

# INDIAN JOURNAL OF MEDICAL ETHICS

**Vol IV 2007 - Supplement**

(incorporating Issues in Medical Ethics, cumulative Vol XV)

[www.ijme.in](http://www.ijme.in)

## **SECOND NATIONAL BIOETHICS CONFERENCE**

**Moral and ethical imperatives of health care technologies  
Scientific, legal and socioeconomic perspectives on use and misuse**

**Use and misuse of technologies in clinical practice  
Research on health care technologies  
Public health and policy dimensions of technologies**



**KEYNOTE ADDRESSES, PROGRAMMES AND ABSTRACTS**

**Convention Centre, National Institute of Mental Health and Neuro Sciences,  
Bangalore 560 029 Karnataka, India**

**December 6-8, 2007**

**Editor Emeritus**

Sunil K Pandya

**Editor**

George Thomas

**Executive Editor**

Sandhya Srinivasan

**Web Editor**

Nobhojit Roy

**Editorial Board**

Amar Jesani, Mumbai

Bashir Mamdani, USA

Meenal Mamdani, USA

Sanjay A Pai, Bangalore

**Editorial Advisory Board**

Arun Bal, Mumbai

Sunita Bandewar, Pune

Sujith Chandy, Vellore

Pramod Dukle, Goa

M D Gupte, Chennai

Suneeta Krishnan, Bangalore

Neha Madhiwalla, Mumbai

Vasantha Muthuswamy, Delhi

Sanjay Nagral, Mumbai

Vikram Patel, Goa

Mala Ramanathan, Trivandrum

G D Ravindran, Bangalore

PK Sarkar, Kolkata

Amit Sengupta, Delhi

**International Advisory Board**

Aasim Ahmad, Pakistan

Solomon Benatar, South Africa

Zulfiqar Ali Bhutta, Pakistan

Fatima Castillo, Phillipines

Somboon Kietinun, Thailand

Bebe Loff, Australia

Ruth Macklin, USA

M Janake Munasinghe, Sri Lanka

Ann Sommerville, UK

Md Humayun Kabir Talukder, Bangladesh

Ross Upshur, Canada

Antony Zwi, Australia

**SUBSCRIPTION RATES**

Period	Indian		International	
	Individual	Institutional	Individual	Institutional
One year	Rs 250	Rs 500	US\$20	US\$40
Two years	Rs 450	Rs 900	US\$35	US\$70
Five years	Rs 1,000	Rs 2,000	US\$80	US\$160
Life	Rs 10,000	Rs 20,000		US\$1,600

Subscribers from other SAARC countries (Bangladesh, Bhutan, Maldives, Nepal, Pakistan and Sri Lanka) may please pay the Indian rates adding Rs 100 per year extra for postage.

**Special one-year subscriptions for Rs 150 are available to students in India.**

Demand drafts /cheques should be in the name of 'Indian Journal of Medical Ethics'.

Please add Rs 30 for out-station cheques (US\$2 for international subscriptions).

Please send your subscriptions and subscription queries to: **Indian Journal of Medical Ethics, c/o Cehat, Sai Ashray, Aaram Society Road, Vakola, Santacruz (E), Mumbai 400055, INDIA** e-mail: [fme@vsnl.net](mailto:fme@vsnl.net)

PLEASE NOTE THE DIFFERENT SUBSCRIPTION RATES FOR PERSONAL AND INSTITUTIONAL SUBSCRIPTIONS

**PLEASE NOTE THE CHANGE OF ADDRESS FOR SUBSCRIPTION CORRESPONDENCE**

**Editorial correspondence**

S Srinivasan, 8 Seadoll, 54 Chimbai Road, Bandra (W), Mumbai 400 050 INDIA.

e-mail: [sandhya\\_srinivasan@vsnl.com](mailto:sandhya_srinivasan@vsnl.com)

(Articles and contributions do not necessarily represent the views of the editors or the Forum for Medical Ethics Society.)

## IJME's National Bioethics Conference-2

This supplement of the *Indian Journal of Medical Ethics* contains some important material for participants. In addition to the conference programme and abstracts of papers to be presented at the various sessions, we present here messages from the organisers, keynote speakers and other well-wishers. Also included are short bionotes of all those presenting papers, organising workshops or chairing sessions.

This is just a brief preview of the rich and varied discussions that we expect at the second NBC. We look forward to your active participation in making this a memorable event.

The *Indian Journal of Medical Ethics* (formerly *Issues in Medical Ethics*) is a platform for discussion on health care ethics, with special reference to the problems of developing countries such as India. It hopes to involve all cadres of, and beneficiaries from, this system, and strengthen the hands of those with ethical values and concern for the underprivileged.

The Journal is owned and published by the Forum for Medical Ethics Society, a not-for-profit, voluntary organisation. The FMES was born out of an effort by a group of concerned doctors to focus attention on the need for ethical norms and practices in health care.

Contributions to the journal, in the form of original papers, research findings, experiences in the field, case studies, debates, news and views on medical ethics, are welcome. All submissions must be in English and are subject to editorial review.

**Contributors are requested to refer to the detailed guidelines for submission available on the journal website.**

CONTENTS

Indian Journal of Medical Ethics

Vol IV 2007 Supplement  
(incorporating Issues in Medical Ethics, cumulative Vol XV)

FROM THE ORGANISERS

**The moral and ethical imperatives of health care technologies: introductory note** ..... S-2  
 GEORGE THOMAS

**Sustaining the *IJME* National Bioethics Conference: secretariat’s report** ..... S-3  
 SUNEETA KRISHNAN

**Conference objectives and programme structure** ..... S-4  
 NATIONAL COORDINATION TEAM

**Concept note** ..... S-5  
 ORGANISING COMMITTEE

**Guidelines and suggestions for participation** ..... S-8  
 ORGANISERS

KEYNOTE ADDRESSES

**Bioethics and Ayurveda** ..... S-9  
 M S VALIATHAN

**Socio-cultural assumptions and economic dimensions of health care technologies: some issues for discussion** ..... S-10  
 PADMINI SWAMINATHAN

**“Moral and ethical imperatives of health care technologies: scientific, legal and socio-economic perspectives on use and misuse”: a message from the British Medical Association** ..... S-11  
 ANN SOMMERVILLE

FELICITATIONS

**Anil Pilgaokar** ..... S-13  
 M MAMDANI, S K PANDYA, M GUPTA

**C M Francis** ..... S-13  
 T NARAYAN

PROGRAMME AND ABSTRACTS

**Conference programme outline** ..... S-14

**Conference programme day one** ..... S-16

**Conference programme day two** ..... S-19

**Conference programme day three** ..... S-22

**Abstracts day one** ..... S-24

**Abstracts day two** ..... S-28

**Abstracts day three** ..... S-32

Map ..... S-12

Bionotes of participants ..... S-38

Conference organisers and financial acknowledgements ..... Back page

## FROM THE ORGANISERS

# The moral and ethical imperatives of health care technologies: introductory note

**GEORGE THOMAS**

---

When I was a medical student in the decade between 1976 and 1986, it was already obvious that advances in technology were making possible interventions on the human body that had till then been merely the stuff of science fiction. In the decades that followed, and now in the twenty first century, it is clear that we have already galloped past a technological threshold. Now human life, the creation or initiation of it, the living and the leaving of it, are all subject to manipulation by medical scientists at a scale unparalleled in human history. It is also clear that society worldwide is struggling to come to grips with unforeseen ethical issues that the rocketing progress of science in health brings in its wake. Some of the problems are universal: for example, what to do with the terminally ill for whom the act of living every day is an intolerable burden. Some of the problems are perhaps specific to countries like India that are unable to assure a basic, dignified standard of living and health care to all its people, for example life- saving dialysis for a patient with chronic renal failure.

Many authors have written, sometimes with dismay, about the ethical and social issues that arise with the use of technology in medical care. One of the most well-known of these critics is Ivan Illich. In his book *Medical nemesis*, he bemoaned the

“medicalisation” of life and death. This is an extreme view and serves to caution all of us, not merely clinicians, against making the cure of disease more grievous than the endurance thereof, to paraphrase Dr Robert Hutchison.

Ethics in a society is not static, and continually evolves to grapple with new problems that arise. However, in the field of medical care there appears to be a definite lag between the evolution of technology and societal response as evidenced by the provision of safeguards to ensure the ethical use of technology. The four pillars of medical ethics - beneficence, non-maleficence, autonomy and equity - may be enough for an individual medical practitioner faced with an ethical conundrum, but they are hardly sufficient to inform the choices of civil society. One of the best methods of achieving a consensus position as to what is good for people is a wide and open debate. This conference is an attempt in that direction. The abstracts in this volume give a flavour of the multiple and varied ethical questions that inevitably come along with technological advances. The fact that so many people from so many different disciplines are thinking about these problems and suggesting ethical solutions is a cause for optimism.

## FROM THE ORGANISERS

### Sustaining the National Bioethics Conference: secretariat's report

SUNEETA KRISHNAN

---

The First National Bioethics Conference (NBC) held in Mumbai in November 2005 was a resounding success. Over 400 participants attended although only 150 were expected. Intense dialogue and debate took place, and have continued in the pages of the *Indian Journal of Medical Ethics*. Further, an independent, participatory, and national process was established to convene future such national conferences. Given the high standards that had been set, organising the Second National Conference was indeed a daunting task. We have faced several challenges but have also had many strengths to draw upon.

Recognising the need to galvanise new bioethics initiatives in the country and ensure opportunities for a broad range of groups and institutions to shape the national discourse, at the close of the first NBC, the national organising committee (NOC) recommended that *IJME* publish a call for proposals to host the second NBC. This call, in the January-March 2006 issue, yielded just one proposal - from the Bangalore Bioethics Forum, an informal network of clinicians, researchers, and activists in Karnataka, India - and illustrated the very first of several challenges. We hope that interest in, and institutional resources for, hosting the NBC will increase with each edition.

In recognition of the fact that close collaboration between the Mumbai group that organised the first NBC and the Bangalore group would be essential for the conference's success, it was decided that rather than having a single conference coordinator, the second NBC would be coordinated by a group of Bangalore- and Mumbai-based individuals.

We located the secretariat at the project offices of the Samata Health Study, which had the necessary infrastructure to support conference planning activities. The secretariat, funded in part by the Centre for Studies in Ethics and Rights and the Samata Health Study group, has been anchored by Abraham Thomas from its inception in May 2006. The secretariat has had administrative and accounting support from Jayanthi Bhat and Padma Ramaiah in Bangalore and from Mahendra Shinde and Smita More in Bombay.

During the second half of 2006, the conference coordinators, secretariat, *IJME* editors and a number of other members of

our national network contributed to the development of the conference themes. A proposal to fund the conference was sent to funding agencies and an invitation was sent to a range of academic, clinical, and practice organisations - governmental and non-governmental - to join the NOC. While we reached out to institutions around the country, we made an intensive effort to reach organisations in southern India in an attempt to capitalise on Bangalore's geographical location in south central India. The response was tremendous - 38 organisations formally joined the NOC while several others have actively contributed to conference planning through, for example, participation in the local organising committee LOC. These dynamic volunteers have been another critical strength.

Subsequent to the formation of the NOC, *IJME* published a call for abstracts and workshop proposals which generated an enthusiastic response. Although submissions trickled in during the first few months, we were barraged with online, email and postal submissions in the final few weeks before the July 2007 deadline (as was the case with the first NBC). We received nearly 150 submissions, but have been able to accommodate fewer than half of these in the programme. A rigorous process was followed for selection of abstracts: following blinded review by NOC members and *IJME* editorial board members, final selection - also blinded -- of shortlisted abstracts was done by the programme committee.

The most formidable challenge has been obtaining funds. Thanks to the assiduous efforts of the organisers, and the resounding success of the first NBC, we have managed to raise sufficient funds to conduct the conference.

Sustaining the momentum of the conference has not been easy. However, the strength of our process has been that it was not dependent on individuals. We have been able to juggle multiple responsibilities - though not always seamlessly - in such a way that today we have a final conference agenda and programme. We look forward to many stimulating and thought-provoking discussions in the days ahead.

## FROM THE ORGANISERS

### Conference objectives and programme structure

#### NATIONAL COORDINATION TEAM

---

The *Indian Journal of Medical Ethics (IJME)* is the first specialised bioethics journal in India and has been in print for the last 15 years. Beginning as a voluntary effort of a small group of concerned professionals, it has evolved into a peer-reviewed, indexed journal that serves as a broad platform for scientific exchange and debates on bioethics. To further expand this platform, the *IJME* initiated the National Bioethics Conference (NBC) in 2005.

The Second NBC has been organised in a fashion similar to the first with an emphasis on an independent, participatory and national process. Thirty eight diverse organisations from across India came together to form the national organising committee (NOC), and were guided by four eminent national advisors. Two key changes were made in the organisational structure to address the challenge of holding the conference in different parts of the country each time. First, one national coordinator was replaced by a national coordination team of four individuals, two based at the conference location and two *IJME* appointees. Second, the conference venue (Bangalore) was determined on the basis of responses to a call for proposals published in the *IJME*. The diversity and commitment demonstrated by this group illustrate the need for and feasibility of such an initiative.

#### **Objectives**

The NBC has been conceived as a regular platform for showcasing institutional and individual engagements with bioethics and for enhancing interest in bioethics at a national level. Specifically, the NBC aims to enhance awareness of, sensitivity to, and enquiry on bioethics; to facilitate inter-disciplinary interaction, discussion and communication on bioethics; and to provide a platform for popularising the discipline and providing an impetus for its growth. The Second NBC 2007 will promote critical examination of and perspective-building on the ethical dimensions of health care technologies in clinical practice, research and public health and policies.

#### **Structure**

The conference programme reflects our attempt to ensure the representation of varied perspectives on the conference

theme, focusing specifically on insights emerging from within India and, more broadly, in the South Asian region. Five plenary sessions will be held during the three-day conference. While the inaugural and closing ceremonies will focus on the broad theme of the conference, the remaining three plenary sessions will focus on the three conference sub-themes: use and misuse of technologies in clinical practice, research on health care technologies, and public health and policy dimensions of technologies.

A total of three parallel paper and poster sessions, two media sessions and two workshop sessions will also be held. The latter will provide opportunities for small-group interaction and learning. The workshops will involve at least one of the following features: (a) demonstration of new methods and/or skills (e.g. setting up and running an ethics review board); (b) learning exercises (e.g. case study based learning about ethical issues in medical device development); (c) participatory sharing of experiences (e.g. through personal testimonies); and (e) simulation exercises (e.g. conducting ethical review of proposals). Finally, based on feedback from the first NBC, we have created space in the programme for a parallel session featuring four panels of international experts on bioethics. Topics of global and national relevance will be examined and discussed in these sessions.

