to establish a consensus framework for ethical approval procedures during a national disaster

Chair/ Facilitators: Prof. J.S.Edirisinghe & Prof. Leonard de Castro

Objective:

- A. To discuss issues pertaining to ethical approval procedures during a national disaster.
- B. Develop consensus framework that could be adapted to local settings
- C. To identify institutions/authorities/agencies if already in existence, if not, develop strategy through consensus for establishing such institutions/authorities/agencies for implementation.

12.30pm – 01.30pm Lunch

Sixth session (01.30pm – 02.30pm)

Development of a teaching module

Chair/ Facilitators: Prof. Aasim Ahmad & Prof. Sleman Sutaryo

Objective:

Plan to initiate the process of designing a disaster related ethics module and a set of slides to be agreed by the core group so that this could be used by the group members for future events as a guide/module/core structure in their own countries or other meetings . These sets of slides can be deposited in the Supercourse (<http://www.pitt.edu/~super1/>). [Supercourse is a global repository of lectures on public health and prevention targeting educators across the world. Supercourse has a network of over 38000 scientists in 151 countries who are sharing for free a library of over 2850 lectures. The concept of the Supercourse and its lecture style has been described as the Global Health Network University and the Hypertext Comic Books].

Task to be completed during the meeting

1. Appoint a core group
2. Define tasks

Seventh session (02.30pm – 03.30pm)

Consensus generation document

Chair/ Facilitators: Dr. Athula Sumathipala & Ms. Sandhya Sirinivasan

Objective:

Plan for a consensus generation among international experts on what types of human subject research are acceptable to do after disasters and at what stages of disaster recovery process (to aim for a research grant).

Strategy:

Using Delphi technique and other qualitative approaches. A 5 minutes presentation by Dr. Athula Sumathipala to outline the task

Task:

Identify a core group to undertake. To liaise with the mapping group and use that evidence to develop consensus. Identify key players to be invited for it.

03.30pm – 03.45pm Tea

Final session (03.45pm – 04.45pm)

Future activities and closing remarks

Chair/ Facilitators: Dr. Darryl Macer & Dr. Nimal Kasturiaratchi

Identify any other potential future collaborations; training and research in disaster related ethical issues & Discussions

Recommended Reading

History, philosophy and principles of bioethics

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About Rules, Regulations & Declarations...

(http://www.codex.vr.se/codex_eng/codex/oversikter/ovrigt/regler.html)

There are many different types of ethical and legal regulations that are obligatory to varying degrees. In this section, we introduce most types, on roughly a decreasing scale from the most obligatory to the completely voluntary. In practice, a regulation's status is often unclear and a more thorough assessment of its obligatory character is necessary.

Laws are established by the parliament and include sanctions of various types. Of similar legally binding character are ordinances, which are issued by the government, and authorities' regulations and directives, which are issued with support from laws and ordinances and after authorization from parliament and the government. Furthermore, authorities may make decisions in various cases after authorization from parliament and the government. General counsel is the authorities' recommendations on application of statutes, which are to be followed - failure to do so can result in sanctions in certain cases. Regulations are binding rules whereas general counsel "contains recommendations on how a statute can or should be applied and does not exclude other ways to attain the goal addressed in the statute". The difference between an obligatory or binding rule and one that is "non-binding" is often evident in word usage: the former uses words like "shall", "must" and "is obligated to", whereas the latter uses words like "should".

Conventions are a type of agreement, a voluntary framework that participating countries bind themselves to follow. An example is the European Convention on Human Rights and Biomedicine. Conventions contain a much greater degree of voluntariness, and even if obligatory by international law they are often unclear - at least in practice - with regard to sanctions. These agreements are often entered into by countries or organizations and are less often directed toward individuals. Most often, similar terms are used, such as treaties, agreements, act, charter, concordat, covenant, pact, and protocol.

The status of guidelines varies, and can thus be binding to varying degrees. The word 'rules' often stands for just such guidelines but can also be used more widely, for all types of guiding principles, of which the name of this website is one example. Such documents' legal status must be examined in each individual case.

Declarations, resolutions and statements represent the declaration of a certain interpretation and are generally issued by organizations. Normally, they consist of appeals for certain ethical approaches. They are sometimes also described as decisions, as in the case of WHO. These are normally not binding, but can occasionally be given the same status as conventions. Members of the organization are naturally expected to follow its declarations - and consequences of not doing so can be warnings and, ultimately, dismissal from the organization. Generally, these documents can be called the organization's policy documents. Occasionally, even declarations can have a high status, such as the Helsinki Declaration, which forms the basis for research ethics committees and similar bodies around the world (which often have support through laws). Other variants that sometimes occur are recommendations, opinions, statements, position papers and expert's reports. These are most often not intended to be binding, but Swedish authorities, for instance, have considered it problematic to depart from the Council of Europe's recommendations.

Ethical codes most often have an even more pronounced voluntary character. Some are linked to the means to impose sanctions, usually dismissal from the organization that adopted the code in question, whereas others have no such means available. They usually take up relations not regulated by law and often concentrate on how those affected by the code conduct themselves in relation to their work, as well as the consequences the work can have for other people, the organization, the environment, etc. Whereas declarations and policy documents are often drawn up by associations of organizations, codes often belong to an individual organization, particularly in cases of work ethics codes. Finally, appeals and manifestos can be created by individuals, temporary groups or conferences, and in principal lack the means to impose sanctions.

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