Two pre-conference workshops are also being organised. The Public Health Foundation of India has invited national and international public health and ethics experts review their planned course on public health ethics. A short module on teaching methods in public health ethics will also be demonstrated. A second pre-conference workshop, coordinated by the *IJME* and partner organisations, focuses on enhancing medical students' knowledge and understanding of bioethics through various activities such as debates, essay writing competitions and film screenings.

We hope that you will find this programme stimulating and inspiring.

## FROM THE ORGANISERS

### Concept note

#### ORGANISING COMMITTEE

---

Developments in technology have been crucial in shaping health care all over the world. Today, physicians utilise and depend on a wide range of tools to guide and support their healing practices, and new relationships between health care professionals, patients and industry have emerged. In the field of public health, the impact of technology has been dramatic. Measures such as immunisation, antenatal screening and purification of water have contributed significantly to lowering mortality and transforming the demographic profile of entire regions. Advances in health care technologies include the development of an array of diagnostics such as the ultrasound scan, magnetic resonance imaging, DNA-based laboratory tests, and treatments using genes and stem cells

Although many of these diagnostic and treatment modalities have improved standards of care, their abuse has simultaneously led to an adverse impact on clinical practice and outcomes. Market forces have influenced the development and use of technology and at times led to inappropriate treatment. Further, as a result of these forces, the cost of these technologies is often so prohibitive that the gap in access to health care technology between socio-economically privileged and disadvantaged individuals and communities has been widened. The costs of innovation and the pressure to stay technologically advanced have often prompted health care professionals and institutions to adopt strategies such as increases in the cost of care, advertising, and outsourcing of various services to maintain their profit margins.

Today in India, the State and State-run institutions are no longer the focal point of health care development and provision. In fact, corporations and private providers, who are primarily unregulated, increasingly control the development of health care technology and its use. The increasing application of health care technologies may also be related to expansions in foreign investment in health care and medical tourism. These developments give rise to ethical questions such as those related to the appropriateness and equitable distribution of technologies; the need for setting priorities in research; the role of government and/or independent agencies in regulating research and the use of health care technologies; and the control of intellectual property.

In view of the importance of health care technologies and the social, economic, legal and moral dimensions that shape their development, use and misuse, *IJME* has decided to focus its second National Bioethics Conference on health care

technologies. The conference aims to facilitate comprehensive debates and dialogues on health care technologies in the contexts of clinical practice, research, and public health and policy.

#### **Conference sub-theme 1: technologies in medical practice**

Medical technologies dominate present day clinical practice. However, advances in technological know-how have not necessarily been accompanied by systemic changes in public policy that are required to make these benefits accessible and affordable. Thus, health care providers who work in resource-poor settings confront a range of challenges related to the distribution of technological advances. They are compelled to ration or, often, do without the latest technological aids that can serve their patients better. Further, in a largely market-based health care system, there is a heavy burden on the poor to pay for services; this creates a dichotomy between those who have the means to pay and therefore have access to technology-based care and those who cannot afford to pay, and do not have access. This dichotomy is particularly apparent in the treatment of chronic diseases, including cases in which organ transplantation may be necessary. Another challenge that has emerged is linked to the fact that hi-tech treatment-oriented solutions are given more attention, leading to the neglect of simpler prevention-focused responses.

Particular ethical issues have arisen in the use of technological means to prolong life. The possibility of prolonging human life by artificial means has radically transformed our understanding of life, death, and the acceptable quality of life. Several cases, now historic, have brought to the fore the moral conflict between the health care system and civil society in the context of life prolongation. Families have gone to court demanding the right to withdraw life support and allow their loved ones to die a "natural" death. These documented cases represent just the tip of the iceberg. Providers and families are compelled to make these choices routinely in the course of their work, often despite the lack of institutional understanding or support.

Another area where the use of technology has become particularly controversial is in the field of artificial reproduction and reproductive health. The possibility of using technological means to predict or even influence the characteristics of the foetus has created a whole range of ethical debates. Most noteworthy in the Indian context is the widespread use of diagnostics to determine or select the sex of the foetus, a practice

that has distorted sex ratios in several states. This provides a classic example of the manner in which the deployment of a technological innovation in a market-driven health care system adapts to suit dominant interests. Debates on the ethics of assisted reproductive technologies have brought to the fore the intersections between gender, society, national policy and regulation, and ethical practice.

The above has, in some sense, overshadowed an equally long and important debate on eugenics. Increasingly sophisticated tools are now available due to technological advances in diagnosis of foetal abnormalities and "undesired" genetic traits. The impacts of these tools include eugenic abortions, reduced access to health care (through restrictions on health insurance, for example), and stigmatisation.

Other ethical issues related to the use of technology in health care are in the arena of professional education. Providers face the challenge of having to continually update their knowledge and skills. Moreover, there has been sustained pressure from various quarters to expand the cadre of health professionals who can deploy health care technologies. One example is the training of paraprofessional health workers to conduct medical abortions. A key challenge is the expansion of access to the benefits of health care technologies at the same time as ensuring their safe and scientific use. Although trained professionals are liable to make mistakes, there are virtually no institutional mechanisms to monitor the use of technology by the broad array of health workers (registered and unregistered) practising in countries like India.

### **Conference sub-theme 2: research on health care technologies**

Research on health care technologies has been a hotly debated subject in bioethics. This is particularly so in fields such as vaccine and drug development, genomics, artificial reproduction and stem cell research. Concerns related to justice have been at the crux of these debates. Although there has been a rapid increase in research in the developing world, the extent to which the people of these countries share in the benefits of this research has been questioned. Some have argued that it is the global market that determines the relevance and access to the products of research, particularly in the case of developing countries.

The explosion of research activity has led to completely new arrangements for conducting health research in different parts of the world. The growth of contract research organisations and the outsourcing of trials have raised several questions about research oversight and mechanisms for demanding accountability from dispersed and often unrelated stakeholders.

Research on emerging health care technologies such as genomics and stem cells raise fundamental questions about the meaning of life and personhood. The possibility of mapping the genetic makeup of entire populations has implications for the human rights of individuals and communities who are found to possess genetic traits that make them either susceptible or resistant to particular diseases. Further, the patenting of life forms (including cell functions and pathways) has raised important

questions regarding what may be patented and under what terms. The burgeoning number of lawsuits in the western world is evidence of the contentiousness of these issues.

Other issues that are relevant in discussions of the ethics of research on health care technologies include the participation (or exclusion) of vulnerable groups as well as the quality of informed consent. There is often a very fine line between treatment/care and research because both are undertaken in the same setting and by the same professional. Thus, the conditions of consent, including the motivations for participation in research, must be critically examined.

Setting priorities in research on health care technologies also poses several ethical dilemmas. Not only is there a need for attention to the ethical dimensions of medical research that is being undertaken, but the ethical implications of neglected areas of research also need to be considered. Communicable diseases, nutritional deficiencies and occupational hazards are major causes of morbidity and mortality in developing countries. Nonetheless, there is a very little investment in research on these issues. Technological advances in the prevention and control of these adverse health outcomes have been less than satisfactory. Developing affordable technologies and scaling up available affordable technologies have also not received adequate attention.

### **Conference sub-theme 3: health care technologies, public health and policies**

Any technology, when used on a wide scale, has important consequences for society. This is particularly evident in the case of food and agricultural technology. Large numbers of people all over the world still suffer from malnutrition. Developing nations have limited political clout when it comes to issues such as gene modification, intellectual property rights, biodiversity, conservation, and the erosion of traditional farming practices. Despite nearly a decade of discussions on labelling, marketing restrictions and banning genetically modified foods, many constituencies continue to view current regulations as extremely weak. Further, some argue that developing nations have become laboratories for research on food technologies, agriculture, and biotechnology. Others contend that these developments will make significant contributions to end world hunger, poverty, and malnutrition.

Another example of the profound impact of technology on human society is in the development and deployment of vaccines. Ensuring appropriate coverage, a necessary condition for the effective use of vaccines, brings into focus the State's roles and responsibilities in health care delivery. Firstly, the State has to enlist community support and participation, and, secondly, it has to make resources available to ensure coverage. Both these aspects raise several ethical dilemmas related to individual freedom, the use of State power as well as the welfare function of the State. Large conglomerations drive vaccine research; and involve both private and public (State) entities. Thus, private interests have the potential to exert considerable influence on governments and international organisations in the making



of vaccine-related policies. Questions remain about the future availability of these vaccines and their costs

While technology has vastly expanded the range of health care options, it has led to a massive increase in the cost of health care. Prohibitive costs have meant that health care is out of reach for a significant proportion of the population, and this has led to indebtedness and further exacerbation of poverty. Paradoxically, the growth of medical technology has levelled international barriers. Medical tourism has become a popular policy option for developing countries that have a large trained professional workforce and access to technology. While it is conjectured that the revenues from medical tourism will benefit the local population, there is little documented evidence to support this contention. On the contrary, the development of hi-tech infrastructure necessary to promote medical tourism has

led to human, financial and material resources being diverted away from institutions accessible and available to the local population. The superimposition of a highly modernised health care system on societies where primary care remains a pressing need is fraught with ethical dilemmas.

Ethical issues also emerge at the intersections of policies on trade and health. For example, intellectual property rights, compulsory licensing, and international trade agreements have had important implications for drug pricing and access in developing countries. The balancing of economic and health concerns merits close attention.

*This paper is based on material written by members of the NBC organising committee.*

## FROM THE ORGANISERS

### Guidelines and suggestions for participation

#### **ORGANISING COMMITTEE**

---

To facilitate discussions, participants are asked to consider the below guidelines for constructive contributions:

- Introductions: When posing questions in plenaries and parallel sessions, please briefly introduce yourself to the group (your name, occupation and institutional affiliation).
- Please keep questions/comments on-topic and brief (within 1 - 1.5 minutes).
- Please be respectful of your fellow participants.

**Remember:** This conference will only be as useful as its participants make it.

---

#### **Your contribution is valuable**

There are many ways to participate in the conference. Please consider the suggestions below:

- Share your experience, as an individual or on behalf of your organisation. Where possible, please provide examples.
- Ask questions and answer questions asked by others. If you use terminology that may be exclusive to your field, please include brief definitions for the group.
- Network, network, network: Explore ways to form local, regional and international partnerships with your fellow participants.
- Spread the word: Share what you learn at the conference with your colleagues, students and friends.

---

#### **Effective communication**

Recognising the diversity of our group, the conference coordinators would like to remind participants to consider the following general guidelines for communication. Bear in mind that conference participants are diverse: gender, cultural identity, profit/non-profit, academic/activist, language/dialects, religious/non-religious philosophies, and much, much more.

- Be sensitive when posing questions or sharing comments: Please bear in mind that English may not be the first language of some participants; that participants come from diverse fields and backgrounds - not all fields define similar terms in the same ways. Whenever possible, please avoid the use of jargon, idioms, and colloquialisms.

- Avoid comments that may be easily misinterpreted or considered offensive to a particular group.

- Best practice: Be sensitive, proceed carefully, and assume the best spirit and motive for each participant, until absolutely proven otherwise.

---

#### **Conference code of conduct**

One of the greatest strengths of the NBC is its diversity. Our participants come with widely varying views on health, politics, ethics, and how (and even if) these fields overlap and interact. We see this diversity as a strength and ask that all participants appreciate this dialogue and debate as a vital, constructive part of the dialogue.

The IJME and NBC are dedicated to the free and respectful exchange of information and ideas on contemporary ethical challenges in health promotion. We are committed to maintaining a safe, equal, and open platform for discussion, in which participants with differing views feel free to express themselves. We, therefore, encourage all participants to focus their contributions to the dialogue. Abusive language or personal attacks should be avoided at all times. This includes, but is not limited to:

- Harmful, threatening, abusive, harassing, defamatory, vulgar, obscene, libellous, hateful, or otherwise objectionable comments.
- Comments invading another person's privacy.
- Comments attacking another participant rather than the content of a participant's statement, argument or position. Constructive disagreement is encouraged; however, please comment only on the argument or position taken, rather than against the person.
- Comments containing racial, religious, sexual or ethnic slurs or insults related to mental, physical or intellectual qualities should be avoided at all times.

---

Thank you for your participation and for helping the National Bioethics Conference maintain its open and fair dialogue.

***Adapted from EcoRes Forum's E-conference guidelines.***

## KEYNOTE ADDRESS

# Bioethics and Ayurveda

**M S VALIATHAN**

---

Bioethics is a broad term which subsumes much of medical ethics. Among the products of biological evolution, humans are unique because they not only take part in the evolutionary process like all other species but also command the future. But, as noted by Professor Markl, human concepts and inventiveness are no more than nature's way of acting upon itself and forming its own future. Humankind is therefore responsible for the future and is obliged to act in accordance with the dictates of reason and moral norms. If human conduct in disregard of bioethics leads to the devastation of earth and the extinction of life, discussions on medical ethics would be no longer necessary.

The conference programme covers a range of topics in medical ethics but leaves out the ethical aspects of traditional medicine which has been practised in India uninterruptedly since at least the time of the Buddha. As traditional medicine or Ayurveda provides the health care needs of millions of Indians and trains over 10,000 doctors every year, it is important to look at the ethical concepts which have sustained it over many centuries. Bioethics is no stranger to Ayurveda which regards the universe, including of course humans, as composed of five elements, and human beings as no more than cosmic resonators. The homology between the human microcosm and the universal macrocosm is a doctrine which pervades Ayurvedic dietetics, therapeutics and every other form of treatment.

Good health was similarly viewed as a manifestation of equilibrium among the constituents of the body, and between

the body and the physical world. Ill health was therefore a temporary lapse into disequilibrium which was primed to correct on its own. All that medicine sought to do was to facilitate the recovery of equilibrium. The care of patients included diagnosis by interrogation and examination; prognosis; and treatment which invariably involved changes in life style, diet, medicinal formulations, medical procedures such as panchakarma and surgery. The decision on treating complex and fatal diseases had to be taken after explaining the risk to the patients and relatives. For major surgery, royal permission was additionally necessary. When the patient was too poor to undergo a costly treatment, a "no-frills" protocol for treatment was advised. The physician had to so conduct himself that the patient would look upon him as his father and mother.

Great emphasis was placed on the training of physicians, which took place in gurukulas or in universities such as Takshasila. The qualifications of the teacher and student were explicitly laid down and, on acceptance into traineeship, the student had to take an elaborate oath in a sacred ceremony. The oath covered every aspect of a physician's code including his personal, academic, professional and social conduct. It is a classic in the history of medical ethics.

Ethics was not discussed as a separate subject in the manner of, say, protocol for medical debate in the ancient Ayurvedic texts. It was dissolved in the concepts and procedures invisibly much as sugar is dissolved in a syrupy formulation.

## KEYNOTE ADDRESS

# Socio-cultural assumptions and economic dimensions of health care technologies: some issues for discussion

**PADMINI SWAMINATHAN**

---

The growth in health care technologies, the increase in total as well as per capita health expenditures in a context where not even primary health care is guaranteed to citizens, among other things, calls for an assessment of not just the technology (or technologies) but also the context in which these technologies function and the manner in which the operation of these technologies alters the context in which health care transactions occur. The theme of technologically mediated health care has several components: the issues of what constitute health care technologies; public policies to deal with aspects such as training, diffusion and regulation of use of these technologies; the financial implications for users of these technologies and subsidies, if any, for facilitating access to these technologies; remedies [legal and otherwise] for adverse outcomes of these technologies; databases to facilitate planning for health care technologies, etc.

This presentation will not engage with health care technologies per se but attempt a mapping of the socio-economic-cultural context over which certain health care technologies have been superimposed. Simultaneously, in several other contexts such technologies do not exist despite the pressing need for such technologies. The co-existence of such seemingly contradictory contexts notwithstanding, the theme of health care technologies has become a site of contestation among the several stakeholders (producers and users of technology, developed and developing countries, public and private sectors, the state and its citizens, etc). Since very often discussions as well as decisions are not contextualised spatially or temporally, and/or by differentiating population by class, age, sex, religion,

location, marital status, etc, more heat than light is the order of the day.

The presentation will focus on two themes to illustrate the Indian government's failure to evolve its policies towards health care and health care technologies taking into consideration the country's diverse socio-economic-cultural context. One, the Indian nation's obsession with the theme of population control, and the translation of this obsession into coercive population policies of which health care technologies are a part, is symptomatic of the manner in which grave injustices have been done to large segments of the population across the country and in particular to women whose bodies have been the sites of invasive technologies, with little or no thought to the person of the woman or to the health implications of such invasion.

The second theme will attempt to address the issue of the adverse health outcomes of occupations where little or no technology exists to mitigate hazards. Once again the criminal negligence to take cognisance of the context and conditions in which large segments of the population work has resulted in almost no investment in technologies to address even the most visible inhuman conditions of such work, even when the execution of such tasks have resulted in death to the workers concerned. Another work-related health outcome not openly admitted because of fear of social stigma, and, therefore not addressed by policies of health care technology, is the increase in cases of infertility among men working in industries such as dyeing and bleaching. In short, the presentation will attempt to highlight the significance of contexts that inform - or misinform - decisions to invest in health care technologies.

## KEYNOTE ADDRESS

# “Moral and ethical imperatives of health care technologies: scientific, legal and socio-economic perspectives on use and misuse”: a message from the British Medical Association

**ANN SOMMERVILLE**

---

On behalf of the British Medical Association (BMA), I wish to congratulate the organisers and participants of this timely and important conference. The themes for debate and the questions addressed are becoming increasingly urgent. They indicate changing public and professional perceptions of the function of medicine and the core purpose of health care technologies. The spectrum of topics to be discussed in Bangalore shows very clearly that current ethical dilemmas override geographical boundaries and are experienced in various forms around the world. If the conference as a whole neatly reflects the wide range of dilemmas increasingly faced by health professionals, the focus in some sessions on the specifically local and cultural context of decision-making reminds us that ethics is not just about abstract principles but also about achieving an overall balance of benefit over harm. It is not about inflexible rules but about weighing up the issues within a particular context and with regard to the wishes, rights and values of the individuals involved.

Although significant international consensus exists on some basic ethical issues such as the duty to seek informed consent, to protect the confidentiality of identifiable health data and to respect the rights of participants in clinical trials, new technologies continuously challenge that consensus. They require us to rethink how widely accepted ethical principles can be applied to newly arising dilemmas. The UK, for example, is grappling with many of the dilemmas you are debating, such as how to make the best use of information technology for public health purposes while protecting patient privacy; whether it is possible to have informed consent in very complex clinical trials where the risks are unknown and volunteers are highly paid; how to have a fair system of allocating scarce resources without marginalising some groups and when to withdraw life-prolonging treatment at the end of life. Variations of such topics are also featured for debate in the influential *Indian Journal of Medical Ethics (IJME)* which examines controversies such as how medical technology can be subservient to commercial goals, for example, in the sale of kidneys for transplantation (1).

The central theme of the conference is the ethical aspects of how health care technologies are used or misused: a theme which organisations like the BMA and publications like *IJME* also explore. Both have, for example, highlighted the role of doctors and medical knowledge in judicial procedures such as

interrogation and capital punishment (2). We may well consider that a misuse of medical technology but around the world, scientists are increasingly scrutinising how therapies developed for one purpose - healing, palliating or preventing disease - can also be adapted for a variety of other purposes. Some of these functions may be innocuous insofar as they mainly just reflect the vanity of people who wish to use medical technology for relatively trivial cosmetic or lifestyle purposes. But some of the new functions hold real risks. The use of drugs as weapons is just one example, as the use of opioid chemicals and anaesthetic agents attracts attention as part of what has been termed the “militarisation of biology”. Various governments are interested in how compounds which inhibit the function of the central nervous system could be used as “non-lethal weapons”. Reports by bodies such as the BMA (3) describe the alarming gap between the rapid pace of scientific discoveries that could be misused and the relatively slow development of international agreements to control them.

Clearly, health care technologies hold both a promise and a threat. The promise is seen - not just in caring for the sick but also in the social and lifestyle choices offered to people who are not sick. We may have misgivings about how cosmetic surgery and other elective procedures are used to modify normal facets of life or how pharmaceutical products are used for recreational purposes. Such use of medical technology questions what we understand by terms such as “disease”, “health” and the “purpose of medicine”. It not only represents the medicalisation of life but encourages healthy people to undertake what may be seen as unnecessary or even risky medical procedures for relatively trivial gains.

Many techniques that involve attempts to medically modify aspects of ourselves or our children are seen as ethically problematic. Just as cosmetic surgery may be controversial, partly because our bodies are symbolic of our shared humanity, there are even more concerns arising from interference with the brain. The brain is intrinsically linked with our personality and individuality and the long-term effects of interfering with this very complex system are unknown. Nevertheless, drugs or medical techniques originally designed to deal with aspects of mental impairment are also being used to improve concentration in people with “normal” mental functioning. Studies show, for example, that American students increasingly

use drugs such as Ritalin to improve cognition prior to exams. Technologies such as trans-cranial magnetic stimulation, developed to treat depression and Parkinson's disease may also be able to improve mental functioning in healthy individuals. These are cosmetic interventions for the brain. Anti-depressants and mood enhancers, such as Prozac, are sought to improve confidence and self-image. Medical ethics is about balancing the harms and benefits of any intervention but perhaps we need to consider whether these uses represent a "misuse" or are simply what medicine has become in the twenty first century.

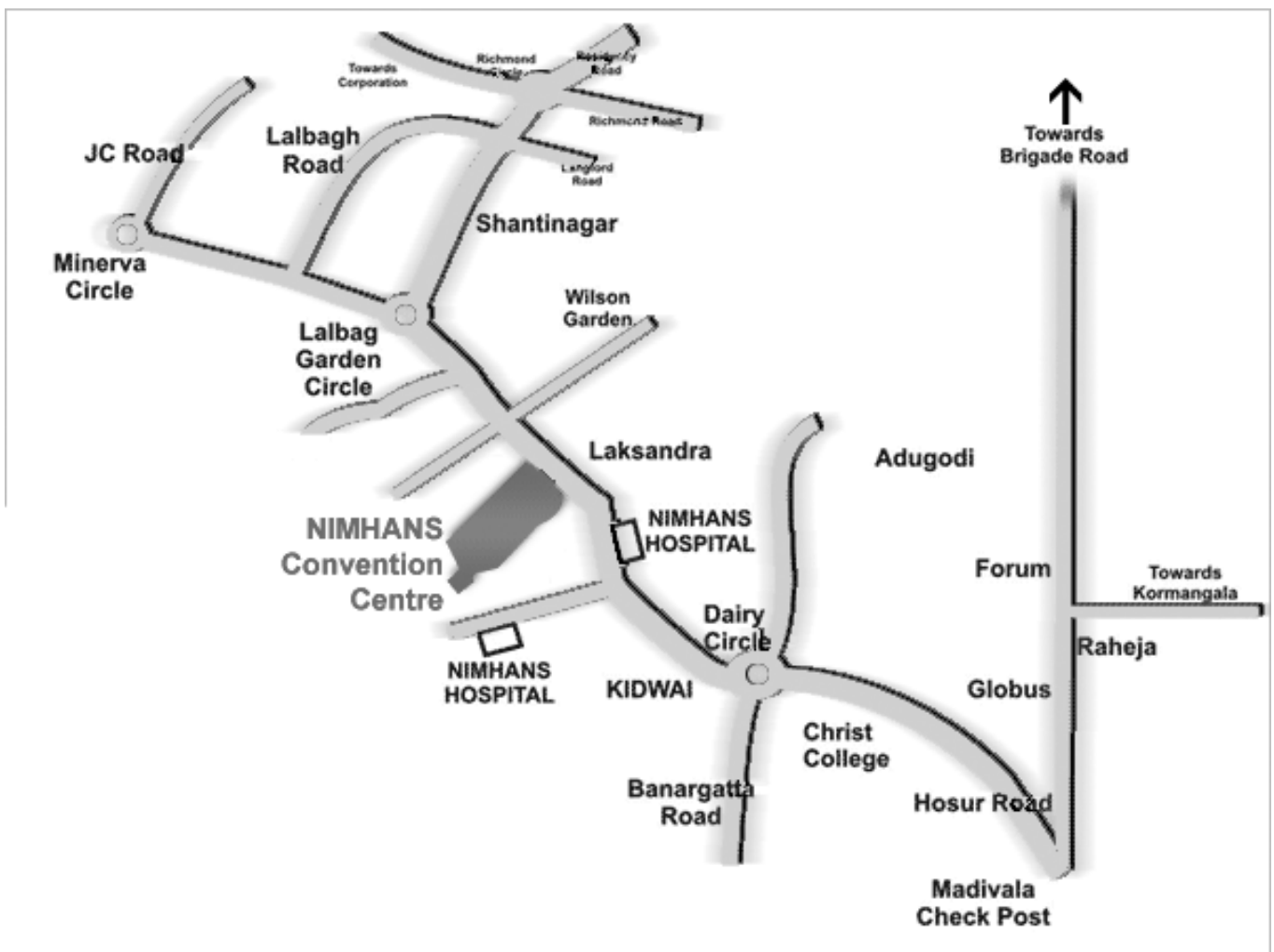
The rapid development of medical technologies not only allows more choices but inevitably also creates more dilemmas about when they should be used and whether their use should be

restricted to clinical scenarios or applied to social goals and individual lifestyle preferences.

The topics highlighted in this conference highlight a wide range of ways that health care technologies can be used or subverted. Hopefully, we can all learn from the conference conclusions and outcome.

**References**

1. *Indian J Med Ethics* 2007;4 (2): 52-3.
2. In 2001, the BMA published its book "The Medical Profession and Human Rights"; the *IJME* featured such issues in Oct-Dec 2004 and Oct-Dec 2006.
3. This is an issue on which the BMA has published three reports - *Biotechnology, weapons and humanity* I and II and, in 2007, its report *The use of drugs as weapons*.



## FELICITATIONS

### Anil Pilgaokar

---

Anil Pilgaokar was born on May 12, 1937 in Bombay. He is the fourth and the youngest son of Sushila (*nee* Mukta Kamat) and Kamalnath Purushottam Pilgaokar. Anil's grandfather was a physician and so was his father, a graduate of JJ Medical College, Bombay.

Anil went to school at St Teresa's High School in Girgaum from 1945 to 1953. He received a Bachelor of Science in Chemistry in 1958 from Wilson College and a Masters in biochemistry from GS Medical College for which his thesis was on hormones in health and disease. He was awarded a Ford Foundation fellowship to pursue research at TN Medical College in 1964-65 and the All India Research Scholarship in Biochemistry to pursue a PhD at the Hindustan Antibiotics Ltd at Pimpri. I am not sure why he did not complete his doctoral thesis but one factor was surely the abominable food and sanitation in the student dorms provided by HAL!

He continued research in biochemistry and food technology at BARC from 1966 to 1972 and then shifted gears, leaving behind academia, to join UniChem. His job involved training sales representatives and he shifted to Aphali Pharmaceuticals as marketing manager from 1976 to 1978. He worked as a freelance consultant for the pharmaceutical industry until 1980 and at the same time he also continued his interest in Ayurvedic medicine, obtaining the degree "Ayurvedic Bhashak" from Karnataka in 1978.

Around this time he made the decision to quit gainful employment and immerse himself in voluntary activities. Since then he has been involved with many non-governmental organisations which were fledgling organisations then and are eminent and respected institutions now such as LOCOST, FRCH, CEHAT, MASUM, ACASH, Anusandhan Trust, GM Trust, to name just a few. He has been a loyal member of Medico Friend Circle, taking on the task of convener in the early 1990s.

He was a founding member of the Forum for Medical Ethics Society along with Drs Arun Bal, Amar Jesani and Sunil Pandya. FMES went on to publish. *Issues in Medical Ethics* out of Dr Pandya's neurosurgery office at KEM Hospital in 1993. This journal is now called the *Indian Journal of Medical Ethics*.

In recognition and deep appreciation of his contribution to public health activism and the field of bioethics in India, the national organising committee of the Second National Bioethics Conference deems it an honour to felicitate Anil Pilgaokar.

### C M Francis

---

Dr C M Francis has a distinguished academic background. He graduated in medicine from Madras Medical College and received a doctoral degree from Cambridge University, UK. He was a visiting professor in the faculty of medicine at the University of Toronto. At a young age he became dean of the Government Medical College in Calicut, Kerala state. He subsequently headed two other government medical colleges in Kerala. He was the founder-director of Sree Chitra Tirunal Medical Centre for Advanced Studies in Specialties. He later was Dean of St John's Medical College, Bangalore, which was one of the earliest medical colleges to systematically introduce the teaching of medical ethics to undergraduate medical students.

He has been a member of the syndicate, senate and academic council of several universities. He has also been a member of the governing bodies of a number of hospitals and ethics committees. He was the director of St Martha's Hospital, Bangalore, and later coordinator, continuing medical education at Christian Medical College, Vellore. He was founder-president of the Indian Society of Health Administrators and of the Society for Community Health, Awareness, Research and Action. He was founder-convener of CBR Forum for persons with disabilities. As editor of *Health Action* for a few years, he continued the tradition of the magazine.

This rich experience was distilled into a book on medical ethics in 1993, filling in a gap in Indian literature on the topic. The second edition published in 2004 was when he was a senior consultant with the Community Cell (CHC), Bangalore. CHC was invited to help the Rajiv Gandhi University of Health Sciences in Karnataka to introduce medical ethics into the undergraduate medical curriculum. The book by Dr Francis was prescribed as reading material on the subject by the university. Dr Francis has been a supporter, promoter and practitioner of bioethics over several years, always available to discuss ethical dilemmas and problems and to advice institutions and individuals. He has also explored medical ethics from a cross cultural point of view especially medical ethics in the Indian tradition.

In recognition of a long standing commitment to medical ethics and to the realisation of health human rights, the national organising committee of the Second National Bioethics Conference deems it an honour to felicitate CM Francis.

## CONFERENCE PROGRAMME OUTLINE

TIME	DAY ONE DECEMBER 6, 2007	VENUE
8 - 9.00 am	<b>Registration</b>	
9 - 11.00 am	<b>PLENARY I: Inauguration</b>	Main auditorium
11.30 - 1 pm	<b>PARALLEL PAPER AND POSTER PRESENTATIONS I</b>	
	Group 1: Reproductive and sexual health ethics	Main auditorium
	Group 2: Public health ethics	Auditorium B
	Group 3: Clinical trials	Auditorium C
	Group 4: Information technology and media	Boardroom
	Group 5: Poster presentations	Poster Hall 1st floor
2 - 3.30 pm	<b>PARALLEL WORKSHOPS I</b>	
	Workshop 1: Ethics of transplantation	Main auditorium
	Workshop 2: Impact of health care technologies on women	Auditorium B
	Workshop 3: Ethical issues in health care provision and research with sexual minorities	Auditorium C
	Workshop 4: Role of community advisory boards in clinical trials and clinical care in HIV/AIDS	Boardroom
	Workshop 5: Health care technologies, public health and policies: is health a human right or a matter of money? The impact of patents on essential innovations and access to essential drugs	Lecture hall 1
	Workshop 6: On ethical review of proposals in resource-poor settings	Lecture hall 2
	Workshop 7: Aspirations of patients with chronic or terminal disorders: a long life or a good death? The impact of medical technology and interventions on patient aspirations.	Lecture hall 3
4 - 5.30 pm	<b>PLENARY II: Use and misuse of technologies in clinical practice</b>	Main auditorium
5.30 - 7.30 pm	<b>Media session I:</b> Film screening followed by discussion	Main auditorium
TIME	DAY TWO DECEMBER 7, 2007	VENUE
8.30 - 9.00 am	<b>Registration</b>	
9 - 10.30 am	<b>PLENARY III: Research on health care technologies</b>	Main auditorium
11 am - 12.30 pm	<b>PARALLEL PAPER AND POSTER PRESENTATIONS II</b>	
	Group 1: Women and health	Main auditorium
	Group 2: Informed consent	Auditorium B
	Group 3: Clinical care and research	Auditorium C
	Group 4: Beginning and end of life	Boardroom
	Group 5: Poster presentations	Poster hall 1st floor
1.30 - 3 pm	<b>PARALLEL WORKSHOPS II</b>	
	Workshop 1: Innovative ways of dealing with ethical issues for AIDS vaccine trials in developing countries	Main auditorium
	Workshop 2: 'New' reproductive and genetic technologies: ethics and women	Auditorium B
	Workshop 3: Developing a South-North advocacy agenda for ethical clinical trials: Indian and European perspectives	Auditorium C
	Workshop 4: Ethical issues in the development of medical devices: Case study of the Chitra Heart Valve	Boardroom
	Workshop 5: A beginner's guide to setting up and running an institutional ethics committee	Lecture hall 1
	Workshop 6: The hows and whys of presenting to an institutional review board	Lecture hall 2
	Workshop 7: Future of medical informatics and tele-health in India: setting an ethical agenda	Lecture hall 3
3.30 - 5 pm	<b>PLENARY IV: Public health and policy dimensions of technologies</b>	Main auditorium
5.30 - 7.30 pm	<b>Media session II:</b> Case studies and discussion	Main auditorium



<b>TIME</b>	<b>DAY THREE DECEMBER 8, 2007</b>	<b>VENUE</b>
8.30 - 9.00 am	<b>Registration</b>	
9 - 10.30 am	<b>PARALLEL PAPER AND POSTER PRESENTATIONS III</b>	
	Group 1: Mental health	Main auditorium
	Group 2: IPR and international trade	Auditorium B
	Group 3: HIV/AIDS	Auditorium C
	Group 4: Oversight	Boardroom
11 am - 12.30 pm	<b>INTERNATIONAL BIOETHICS PANELS</b>	
	Group 1: Ethics in international research	Main auditorium
	Group 2: Public health ethics	Auditorium B
	Group 3: Bioethics across cultures and medical systems	Auditorium C
	Group 4: Bioethics education and oversight	Boardroom
12.30 - 2.00 pm	<b>PLENARY V: Closing session</b>	Main auditorium

### **PRE-CONFERENCE PROGRAMME, DECEMBER 5, 2007**

<b>TIME</b>		<b>VENUE</b>
9.45 am - 7 pm	Public Health Foundation of India: Teaching public health ethics in India	Boardroom
2 - 7.30 pm	Conference organisers: Students' forum	Main auditorium

## CONFERENCE PROGRAMME

TIME	DAY ONE DECEMBER 6, 2007	VENUE
8 - 9.00 am	<b>Registration</b>	
9 - 11.00 am	<b>PLENARY I: INAUGURATION</b>	Main auditorium
	<p><b>Chairpersons:</b> <b>Vasantha Muthuswamy</b>, senior deputy director general, Indian Council of Medical Research, New Delhi, <b>Amar Jesani</b>, member, coordination team, Second National Bioethics Conference</p> <p><b>Welcome:</b> <b>George Thomas</b>, editor, <i>Indian Journal of Medical Ethics</i>, Mumbai</p> <p><b>Objectives of the conference:</b> <b>Amar Jesani</b></p> <p><b>Release of book on bioethics</b></p> <p>Chief guest, <b>M S Valiathan</b>, former vice chancellor, Manipal Academy of Higher Education, Manipal and former director, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram</p> <p><b>Felicitation of C M Francis and Anil Pilgaokar:</b> <b>M S Valiathan</b> and <b>Vasantha Muthuswamy</b></p> <p><b>Keynote address</b> <b>Abhay Bang</b>, director, SEARCH, Gadchiroli, Maharashtra <i>Ethical perspective on research in primary health care</i></p> <p><b>Keynote address</b> <b>Padmini Swaminathan</b>, director, Madras Institute of Development Studies, Chennai <i>Socio-economic dimensions of health care technologies</i></p> <p><b>Inaugural address:</b> <b>M S Valiathan</b></p> <p><b>Chairperson's remarks :</b> <b>Vasantha Muthuswamy</b></p> <p><b>Vote of thanks and announcements:</b> <b>Girish Rao</b>, assistant professor, National Institute of Mental Health and Neurosciences</p>	
11 - 11.30 am	TEA BREAK	Dining hall
11.30 - 1 pm	<b>PARALLEL PAPER AND POSTER PRESENTATIONS I</b>	
11.30 - 1 pm	<b>GROUP 1: REPRODUCTIVE AND SEXUAL HEALTH ETHICS</b>	Main auditorium
	<p><b>Chairpersons:</b> <b>Kalpana Kannabiran</b>, NALSAR University of Law, Hyderabad, <b>Asha Kilaru</b>, Belaku Trust, Bangalore</p> <p>1: <b>Ilias Mahmud:</b> <i>Ethical dilemmas in conducting research on reproductive and sexual health in rural Bangladesh</i></p> <p>2: <b>Shirin Shikalgar, Mahesh Kharat, Sucheta Kadam, Latika Karve, Sanjay Mehendale, Seema Sahay, Vikrant Sahasrabudde, Sten Vermund:</b> <i>Biomedical research participation: concerns of HIV-infected women regarding participating in a cervical cancer screening study</i></p> <p>3: <b>Ritu Mathur, Anant Bhan:</b> <i>Menstrual suppression as a lifestyle choice: autonomy to control body functions or medicalisation of women's bodies?</i></p> <p>4. <b>Supriya Bijlwan:</b> <i>New reproductive technologies and questions of choice</i></p>	
11.30 - 1 pm	<b>GROUP 2: PUBLIC HEALTH ETHICS</b>	Auditorium B
	<p><b>Chairpersons:</b> <b>Thelma Narayan</b>, Community Health Cell, Bangalore, <b>Tarun Kumar</b>, Bapuji Dental College and Hospital, Davangere</p> <p>1: <b>Angus Dawson:</b> <i>Mass public health interventions in India: some ethical issues</i></p> <p>2: <b>Leni Chaudhuri:</b> <i>Use of coercion in public health interventions</i></p> <p>3: <b>Anjani Jani, Swatija Manorama:</b> <i>Ageing women and health care technologies, public health and policies</i></p> <p>4: <b>Jayna Kothari:</b> <i>Newer reproductive technologies and the law: the case for equality</i></p>	

11.30 - 1 pm	<b>GROUP 3: CLINICAL TRIALS</b>	Auditorium C
	<b>Chairpersons:</b> Anoop Kumar Thekkuveetil, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram, Jagadeesh N Reddy, Vydehi Institute of Medical Sciences, Bangalore	
	1: Prathap Tharyan: Evidence-based ethics and clinical research in India.	
	2: Anandi Yuvaraj, Paramita Kundu, Ananth Thambinayagam: Protecting the rights and interests of trial participants, users and communities: an advocacy project of the Global Campaign for Microbicides	
	3: Adarsh Gangadhar: Analysis of legal remedies available to subjects of clinical trials	
	4. M G Sreekumar, Nabeel MK: Ethical issues in biomedical e-publishing	
11.30 - 1 pm	<b>GROUP 4: INFORMATION TECHNOLOGY AND MEDIA</b>	Boardroom
	<b>Chairpersons:</b> VR Muraleedharan, Indian Institute of Technology, Madras: Chennai, Preeti Nayak, Sama: Resource Group for Women and Health, New Delhi	
	1: Rajesh Kumar Sinha: Privacy and confidentiality of health information: An emerging issue in implementing health information technology	
	2: G K Karanth: Patient, doctor and telemedicine: ethical concerns	
	3: Usha Raman: Reporting the ethics of science: how the media frame ethical issues in scientific research	
	4: Geeta Vemuganti, Virender Sangwan, Balasubramanian Doairaja, Nageshwar Rao Gullapalli: Response of the people, patients and media to the first clinical trial of cell therapy	
11.30 - 1 pm	<b>GROUP 5: POSTER PRESENTATIONS</b>	Poster hall 1st floor
	<b>Moderators:</b> Sanjay A Pai, Manipal Hospital, Bangalore, Hemlata Pisal, MASUM, Pune	
	1. C V Sowmini: Towards a new bioethical paradigm for caring for dementia patients in India, informed by a developed-country paradigm	
	2. Sachin Sharma: Ethics, psychiatry and psychiatric research	
	3. Zulfiker Ali, E Urmila: Advances in neonatology: ethical dilemmas from Neonatal Intensive Care Units	
	4. N Vijaya Raaghavan: Ethics in telemedicine	
	5. Mufid Baig, Meena Satale, Amit Nirmalkar, Preeti Gedam, Pramod Vhadge, Shubhangi Sapkal, Arun Risbud, Sanjay Mehendale, Seema Sahay: Making a meaningful HIV test report disclosure	
	6. Ajith Kumar: Ethical issues in the demand for free second line HIV treatment	
	7. Ajith Kumar: Public health programmes vs individual rights: addressing the ethical dilemmas	
1 - 2 pm	LUNCH	Dining hall
2 - 3.30 pm	<b>PARALLEL WORKSHOPS I</b>	
2 - 3.30 pm	<b>Workshop 1: Ethics of transplantation</b>	Main auditorium
	<b>Coordinator:</b> Kishore Phadke, paediatric nephrologist and secretary, Zonal Coordination Committee for Transplantation, Karnataka	
	<b>NOC facilitator:</b> K Mathiharan, Institute of Legal Medicine, Chennai	
	<b>Resource persons:</b> S V Joga Rao, senior advocate and health care consultant, Bangalore: The 1994 HOTA Act, what has it achieved? H Sudarshan, former chairman, Health Task Force, ministry of health and family welfare, government of Karnataka: Organ Trading: Karnataka and the national scene Sanjay Nagral, liver transplant surgeon, Jaslok Hospital and Research Centre, Mumbai: Ethical aspects of living related and cadaveric transplantation V N Subba Rao, chairperson, Karnataka Media Academy: Transplantation - The role of media	
	<b>Participants:</b> all invited <b>Methods:</b> panel presentations, discussion	
2 - 3.30 pm	<b>Workshop 2: Impact of health care technologies on women</b>	Auditorium B
	<b>Coordinator:</b> Chitra Kannabiran, L V Prasad Eye Institute, Hyderabad	
	<b>NOC facilitator:</b> Sangeeta Rege, CEHAT, Mumbai	
	<b>Resource persons:</b> Evita Fernandez, gynaecologist and managing director, Fernandez Hospitals, Hyderabad Annie Hasan, consultant and head of the department of genetics and molecular medicine, Kamineni Hospitals and senior scientific officer, Bhagawan Mahaveer Hospital and Research Centre Kalpana Kannabiran: NALSAR University of Law, Hyderabad P M Bhargava: founding director (retired), Centre for Cellular and Molecular Biology, Hyderabad and former member, Knowledge Commission, government of India, New Delhi	
	<b>Participants:</b> all invited <b>Methods:</b> panel presentations, discussion	

2 - 3.30 pm	<b>Workshop 3: Ethical issues in health care provision and research with sexual minorities</b>	Auditorium C
	<b>Coordinator:</b> Reginald Watts, Sangama, Bangalore <b>NOC facilitator:</b> Vinay Chandran, Swabhava, Bangalore <b>Resource persons:</b> Anant Bhan, independent researcher, Pune <b>Participants:</b> all invited <b>Methods:</b> presentations, case studies in the form of personal testimonies	
2 - 3.30 pm	<b>Workshop 4: Role of community advisory boards in clinical trials and clinical care in HIV/AIDS</b>	Boardroom
	<b>Coordinator:</b> Seema Sahay, NARI, Pune <b>NOC facilitator:</b> Geeta Vemuganti, L V Prasad Eye Institute, Hyderabad <b>Resource persons:</b> V N Karandikar, chairperson, community advisory board, NARI Sanjay Mehendale, epidemiologist, clinical trial specialist, NARI Shirin Shikalgar, vaccine trial counselor and community staff George Swamy, community advisory board member and partner NGO director <b>Participants:</b> 35 - 40 <b>Methods:</b> presentations, case studies and group exercises	
2 - 3.30 pm	<b>Workshop 5: Health care technologies, public health and policies: is health a human right or a matter of money? The impact of patents on essential innovations and access to essential drugs</b>	Lecture hall 1
	<b>Coordinator:</b> Christiane Fischer, public health physician, BUKO Pharma-Kampagne, Germany <b>NOC facilitator:</b> Devadass PK, Bangalore Medical College and Research Institute, Bangalore <b>Resource persons:</b> T Jayashree, documentary film maker Sangama, Bangalore, India Zafrullah Chowdhary, director of Gonoshastaya Kendra, Bangladesh <b>Participants:</b> 20 <b>Methods:</b> presentations, ranking and prioritisation exercise, group work	
2 - 3.30 pm	<b>Workshop 6: On ethical review of proposals in resource-poor settings</b>	Lecture hall 2
	<b>Coordinator:</b> Anoop Kumar Thekkuveetil, Biomedical Technology Wing, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram <b>NOC facilitator:</b> Sivakami M, Institute for Social and Economic Change, Bangalore <b>Resource persons:</b> Mala Ramanathan, Achutha Menon Centre for Health Science Studies, Thiruvananthapuram Sankara Sarma, Achutha Menon Centre for Health Science Studies, Thiruvananthapuram Girish Menon, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram <b>Participants:</b> 25 - 30 <b>Methods:</b> panel presentations, group work and discussion	
2 - 3.30 pm	<b>Workshop 7: Aspirations of patients with chronic or terminal disorders: a long life or a good death? The impact of medical technology and interventions on patient aspirations</b>	Lecture hall 3
	<b>Coordinator:</b> Sridevi Seetharam, Swami Vivekananda Youth Movement, Mysore District. <b>NOC facilitator:</b> Venkatesh Krishnamoorthy, Nephrology-Urology Trust, Bangalore. <b>Resource persons:</b> Daphne Viveka Furtado, Society of the Sacred Heart, Patna. CB Keshavamurthy, interventional cardiologist, Vikram Hospital and Heart Care, Mysore. <b>Participants:</b> 20 <b>Methods:</b> brief presentations, case studies, discussion	
3.30 - 4 pm	TEA BREAK	Dining hall
4 - 5.30 pm	<b>PLENARY II: USE AND MISUSE OF TECHNOLOGIES IN CLINICAL PRACTICE</b>	Main auditorium
	<b>Chairpersons:</b> Prem Pais, St John's National Academy of Health Sciences, Bangalore, Prabha Chandra, member, coordination team, Second National Bioethics Conference	
	<b>Key note address 1:</b> Sriram Rajagopal, department of cardiology, Southern Railway Headquarters Hospital, Chennai <i>Ethics in clinical practice involving hi-tech medical care</i>	
	<b>Key note address 2:</b> George Thomas, St Isabel's Hospital, Chennai and editor, <i>Indian Journal of Medical Ethics General practice and out-reach services</i>	
	<b>Key note address 3:</b> Arjun Rajagopalan, Sundaram Medical Foundation and Hospital, Chennai <i>Diagnostic technologies in clinical practice</i>	
	<b>Key note address 4:</b> Vandana Gupta, founder, V Care, Mumbai <i>User perspectives and rights</i>	
5.30 - 7.30 pm	<b>Media session I:</b> film screening followed by discussion	Main auditorium

## CONFERENCE PROGRAMME

TIME	DAY TWO DECEMBER 7, 2007	VENUE
8.30 - 9.00 am	<b>Registration</b>	
9 - 10.30 am	<b>PLENARY III: RESEARCH ON HEALTH CARE TECHNOLOGIES</b>	Main auditorium
	<p><b>Chairpersons:</b> Prathap Tharyan, Christian Medical College, Vellore, Neha Madhiwalla, member, coordination team, Second National Bioethics Conference</p> <p><b>Keynote address 1:</b>  <b>Muraleedharan CV</b>, Biomedical Technology Wing, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram  <i>Research in medical/surgical devices, instruments and biomaterial</i></p> <p><b>Keynote address 2:</b>  <b>P M Bhargava</b>, founding director (retired), Centre for Cellular and Molecular Biology, Hyderabad and former member, Knowledge Commission, Government of India, New Delhi  <i>Ethical challenges in genetic and stem cell research</i></p> <p><b>Keynote address 3:</b>  <b>Mala Srivastava</b>, head, business strategy, Clinigene International Ltd, Bangalore  <i>Ethical challenges faced by clinical/contract research organisations in clinical trials</i></p> <p><b>Keynote address 4:</b>  <b>Mala Ramanathan</b>, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram  <i>Research on reproductive and contraceptive technologies</i></p>	
10.30 - 11 am	TEA BREAK	Dining hall
11 am - 12.30 pm	<b>PARALLEL PAPER AND POSTER PRESENTATIONS II</b>	
11 am - 12.30 pm	<b>GROUP: 1: WOMEN AND HEALTH</b>	Main auditorium
	<p><b>Chairpersons:</b> Sivakami M, Institute of Social and Economic Change, Bangalore, V Nagaraj, National Law School of India University, Bangalore</p> <p>1: <b>Sunita Puri</b>: <i>"There is such a thing as too many daughters, but not too many sons": The intersection of medical technology, son preference and sex selection among South Asian immigrants in the United States</i></p> <p>2: <b>Victoria Loblay</b>: <i>Everyday ethics: ultrasound and sex-determination in Australia</i></p> <p>3: <b>Abhijit Das</b>: <i>Technology, quality and rights: an exploration</i></p> <p>4: <b>Anant Bhan</b>: <i>Ethical issues in the conduct of HPV vaccine trials in the developing world</i></p>	
11 am - 12.30 pm	<b>GROUP: 2: INFORMED CONSENT</b>	Auditorium B
	<p><b>Chairpersons:</b> Sanjay Mehendale, National AIDS Research Institute, Pune, Sangameshwar BM, Karnataka Health Promotion Trust, Bangalore</p> <p>1: <b>Sanjeev Jain, Meera Purushottam, Shobana Kubendran</b>: <i>Consent issues in genetics of late onset and behavioural disorders</i></p> <p>2: <b>Simble Susan Thomas, Rajendiran Duraisamy, Baiju Julian</b>: <i>The procedure of informed consent in Indian clinical research: Directions towards improving the quality of provision of information</i></p> <p>3: <b>Sridevi Seetharam, Renzo Zanotti</b>: <i>Reluctance of patients to take autonomous decisions: What is the relevance of the informed consent process in new medical technological interventions?</i></p> <p>4: <b>Rajiv Sarkar, Edward Wilson Grandin, Beryl Primrose Gladstone, Gangadeep Kang, Jayaprakash Mulyil</b>: <i>Comprehension of informed consent among participating families in a birth cohort study on diarrhoeal disease.</i></p>	
11 am - 12.30 pm	<b>GROUP: 3: CLINICAL CARE AND RESEARCH</b>	Auditorium C
	<p><b>Chairpersons:</b> Kavita Sivaramkrishnan, Public Health Foundation of India, New Delhi, Stephen Fernandez, FIAMC Biomedical Ethics Centre, Mumbai</p> <p>1: <b>Helen E Sheehan</b>: <i>Issues in patient use of Indian systems of medicine</i></p> <p>2: <b>M A Jothi Rajan, Arockiam Thaddeus</b>: <i>Practice of traditional medicine for hepatitis cure in Atchampathu village: a case study of adherence to bioethical principles</i></p> <p>3: <b>Ajay Radhakrishna, Nabeel M K, Abdul Jameel Shareef, Naveen C Balan</b>: <i>Medical innovations in orthopaedics: addressing issues of cost and benefit in relation to ethical resource allocation</i></p> <p>4: <b>B C Rao</b>: <i>Some ethical issues in primary care</i></p>	

11 am - 12.30 pm	<b>GROUP 4: BEGINNING AND END OF LIFE</b>	Boardroom
	<p><b>Chairpersons:</b> <b>S Ramalingam</b>, PSG Institute of Medical Sciences and Research, Coimbatore, <b>B Sanjeev Rai</b>, Father Mueller Medical College, Mangalore</p> <p>1: <b>Daphne Viveka Furtado:</b> <i>When 'enough is enough': withdrawal of technological life-support: a case of euthanasia or disproportionate means?</i></p> <p>2: <b>Sreekumar N:</b> <i>Health care technologies as counter-death technologies: a philosophical appraisal</i></p> <p>3: <b>Zulfiker Ali:</b> <i>Selection criteria in the NICU (Neonatal Intensive Care Unit): Who should get effective critical care?</i></p> <p>4: <b>Fiona Miller:</b> <i>The complex promise of newborn screening</i></p>	
11 am - 12.30 pm	<b>GROUP 5: POSTER PRESENTATIONS</b>	Poster hall 1st floor
	<p><b>Chairpersons:</b> <b>S Srinivasan</b>, LOCOST, Vadodara, <b>Balaji Sampath</b>, AID India, Chennai</p> <p>1. <b>Asha Kilaru, Baneen Karachiwala, Tejaswini :</b> <i>Women's and providers' perceptions of ultrasound in pregnancy in rural communities and the ethical implications</i></p> <p>2. <b>Athula Sumathipala, Siribaddana Sisira, Hewege Suwin, Lekamwattage Manura, Athukorale Manjula, Siriwardhana Chesmal, Joanna Murray, Martin Prince:</b> <i>Informed consent in Sri Lanka: views of ethics committee members</i></p> <p>3. <b>Suwin Hewege, Athula Sumathipala, Sisira Siribaddana, Manura Lekamwattage, Manjula Athukorale, Chesmal Siriwardhana, Joanna Murray, Martin Prince:</b> <i>Informed consent in Sri Lanka: review of research conducted in Sri Lanka to understand the progress of the informed consent process</i></p> <p>4. <b>Sukanya Rangamani:</b> <i>Ethical dilemmas in informed consent process in an environmental and occupational health research study</i></p> <p>5. <b>Rajendiran Duraisamy, Simble Susan Thomas, Baiju Julian:</b> <i>Misuse of animals for experimentation purposes: an ethical dilemma?</i></p> <p>6. <b>Achintya Mitra:</b> <i>Ethical issues of past and present with special emphasis on Indian systems of medicine</i></p> <p>7. <b>Prashant Raymus:</b> <i>Unit cost of selected health care services in Maharashtra</i></p> <p>8. <b>Tine Abraham:</b> <i>Bioethics and trade</i></p> <p>9. <b>Nagasubramaniam S, Sanjay A Pai, Bopanna PP, Arya BYT, Parameshwara G, Nagendraswamy SC, Chanda Kulkarni, Kartik Nagesh, B G Dharmanand, Thomas Xavier, Kshama Devi:</b> <i>Data from an IRB in a private corporate hospital: lessons learnt from a review of protocols.</i></p>	
12.30 - 1.30 pm	LUNCH	Dining hall
1.30 - 3 pm	<b>PARALLEL WORKSHOPS II</b>	
1.30 - 3 pm	<b>Workshop 1: Innovative ways of dealing with ethical issues for AIDS vaccine trials in developing countries</b>	Main auditorium
	<p><b>Coordinator:</b> <b>Sweta Das</b>, International AIDS Vaccine Initiative, New Delhi  <b>NOC facilitator:</b> <b>Devadass PK</b>, Bangalore Medical College, Bangalore  <b>Resource persons:</b> <b>Ruth Macklin</b>, department of Epidemiology and Population Health, Albert Einstein College of Medicine, Bronx, NY, USA <b>Sanjay Mehendale</b>, NARI, Pune <b>Seema Sahay</b>, NARI, Pune <b>Sushma Kapoor</b>, International AIDS Vaccine Initiative, New Delhi  <b>Participants:</b> all invited <b>Methods:</b> panel presentations, discussion</p>	
1.30 - 3 pm	<b>Workshop 2: 'New' reproductive and genetic technologies: ethics and women</b>	Auditorium B
	<p><b>Coordinators:</b> <b>Deepa V, Preeti Naik</b>, SAMA Resource Group for Women, New Delhi  <b>NOC facilitator:</b> <b>Meera Pillai</b>, independent consultant  <b>Resource persons:</b> <b>Young Gyunk Paik</b>, Korean Women's Link, South Korea <b>Farida Akhter</b>, UBINIG, Bangladesh <b>Sarojini NB</b>, SAMA, New Delhi  <b>Participants:</b> all invited <b>Methods:</b> presentations, discussion</p>	
1.30 - 3 pm	<b>Workshop 3: Developing a South-North advocacy agenda for ethical clinical trials: Indian and European perspectives</b>	Auditorium C
	<p><b>Coordinator:</b> <b>Thelma Narayan</b>, Community Health Cell, Bangalore  <b>NOC facilitator:</b> <b>Sridevi Seetharam</b>, Swami Vivekananda Youth Movement, Mysore District  <b>Resource persons:</b> <b>Jacob Sijtsma</b>, WEMOS, Amsterdam, Netherlands <b>Liontjen Laterveer</b>, WEMOS, Amsterdam, Netherlands  <b>Participants:</b> all invited <b>Methods:</b> panel discussion, case studies and discussion</p>	

1.30 - 3 pm	<b>Workshop 4: Ethical issues in development of medical devices: case study of Chitra Heart Valve</b>	Boardroom
	<b>Coordinator:</b> Muraleedharan CV, Biomedical Technology Wing, SCTIMST, Thiruvananthapuram <b>NOC facilitator:</b> Sanjeev Jain, NIMHANS, Bangalore <b>Resource persons:</b> D S Nagesh, SCTIMST S N Pal, HSCC (India) Ltd Anoop Kumar Thekkuveetil, SCTIMST M D Nair, SCTIMST Girish Menon, SCTIMST <b>Participants:</b> all invited <b>Methods:</b> panel presentations, discussion	
1.30 - 3 pm	<b>Workshop 5: A beginner's guide to setting up and running an institutional ethics committee</b>	Lecture hall 1
	<b>Coordinator:</b> Prabha Desikan, institutional review board, Bhopal Memorial Hospital and Research Centre, Bhopal <b>NOC facilitator:</b> Jameela George, Emmanuel Hospital Association, New Delhi <b>Resource persons:</b> Anant Bhan, independent researcher in bioethics and public health, Pune Mala Ramanathan, Achutha Menon Centre for Health Science Studies, SCTIMST, Thiruvananthapuram S P Kalantri, department of medicine, Mahatma Gandhi Inst of Medical Sciences, Sewagram, Wardha Ashish Goel, department of medicine, All India Institute of Medical Sciences, Ansari Nagar, New Delhi <b>Participants:</b> 30-40 <b>Methods:</b> presentations, group work, evolving a support group of IEC members	
1.30 - 3 pm	<b>Workshop 6: The hows and whys of presenting to an institutional review board</b>	Lecture hall 2
	<b>Coordinator:</b> Geeta Vemuganti, LV Prasad Eye Institute, Hyderabad <b>NOC facilitator:</b> Padmaja Udaykumar, Kasturba Medical College Hospital, Mangalore <b>Resource persons:</b> Usha Raman, LV Prasad Eye Institute, Hyderabad Subhabrata Chakrabarti, LV Prasad Eye Institute, Hyderabad Rangarajan TNC, L V Prasad Eye Institute, Banjara Hills, Hyderabad <b>Participants:</b> not specified <b>Methods:</b> panel presentations, discussion, formulation of ethics review submission checklist	
1.30 - 3 pm	<b>Workshop 7: Future of medical informatics and tele-health in India: setting an ethical agenda</b>	Lecture hall 3
	<b>Coordinator:</b> Nabeel M K, Centre for Tele-health and Medical Informatics, Academy of Medical Sciences, Kerala <b>NOC facilitator:</b> Bhargavi Rao, Environment Support Group, Bangalore <b>Resource persons:</b> MR Hariharan Nair, retired high court judge and chairperson, institutional ethics committee, SCTIMST, Thiruvananthapuram MG Bhat, consultant surgeon, informatics and medico-legal expert, Bangalore MG Sreekumar, Indian Institute of Management Kozhikode, visiting professor, University of Malaya, Malaysia Sunil Shroff, consultant urologist, managing trustee, MOHAN Foundation, president, Medical Computer Society of India R Prajeesh, consultant, Integrated Health Care Group, Sobha Renaissance Information Technology, additional secretary, Indian Association of Medical Informatics <b>Participants:</b> 35 <b>Methods:</b> presentations, discussion, group work	
3 - 3.30 pm	TEA BREAK	Dining hall
3.30 - 5 pm	<b>PLENARY IV: PUBLIC HEALTH AND POLICY DIMENSIONS OF TECHNOLOGIES</b>	Main auditorium
	<b>Chairpersons:</b> Ravi Narayan, Community Health Cell, Bangalore, Suneeta Krishnan, member, coordination team, Second National Bioethics Conference <b>Keynote address 1:</b> Rama Baru, Centre for Social Medicine and Community Health, JNU, New Delhi <i>Public policy and socio-economic dimensions of public health</i> <b>Keynote address 2:</b> Anant Phadke, coordinator, SATHI, Pune <i>Vaccine programme and ethics</i> <b>Key note address 3:</b> Arun Kumar Khanna, Emcure, Pune <i>Role of corporate sector in making medicines accessible</i> <b>Key note address 4:</b> Anand Grover, Lawyers Collective, Mumbai/Dellhi <i>Role of laws in making health care technologies accessible</i>	
5.30 - 7.30 pm	<b>Media session II: Moderator:</b> Ammu Joseph, independent journalist, Bangalore	Main auditorium

## CONFERENCE PROGRAMME

TIME	DAY THREE DECEMBER 8, 2007	VENUE
8.30 - 9.00 am	<b>Registration</b>	
9 - 10.30 am	<b>PARALLEL PAPER AND POSTER PRESENTATIONS III</b>	
	<b>GROUP 1: MENTAL HEALTH</b>	Main auditorium
	<b>Chairpersons:</b> <b>Shalini Bharat</b> , Tata Institute of Social Sciences, Mumbai, <b>Gigi Chandy</b> , Christian Medical College, Vellore	
	1: <b>Jagadisha Thirthalli, Kudumallige Suresh, KV Suma, Basappa Venkatesh, Magadi Naveen, Ganesan Venkatasubramanian, Udupi Arunachala, Kengeri Kishorekumar, Bangalore Gangadhar</b> : <i>Ethical issues in community study of severe mental disorders in India: the Thirthahalli experience</i>	
	2: <b>Geetha Desai, Prabha Chandra</b> : <i>Ethical issues in treating pregnant women with severe mental illness</i>	
	3: <b>Veena AS, Prabha Chandra</b> : <i>Should mental health assessments be integral to domestic violence research?</i>	
	4: <b>Evelyn Lacson</b> : <i>Down's screening guidelines: roles, values and the problematic ethical issue of autonomy</i>	
	<b>GROUP 2: IPR AND INTERNATIONAL TRADE</b>	Auditorium B
	<b>Chairpersons:</b> <b>PD Jose</b> , Centre for Public Policy, IIM, Bangalore, <b>Nabeel MK</b> , Academy of Medical Sciences, Kannur	
	1: <b>Vishwas Devaiah</b> : <i>Impact of bioethics on patents</i>	
	2: <b>Nalin Bharti</b> : <i>Post TRIPS world: what next in public health and policies</i>	
	3: <b>Mansoor Saniei, Ladan Naz Zahedi, Saeed Shahraz, Elnaz Jafari Mehr, Saye Sayar, Ala Melati Rad, Roya Sherafat, Mohammad Reza Zali</b> : <i>Biotechnology and Intellectual Property Rights: ethical aspects for biomedical and theological scientists in Iran</i>	
	4: <b>Sanghamitra Pati</b> : <i>E-medicine: an ethical evaluation</i>	
	<b>GROUP 3: HIV/AIDS</b>	Auditorium C
	<b>Chairpersons:</b> <b>Latha Jagannathan</b> , Bangalore Medical Services Trust and Research Institute, Bangalore, <b>Vijay</b> , Swasti, Bangalore	
	1: <b>Seema Sahay, Sanjay Mehendale</b> : <i>Ethical dilemmas in the recruitment of volunteers in the first HIV vaccine trial in Pune, India</i>	
	2: <b>Katharine Shapiro, Katie West, Lori Heise, Sean Philpott</b> : <i>Standards of care in microbicide efficacy trials: a mapping exercise</i>	
	3: <b>Shivaram Chandrashekar</b> : <i>Changing facets of ethics in transfusion medicine</i>	
	4: <b>Sonia J Cheruvillil, Bhavana Nancharla</b> : <i>Do condoms have us covered? Rethinking HIV/AIDS programmes in India</i>	
	<b>GROUP 4: OVERSIGHT</b>	Boardroom
	<b>Chairpersons:</b> <b>GD Ravindran</b> , St John's National Academy of Health Sciences, Bangalore, <b>Sukanya Rangamani</b> , independent consultant, Bangalore	
	1: <b>Rehana S Kamal</b> : <i>Establishing a clinical ethics committee: five years' experience in Pakistan</i>	
	2: <b>Sanjay Mehendale</b> : <i>Profile of members of ethics committees in hospitals and research organisations in Pune city</i>	
	3: <b>Mala Ramanathan</b> : <i>Concerns of potential participants: are the ICMR Guidelines-2000 adequate?</i>	
	4: <b>Shailaja Tetali</b> : <i>Time to plug the holes in the National Blood Policy</i>	
10.30 - 11 am	TEA BREAK	Dining hall



11 am - 12.30 pm	<b>INTERNATIONAL BIOETHICS PANELS</b>	
11 am - 12.30 pm	<b>GROUP 1: ETHICS IN INTERNATIONAL RESEARCH</b>	Main auditorium
	<b>Chairpersons:</b> Sandhya Srinivasan, executive editor, <i>Indian Journal of Medical Ethics</i> , Sunil K Pandya, consulting neurosurgeon, Jaslok Hospital, Mumbai, editor emeritus, <i>Indian Journal of Medical Ethics</i>	
	1: <b>Reidar Lie:</b> <i>Standard of care in international therapeutic research</i>	
	2: <b>Ruth Macklin:</b> <i>Standard of care in international vaccine research</i>	
	3: <b>Bernard Lo:</b> <i>Ethics in stem cell research</i>	
11 am - 12.30 pm	<b>GROUP 2: PUBLIC HEALTH ETHICS</b>	Auditorium B
	<b>Chairperson:</b> Suresh Kumar, Pain and Palliative Care Clinic, Kozhikode, Kerala	
	1: <b>Richard Cash:</b> <i>Culture, ethics and male circumcision</i>	
	2: <b>Brad Crammond:</b> <i>Ethics in HIV/AIDS care</i>	
	3: <b>Angus Dawson:</b> <i>Ethics of cluster randomised trials in public health</i>	
11 am - 12.30 pm	<b>GROUP 3: BIOETHICS ACROSS CULTURES AND MEDICAL SYSTEMS</b>	Auditorium C
	<b>Chairperson:</b> Lester Coutinho, Public Health Institute, Delhi	
	1: <b>Farhat Moazam:</b> <i>Cultural context of bioethics in Pakistan</i>	
	2: <b>Helen E Sheehan:</b> <i>Culture, ethics and alternative medicine</i>	
	3. <b>Young-Gyung Paik:</b> <i>Culture, ethics and genetic technologies in Korea</i>	
	4. <b>Nancy Padian:</b> <i>Culture, ethics and reproductive health: insights from the MIRA trial in Southern Africa</i>	
11 am - 12.30 pm	<b>GROUP 4: BIOETHICS EDUCATION AND OVERSIGHT</b>	Boardroom
	<b>Chairperson:</b> Fr Thomas Kalam, St John's National Academy of Health Sciences, Bangalore	
	1: <b>Sadath A Sayeed:</b> <i>Bioethics education at Harvard Medical School</i>	
	2: <b>Aamir Jafarey:</b> <i>Bioethics education in Pakistan</i>	
	3: <b>Aliya Naheed:</b> <i>Bioethics education and oversight at ICDDR,B and BRAC School of Public Health, Bangladesh</i>	
	4: <b>G D Ravindran:</b> <i>Bioethics education in India</i>	
12.30 - 2.00 pm	<b>PLENARY V: CLOSING SESSION</b>	Main auditorium
	<b>Chairperson:</b> Armida Fernandez, director, Sneha, former dean, LTMG Hospital, Mumbai	
	<b>Conference rapporteurs:</b> <i>Reporting on the conference</i>	
	<b>Valedictory address:</b> Madhava Menon, member, Commission on Centre-State Relations, Government of India, New Delhi	
	<b>Concluding remarks:</b> Armida Fernandez	
	<b>Follow-up and future plans:</b> Coordination team	
2.00 pm onwards	Lunch and departures	Dining hall

## ABSTRACTS DAY 1

### **Ethical dilemmas in conducting research on reproductive and sexual health in rural Bangladesh**

*Ilias Mahmud*

The James P Grant School of Public Health is conducting research to map local understanding and concerns about sexual and reproductive health and the role of providers in a rural area of Bangladesh. The study employed a mixed method approach using semi-structured surveys and in-depth interviews. This paper will present the ethical challenges during data collection.

The ethical challenges that emerged were: keeping confidentiality, obtaining informed consent, compensating respondents' time, deciding on what to do with people suspected of having RTIs/ STIs and, finally, evaluating the benefits to community.

---

### **Biomedical research participation: concerns of HIV-infected women regarding participating in a cervical cancer screening study**

*Shirin Shikalgar, Mahesh Kharat, Sucheta Kadam, Latika Karve, Sanjay Mehendale, Seema Sahay, Vikrant Sahasrabudde, Sten Vermund*

It is important to understand and overcome challenges and obstacles in recruiting HIV-infected women into clinical trials. We studied their concerns in the context of a biomedical research study aimed at screening for early diagnosis of cervical cancer.

The biomedical research study compared the accuracy of screening tests for cervical cancer detection in 300 HIV-infected women. Pre-screening data on textual responses about concerns and barriers for participation were available from 151 HIV-infected women who were recruited through a community involvement programme. Content analysis was done to understand their concerns regarding participation.

18.5% participants expressed a fear of breach of confidentiality of their HIV-positive status. They were afraid that participation might lead to disclosure of their HIV status either to their family (15.2%) or in their workplace (15.8%). In the Indian context, societal restrictions on movement of women (12.5%) and stigmatisation by in-laws and families (14.5%) were factors that limited their participation. Self-perception of the dual burden (12.5%) of HIV infection and participation in biomedical research and financial problems (39.7%) also affected the willingness of women to participate in biomedical research.

Women's unique social and familial responsibilities make it difficult for them to participate in trials. Recruitment strategies should consider the basic social, economical and familial needs of HIV infected women by counselling them and educating their families before offering recruitment in biomedical research. Provision of HIV-related care as part of a comprehensive

reproductive health package should be considered and evaluated for facilitating participation of HIV-infected women in biomedical research.

---

### **Menstrual suppression as a lifestyle choice: autonomy to control body functions or medicalisation of women's bodies?**

*Ritu Mathur, Anant Bhan*

Menstruation is a monthly occurrence for most women. However, many find it an uncomfortable experience. Long-term menstrual suppression, without the customary withdrawal monthly bleeding as seen with oral contraceptive pills, is used as a remedy for medical conditions such as endometriosis. Long-term menstrual suppression is now being developed and marketed as a lifestyle choice for women who are not comfortable with menstruation or who want to avoid it for the sake of convenience. For example, the oral contraceptive 'Seasonale', approved by the US Food and Drug Administration, combines 84 days of active pills with seven days of placebo, reducing the number of pill-induced periods from 13 to four annually. Such drugs could soon be marketed in India as well.

Some of the questions that need to be asked are: Is menstrual suppression safe and a reasonable lifestyle choice? What is the risk-benefit ratio when it is taken as a lifestyle choice? Is there evidence that such medication is safe and effective? What uncertainty exists on its future benefits and harms? Who should use such medication? Do women have enough knowledge to make informed choices?

Disruption of a normal physiological process for non-medical reasons may be acceptable as part of the autonomy women should enjoy over their own bodies. However, no long-term studies have been conducted on the impact that menstrual suppression may have on the fertility or health of women.

The paper will help illuminate an important aspect of the medicalisation of women's bodies and body functions; and the implications on their reproductive, sexual and general health.

---

### **New Reproductive Technologies and questions of choice**

*Supriya Bijlwan*

This paper discusses the issues relating to "reproductive health and questions of choice." New reproductive technologies, the newfound assistants in conception, are heralded as a major step in scientific progress and development in the area of medical science. The amniocentesis test provides an opportunity to detect the genetic "normality" and sex of the foetus. A range of assisted reproductive technologies claim to give women "test-tube" babies without actually treating infertility. Pre-selection

techniques enable a "choice" regarding the sex of the foetus and, perhaps in the near future, other favourable traits such as colour and looks.

These techniques have been criticised because they capitalise on the social stigma attached to infertility. Further, their safety remains an area of concern. Those who use these technologies are ignorant about such ill effects.

I focus on issues of policy in relation to the introduction and implementation of these new reproductive technologies. I propose that such technologies violate women's bodies and are an invasion of their personhood. When science does not study the causes of infertility and its treatment, and when it ignores women's experiences, it only succeeds in providing "technological fixes" without solving the problem.

---

### **Mass public health interventions in India: some ethical issues**

*Angus Dawson*

This paper explores some of the ethical issues that arise during the implementation of mass public health interventions sponsored by external international organisations but delivered in the developing world. The problems that arose in Assam in 2001 as part of the Vitamin A supplementation programme are used as a particular example to illustrate the argument. The focus of discussion is upon the use of arguments appealing to the idea of preventing harm. This idea is intuitively appealing as it is often felt to be better to seek to prevent harm from occurring than to treat it once it emerges. However, preventive interventions can also be ethically contentious, mainly because they are introduced into asymptomatic populations. Even if the risk of harm from the intervention is very low, significant harm can result from a mass programme because of the numbers of people involved. Issues to be discussed in this talk will include both theoretical issues lying at the heart of public health ethics as well as particular ethical issues (eg consent, trust and the balance of harms and benefits). Whilst many such programmes might, all things considered, turn out to be justified, there are many ethical and policy problems that require careful exploration and consideration.

---

### **Use of coercion in public health interventions**

*Leni Chaudhuri*

This paper focuses on the government's use of coercion towards its population control programme, in the provision of reproductive health services. It reviews the history of coercive measures by state agencies and current policies favouring the use of coercion and analyses the human rights violations that these entail. It also looks at the consensus building that the government machinery indulges in to get support for its actions. The paper explores the nature of the exclusion that the community faces because of this coercion. Finally it examines the impact of coercions on the community's health. The paper suggests that not only does the use of coercion violate the rights of the community, it does not fulfil the objectives with

which the services were initiated. The bottom line is that people should have the choice to decide for themselves, and the state should be the facilitator.

---

### **Ageing women and health care technologies, public health and policies**

*Anjani Jani, Swatija Manorama*

There is a need to look at the ethical issues related to health care technologies and public health and policies related to the health of ageing women.

This paper reviews health care technologies such as hormone replacement therapy (HRT) in the context of its ban after years of its promotion and use as the only technology for healthy ageing. An issue in bioethics is the health costs of HRT. Another issue directly concerned with bioethics is the abuse and misuse of long-acting contraceptives and surgical or medical interventions during women's reproductive years, and the effect on their ageing. Public health policies on women's health are restricted to maternal and child health. Current policies related to ageing are essentially gender neutral. Given the proportion of older women in the population it is necessary to have a gender sensitive policy on ageing.

This paper comments on the question of physical and psychological violence against women by denying their health related concerns related to ageing. It discusses limitations in the research methodologies used for reproductive health technologies and proposes ethical trials of long-acting reproductive technologies as well as surgical and medicinal devices used for sterilisation and contraception.

---

### **Newer reproductive technologies and the law: the case for equality**

*Jayna Kothari*

Genetic technology affects family law in many ways. The influence of new genetic knowledge and reproductive rights can be seen in questions relating to parental rights, custody of children and consent. The availability of newer reproductive technologies such as in vitro fertilisation, tissue transplant, pre-implantation genetic diagnosis, freezing of embryos etc is exciting as it means new reproductive choices for women. However, these new technologies also create legal controversies. Some areas of family law that are affected by such newer reproductive options are paternity, the meaning of parental responsibility, the use of genetic knowledge, sex selection and adult choice. Some technologies also necessitate discussions on questions of morality and welfare. The emergence of these controversies needs to be understood so as to inform legal debates in India.

One recent relevant development in India has been the amendment, in 2002, of the Pre-Natal Diagnostics Techniques (Regulation and Prevention of Misuse) Act 1994 to ban pre-conceptual sex selection. The amendment was made as newer reproductive technologies allow for sex selection even before conception. The PNDT Act has thus radically altered the legal

landscape in the field of reproductive rights. This paper will explore these issues using the themes of gender, equality, autonomy and human dignity.

---

### **Evidence-based ethics and clinical research in India**

*Prathap Tharyan*

Ethical decisions are often made using a deontological or a teleological perspective. This paper highlights the need to consider an evidence-based ethical framework when deciding whether research conducted in India is ethical and uses the controversies raised by the trial on risperidone versus placebo in mania to illustrate this need.

An industry-funded, placebo-controlled clinical trial conducted in India of risperidone in the treatment of acute mania invited considerable criticism and debate regarding the ethics of using placebos in clinical research when effective treatments exist; the methods of evaluating the effects of interventions in health care research; the validity of informed consent, particularly in supposedly vulnerable populations and societies; the interpretation of ethical guidelines; and the role of ethics committees, regulatory agencies, sponsors and medical journal editors in international collaborative clinical research. A search for the evidence of the consequences of participation in placebo-controlled trials, particularly in mental health, was undertaken.

Data from systematic reviews reveal that methods that improve the internal validity of clinical trials often involve placebos, and placebo-controlled trials are not automatically ethically dubious, even in vulnerable populations.

A productive interpretation of this debate should appreciate the culturally and economically grounded preferences in setting priorities in research. It should include questions about the evidence that informs ethical opinions in order to prevent harm to participants and subsequent recipients of health care and to restore confidence in the methods and the results of research in health care.

---

### **Protecting the rights and interests of trial participants, users and communities: an advocacy project of the Global Campaign for Microbicides**

*Anandi Yuvaraj, Paramita Kundu, Ananth Thambinayagam*

HIV prevention research poses a variety of ethical and scientific challenges best addressed through broad-based participatory dialogue and meaningful partnerships between communities and researchers. The purpose of this paper is to talk about the work of the Global Campaign for Microbicides (GCM) on ethics and community involvement regarding HIV prevention trials in India and globally.

Several microbicides -- female-initiated methods of HIV/STI prevention -- are currently in clinical trials. These trials often take place in resource-poor settings and enrol particularly vulnerable populations. A core goal of the GCM is to ensure that, as science proceeds, the public interest is protected and the rights and perspectives of trial participants, users and communities are

fully represented and respected. One way to achieve this is to build the capacity of communities to advocate for their rights as trial participants.

Through its community involvement and research ethics initiatives, GCM seeks to engage stakeholders in a dialogue on community involvement, build capacity among community-based and civil society organisations to engage in ethical debates, and catalyse dialogue to inform key decisions on trial design and implementation. GCM-India organises meetings between researchers, policy makers and civil society, facilitating discussions of clinical trial ethics to create shared understanding and build consensus around this issue.

Civil society has an important role to play in the design and conduct of clinical trials, and should be involved at each and every step of the development and testing of novel health technologies like microbicides.

---

### **Analysis of legal remedies available to subjects of clinical trials**

*Adarsh Gangadhar*

Nearly all studies relating to clinical trials have examined issues such as the pros and cons of relaxing norms to facilitate clinical trials in India; the conduct of illegal clinical trials; flaws in existing legislation; the plight of individuals who volunteer to undergo testing in the process of drug development; and changes to be accommodated through legislative prescriptions. There seems to be little literature on the legal recourses that a subject can avail of against the government and other stakeholders involved in the drug development process.

This paper proposes to examine the options available to trial subjects within the existing legal framework. It will examine the following options:

1. As the revised Schedule Y requires compliance with the GCP and Ethical Guidelines, sponsors and investigators are obliged to provide a far-reaching victim compensation package as expected under the guidelines;
2. The informed consent form can be treated as a contract, defining the rights and liabilities of the parties involved. Arbitration clauses can be incorporated to ensure that claims regarding compensation can be resolved expeditiously;
3. A claim can be made against the government for its inability to safeguard the health concerns of the public, thereby breaching its positive obligations under Article 21 of the Constitution;
4. Disciplinary proceedings can be instituted against physicians who fail to comply with guidelines while conducting clinical trials [Chapter VII of Code of Ethics];
5. Remedy can be sought under the tort law, on the basis of negligence; and
6. Criminal liability can be under section 336 of the Indian Penal Code for any rash or negligent act which endangers human life or personal safety.

## Ethical issues in biomedical e-publishing

*M G Sreekumar, Nabeel M K*

Governments the world over are spending millions of dollars to fuel biomedical research. Scientific journals are the source of information on the latest research. Unfortunately, the costs involved in gaining access to scientific journals have often been forbidding, especially in developing countries. At the same time, the proliferation of information has reached exponential proportions with the Internet. The information explosion has been even more marked in the biomedical domain, providing better access to scholarly communication and also enhancing research activities. The time from submission to publication has come down, making the path from the labs to the media shorter and smoother, boosted by the Open Access movement. The lay public also has better access to such information.

However, the same qualities that have improved access to information can raise questions about its quality and reliability. The emergence of newer publishing models as when the author bears the cost of the publishing process, issues of intellectual property rights and the activities of commercial establishments promoting their products and services have their impact as well. This paper addresses such issues from an ethical point of view.

---

## Privacy and confidentiality of health information: an emerging issue in implementing health information technology

*Rajesh Kumar Sinha*

The quality of health care today depends on the physician's ability to obtain complete, accurate, and adequate health information on the patient in a timely fashion.

The application of health information technology includes electronic health records, computer-based patient records, physician digital assistants and decision support systems.

Such applications make it possible to provide information on all users of a health care facility and also help physicians make quality decisions on medical care, research and public health surveillance and intervention. Information security in this area ensures the privacy, confidentiality and integrity of data, making them available only to authorised personnel.

Such applications can also pose a threat to patients' privacy and confidentiality and raise various legal and ethical issues. However, technologies such as audit trail and encryption / decryption biometrics can be used to protect information from unauthorised disclosure and use.

Health information technology must be used in ways that do not pose an unacceptable risk to patient privacy and confidentiality. It must maintain data security and accuracy; prevent its inadvertent release; deter access to unauthorised users; and discourage, detect and punish the inappropriate use of health information.

## Patient, doctor and telemedicine: ethical concerns

*G K Karanth*

The use of telemedicine consultations, especially in remote areas, with specialists in medical metropolises, has been gaining in popularity. Its use in India is perceived as a welcome step forward in forging a private-public participation in health care delivery. While the evolution of guidelines governing ethical issues in telemedicine is in its infancy in India, there has been little debate on the issues in the field. This paper proposes to highlight issues that have defied ethical prescriptions and some which have escaped attention. What is the agency of patients or attendants who seek or get a tele-consultation? Who signs a prescription, and who owns it: the consulting doctor or the prescribing specialist? Should the patient be asked to pay for a telemedicine consultation even if it had been sought without his or her knowledge or consent? Should consent be taken? If a fee is involved, how is it to be shared? Several questions that are apparently administrative in nature do, in fact, contain many ethical concerns.

This paper based on data collected among users and providers of telemedicine focuses on some of these problems and their ethical implications. It argues that that not only should technological innovation be accompanied by a change in mindset, the profession also needs to reflect on its ethical standards.

---

## Reporting the ethics of science: how the media frame ethical issues in scientific research

*Usha Raman*

Over the past few decades, while there is more information available in the public domain on how science is done, there remains a considerable gap between the cultures of doing and consuming science. The mass media play an important role in shaping public attitudes toward science and technology and therefore are an important interface between these two cultures. Through a textual analysis of coverage in two national newspapers, *The Hindu* and *The Times of India*, over a three-month period, from January 2007 to March 2007, this paper examines how the media frame coverage of ethical issues in biomedical research.

---

## Response of the people, patients and media to the first clinical trial of cell therapy

*Geeta Vemuganti, Virender Sangwan, Balasubramanian Dorairaja, Nageshwar Rao Gullapalli*

This report on the public response to the first clinical trial of cell therapy summarises the different kinds of verbal and written responses from the public, patients, and the media to the use of cultivated limbal epithelial transplantation for ocular surface reconstruction, conducted at LV Prasad Eye Institute and supported by the department of biotechnology and the Hyderabad Eye Research Foundation. The period reviewed is from August 2001 till November 2007.

In the initial phase, the media, public and patients did not know the difference between embryonic stem cell and adult stem cells and assumed that this cell therapy involved foetal or embryonic tissues. This placed considerable stress and strain on the team. In the second phase of the project, there came a series of enquiries if this could be extrapolated to other kinds of eye diseases, especially retinal diseases which constitute an irreversible form of blindness. Later enquiries were made about the allogenic use of limbal tissue, and bone marrow derived cells for patients with other diseases, and about guidelines and regulations in India.

Various forms of presentations, publications, guest lectures on these issues led to the acceptance of this trial followed by a spurt of requests from people within and outside the country for holding courses and sharing knowledge.

Scientists and clinicians should anticipate the response of the general public and be prepared to address them at different intervals, particularly when they involve ethical decision making and regulatory authorities. Public forums and efforts at public education can help ease the situation.

## ABSTRACTS DAY TWO

### **“There is such a thing as too many daughters, but not too many sons”: the intersection of medical technology, son preference and sex selection among south Asian immigrants in the United States**

*Sunita Puri*

Prenatal and pre-conception methods of sex selection are illegal in India but legal in the US, where they are used by a number of immigrant families. This study examines social and cultural reasons underlying sex selection in the Indian immigrant community, its impact on women, and the attitudes of American physicians offering sex selection to South Asian immigrants.

Semi-structured interviews were conducted with immigrant South Asian women and men aged 19-65 who utilised sex selection clinic services; second-generation South Asian youth who grew up in families where sex selection was practiced; physician-providers of sex selection; and primary care physicians who had encountered requests for sex selection among their South Asian patients.

Most couples interviewed already had an average of two female children and wanted to ensure the birth of a boy. Physicians offering sex selection argued that patient autonomy and the concept of “choice” in reproductive rights made their practices ethical. Primary care physicians for South Asian families argued that these services were unethical.

This research illustrates the importance of interrogating the bioethical principles of autonomy, beneficence, and the idea of ‘cultural competence,’ as these three major principles have been applied by different physicians to both defend and criticise the development, marketing and use of sex selection technologies. It is my hope that this presentation will contribute both to a discussion of the social and cultural underpinnings of sex selection in the migrant South Asian community, and a discussion of physicians’ and legislators’ responsibilities to recognise and respond to these trends in an ethical manner.

### **Everyday ethics: ultrasound and sex determination in Australia**

*Victoria Loblay*

This paper details ethnographic research undertaken in the ultrasound department of a public hospital in Sydney, Australia. In this particular clinical setting, ultrasound is not performed for the sole purpose of sex determination. However there is no regulation of the practice of sex-determination during routine scans for “medical” purposes. Thus, the negotiation of ethical issues surrounding sex determination and ultrasound often takes place during the process of the ultrasound scan, between individual sonographers, pregnant women, accompanying family members, and the foetal images. Based on data gathered through participant observation and qualitative interviews, I examine how sonographers and patients engage in meaning-making processes during the ultrasound scans, and how these meanings inflect parental decision-making and their desire to know the foetus’ sex. In the absence of formal ethics of sex determination, I discuss how sonographers grapple with their own moral stance on sex determination and its place as part of the clinical management of pregnancy. Based on my analysis, I argue that the practice of sex determination highlights the pivotal role of sonographers as they negotiate the moral territory that inhabits the space between the ethical guidelines that govern their practice.

---

### **Technology, quality and rights: an exploration**

*Abhijit Das*

Large public health programmes like the Family Planning Programme or the Global Polio Eradication Initiative or the DOTS in the case of tuberculosis depend upon certain technologies for the fulfilment of their objectives. Successful, controlled pilot phases are up-scaled and these become part of national and, often, global public health initiatives. Many of the features that are present in the smaller pilots are often ignored

in the up-scaling process, leading to poorer quality and/or lower success. In India the bureaucratic response to such situations has been intensification of the programme, which is known to lead to violations and abuses of human rights. The author has been part of an advocacy effort to improve the quality of care of family planning operations using an adverse outcome accounting framework. This advocacy effort has been successful in combining a scientific and legal approach to introduce far-reaching changes in the design and delivery of family planning and reproductive health services in India - namely, the introduction of quality assurance committees at the district level and the family planning insurance scheme.

In this paper the author explores the potential of using this adverse outcome accounting process in examining alternative technologies for the same public health purpose. The first section outlines the framework, the second section describes the use of this framework in ongoing advocacy work on family planning operations and the third section applies this framework to the Pulse Polio Programme and Revised National Tuberculosis Control Programme as they are being implemented in India.

---

### **Ethical issues in the conduct of HPV vaccine trials in the developing world**

*Anant Bhan*

Human Papilloma Virus (HPV) infection is a leading causal factor for cervical cancer, a major killer of women in the developing world. Prophylactic vaccines have been introduced in the West by pharmaceutical companies. In some parts of the West HPV vaccination has been made mandatory, which has been a controversial step because of opposition from conservative policy makers and religious heads. The vaccine is prohibitively expensive for use in the developing world, including India. Scientists are exploring low cost HPV vaccines for in the developing world and clinical trials of these low cost vaccine candidates are being planned in the developing world.

HPV vaccine research can be controversial given its links with sexuality, a taboo subject in many societies. The prophylactic vaccine needs to be given before the first sexual exposure, hence to adolescent girls. Research and provision of vaccines to adolescent girls have proved to be controversial in the West, and would probably be so in developing countries as well. Parents are often uncomfortable with letting their adolescent daughters participate in research linked to their sexuality and sexual exposure. The issues of privacy, confidentiality, affordability and ensuring post trial obligations would also be relevant.

This paper will deliberate on crucial issues in the introduction of HPV vaccines in the developing world. It will attempt to analyse existing bioethics theories and principles as they apply to this situation.

---

### **Consent issues in genetics of late onset and behavioural disorders**

*Sanjeev Jain, Meera Purushottam, Shobana Kubendran*

Advances in molecular biology and genetics will accelerate our

knowledge about the basic biology of several diseases, including cancer, diabetes, schizophrenia, and late onset disorders. This knowledge may help predict the risk of developing these diseases, and also include access to genome-specific medication or interventions. Novel therapeutics derived from modified human genetic material may become a possibility. Thus consensual participation in genomics research and equitable access to genomics technologies will need to be ensured. The application of these technologies has been fraught with debate and their use in a less scientifically literate or cognisant society such as India raises important questions. Issues regarding privacy of genetic information may be a particular problem in extended communities as it may stigmatise entire families. Health care providers would need to be aware of the tests and interventions but at the same time, treatment for those known to be at risk would need to be ensured. Public health issues and access to these technologies would need to be addressed to ensure that there is no creation of a "genetic underclass" that are denied these treatments purely on account of affordability. We have compared practice guidelines and specific laws governing research and counselling between the European Community, the USA and India, and the WHO guidelines. Though there are broad agreements there are significant deviations in critical areas (such as sharing information between family members). We need to address these issues to inform and guide the practice of genomics based medicine in the coming years.

---

### **The procedure of informed consent in Indian clinical research: directions towards improving the quality of provision of information**

*Simble Susan Thomas, Rajendiran Duraisamy, Baiju Julian*

Obtaining informed consent is based on a process of exchange of information between investigators and potential trial subjects. Such a process guarantees that subjects receive sufficient information to make free and informed choices about their involvement in research.

However, most patients consider the physician-patient relationship to be the same as the investigator-participant relationship. Many subjects enrolled into research programmes are inadequately informed of the study and of the consequent risk/benefits ratio. Poor and illiterate patients face difficulties in asserting an equal relationship with the physician. Even if informed consent meets all given standards, there is a major gap between the information presented and the capacity of the patient to fully understand the risks and benefits of being a subject in a research study.

This paper proposes to examine the informed consent process. It will make suggestions on how an informed consent should be presented to patients and how to ensure that patients are truly fully informed. A simplified format for informed consent will be proposed. It is not sufficient to follow international formats; consent must be contextually adapted to the Indian culture and worldview. The patient's comprehension must be ensured. Finally, the possibility that poor patients give their consent in order to receive treatment without payment will be discussed.

## **The reluctance of patients to take autonomous decisions: what is the relevance of the informed consent process in new medical technological interventions?**

*Sridevi Seetharam, Renzo Zanotti*

New medical technologies are often promoted with scarce information about actual benefits and potential risks, exposing patients to the undesirable use of such technology. In order to understand how patients perceive their role in decisions related to their health care, a study was conducted to assess how rural patients make decisions to undergo surgical interventions. The results are interpreted in the context of the increased demands on the informed consent process posed by the new interventions and reduced intimacy of doctor patient relationship.

A qualitative study was conducted, using semi-structured interviews, on 25 adult patients advised surgery in a rural hospital in South India. The results were analysed using the Grounded Theory approach.

Awareness of social position and power hierarchy emerged as the core variables governing the process of decision-making of the patients. A majority of patients made decisions based on faith or trust in the doctor rather than by an objective evaluation of risks and benefits. They also expressed inhibitions in seeking information or taking an active role in the decision.

While the standard consent process stresses the individual's role in decision making, a majority of rural patients were reluctant to assume such a role. The new interventions also impact personal values and beliefs. Unanticipated risks, insufficient evidence of benefits and the trust-based approach of rural patients place greater responsibility on the medical professionals to help patients feel empowered to make autonomous decisions in line with personal values.

---

## **Comprehension and recall of informed consent among participating families in a birth cohort study on diarrhoeal disease**

*Rajiv Sarkar, Edward Wilson Grandin, Beryl Primrose Gladstone, Gangadeep Kang, Jayaprakash Mulyil*

In research, informed consent provides participants with information to enable them to make an "educated" decision. This study assessed the comprehension of informed consent among participants of a cohort study.

Parents or guardians of children who, after giving consent, participated in three years of twice-weekly follow-up for a diarrhoeal surveillance study, were asked about the study objectives, their reasons for joining and their feelings or concerns about the study process.

Of 368 respondents, 329 (89.4%) recalled that the study was explained during enrolment, but only 159 (43.2%) knew that it was on diarrhoea. Only 50 (13.6%) respondents stated that they knew that they could leave the study at any time. The primary reason for 223 (60.6%) respondents agreeing to participate was

free medical treatment. The majority, 339 (92.1%) respondents, expressed their desire to join similar studies. Approval of the spouse was the most important factor (305, 82.9% of respondents) in the decision to participate. Belonging to the Muslim religion (OR=1.79, p=0.009) and maternal illiteracy (OR=1.69, p=0.035) were factors associated with lack of knowledge about the illness being studied.

Despite informed consent and a high compliance with the study protocol, retention of understanding about a research study was low over a long period of time. This study was conducted in a setting where the government provides free and accessible health care, but the study participants cited free health care as an important reason for participation, highlighting the need for health equity before true informed consent can be obtained.

---

## **Issues in patient use of Indian systems of medicine**

*Helen E Sheehan*

The Indian Systems of Medicine (Ayurveda, Unani, and Siddha) and Homeopathy are supported by Indian's central government, as well as by many state governments, to train medical professionals, provide health services, and perform research on traditional pharmacy and treatments. Policy statements and funding resources sustain the ISM as health providers and as symbols of Indian culture and tradition. Social science and health economics research on health services' access for the poor in India (and elsewhere in South Asia) show that ISM may often be the only or one of many types of health care available. Faced with either limited choice on the one hand or a bewildering array of health provider choices on the other, low income patients are often inadequately served. They may not be able to ascertain the legitimacy and qualifications of the health provider. They may receive a misdiagnosis, incorrect medicines and treatment, which in turn may result in prolonged ill health, indebtedness because of high medical costs, and/or death.

This paper will discuss the status of the ISM system's services as provided by qualified, credential practitioners, and will review the complex array of unqualified practitioners, indicating the problematic intersection of multiple providers for patients in seeking care. The role of the state in providing guidance in regulation of health practitioners, in patient protection, and in assuring access to qualified health services will be raised as a basic, but often overlooked, ethical issue.

---

## **Practice of traditional medicine for hepatitis cure in Atchampathu village: a case study of adherence to bioethical principles**

*M A Jothi Rajan, Arockiam Thaddeus*

Invariably in medical practice, the learned and the affluent think of "English" or Allopathic medicines for health care and cure. In India the literacy rate is poor and the per capita income of the socio-economically downtrodden is low. Health care has become an expensive affair and the poor cannot afford to buy medicines privately. Traditional medical practices offer treatment at an affordable cost with minimum waiting time for consultation



and with satisfaction for the patient and practitioner -- but with no scientific proof that they work. The state's and the medical community's refusal to recognise the services of traditional medicine practitioners is in a way a human rights violation and therefore unethical.

For over a century, in a village known as Atchampathu in the north of Madurai city in Tamil Nadu, a traditional medical practice is used to treat all types of hepatitis. Nearly 125 families render their services to those affected, irrespective of their caste, creed or religion. The fees collected depend on the patient's economic condition and never exceed 50 rupees. About 300 patients who had been cured by this method were interviewed. They attributed the cure to the good and godly nature of the traditional practitioner. Though the practitioners are Hindus by religion the patients who come there are from different faiths.

Though the practice seems to be unscientific without proof of cure, both patients and practitioners follow certain bioethical principles. When the prices of Allopathic medicines go up, the poor in particular may prefer traditional medicines. This could be a public health solution based on bioethical principles.

---

### **Medical innovations in orthopaedics : addressing issues of cost and benefit in relation to ethical resource allocation**

*Ajay Radhakrishnan, Nabeel M K, Abdul Jameel Shareef, Naveen C Balan*

Principles of economic analysis and the issue of ethical resource allocation are not new in medical research but they may not have been given their due. In this paper we aim to address this issue by using the subset of orthopaedic research articles from indexed medical journals. A literature review shows that there has been an increase in orthopaedic research over the years but not proportionate to the phenomenal growth of medical literature overall. The dearth is felt in areas where it is needed the most as in the case of innovative modalities such as computer assisted orthopaedic surgery.

There are also concerns about the quality of such analysis. A search in orthopaedic literature using the keywords "cost effectiveness" obtained a large number of results but only because of the extensive misuse of that term. But even among those published papers containing some cost effectiveness and cost-benefit analysis it was found that many did not use basic analytic principles. This paper outlines the basic concepts in this area and some common analytical methodologies involved such as cost-effectiveness, cost-benefit, cost utility and cost-minimisation. The basic tasks of any economic evaluation are to identify, measure, value and compare the costs and consequences of the alternatives under consideration. This paper urges researchers to take economic analysis more seriously. We should not spend on new procedures without scientific proof of their worth; this would deny resources to another, perhaps more important matter.

### **Some ethical issues in primary care**

*B C Rao*

This paper will highlight ethical dilemmas faced by general practitioners in their day-to-day practice. They work in a context of worsening ethics with the advent of private players in health care. Most providers are practising unethical methods in health care delivery. The implications are: delivery of services that are below par; unlawful gains, unethical practices and rising costs of health care

---

### **When "enough is enough" Withdrawal of technological life-support: a case of euthanasia or disproportionate means?**

*Daphne Viveka Furtado*

The decision to withhold or withdraw mechanical ventilation is a highly controversial issue in these days of advanced medical technology. Having once decided to start artificial support, it becomes increasingly difficult to determine at which point it is ethically acceptable to withdraw it. This paper discusses the ethical aspects of withholding or withdrawing life-support in the light of the internal morality of medicine, the principlist bioethical approach and the understanding of euthanasia.

The ethical issues are related to end-of-life dilemmas, discussed in the context of two recent and similar cases (persons suffering from Duchenne's Muscular Dystrophy) that raised similar questions (respect for autonomy, quality of life, euthanasia) in two different parts of the world (India and Italy). While the media in both countries focused on the need for legalising euthanasia, very little appeared in the press about how euthanasia is defined or understood. This paper falls into the category of "retrospective reflection and analysis" with the dual role of being educative and proactive.

There is a widespread confusion between the notions of "letting die" and "euthanasia". Though both have the same physical result, namely, the death of the patient, they have a radically different moral significance.

In determining withdrawal of life support, the type of treatment, its complexity, cost and possibilities of use must be compared with the expected outcomes and excessive burden in terms of the patient's physical and moral resources. Professionals have an important role in educating the public to the semantics of euthanasia and an ethical assessment of health care technology.

---

### **Health care technologies as counter-death technologies: a philosophical appraisal**

*Sreekumar N*

This paper will examine the underlying philosophical assumptions of the very idea of health care, as understood in modern medical science and its supporting institutions. With corporate interests increasingly influencing the practices of health care professions, the general belief is that the world is witnessing an alarming

transformation in the way the science of medicine is practised. I argue that the major culprit is the philosophy of life that prevails in our times, on the basis of which the notion of health care is defined. This notion is intrinsically related to an idea of welfare. I argue that the paradigm of welfare has lost its direction as it has ceased to be life-oriented. It now operates with a set of technologies which have the potential to be employed for providing genuine care to the human self but fail to do that as they now function merely as "counter-death" technologies. This will enable us to see the futility of such an approach as no one can counter death. Instead of being life-promoting, they become death-preventive. Our general understanding is to conceive life and death as dichotomies, which is not actually the case. This paper will argue that the fundamental philosophical outlook of the medical sciences provides us insights to understand the value of human life. This allows us to use technical knowhow to promote a welfare based on a philosophy of life that views peace and quality of life as defining features of welfare.

---

### **Selection criteria in the NICU: who should get effective critical care?**

*Zulfiker Ali*

There are few tertiary level neonatal intensive care units (NICUs) in India and even government medical colleges do not always have a full fledged NICU. Thus there is a need for a protocol for selection and referral to an NICU. Any selection process raises a number of social and ethical issues.

This paper will discuss the reasoning behind the following criteria for selection to an NICU:

Babies deserving access to prenatal and neonatal specialty care on medical grounds; the critical condition of the baby, co-morbid

conditions, period of viability and gestational age; the financial condition of the parents and the affordability of the treatment; and, finally, the availability of resources in the Centre.

### **The complex promise of newborn screening**

*Fiona Miller*

Population screening of newborns for relatively rare, primarily genetic, diseases (such as phenylketonuria) offers the promise of reduced infant morbidity and mortality. In most developed countries, newborn screening (NBS) has been standard practice since the 1960s. In India and other developing countries (such as the Philippines, Ethiopia and Iran), the emergence of newborn screening is more recent, becoming available to families with the financial means through private laboratories and clinics, and to wider populations through state- or NGO-subsidised pilot studies or programmes in several hospitals or cities in India.

The promise of NBS is complex, raising difficult policy questions about the priority to be placed on these public health initiatives, and the ethics of these multi-faceted interventions. In this paper, we report on a study of NBS in Ontario, Canada, using this data as a platform to consider the implications of the introduction of NBS in India. Our mixed methods study suggests that consumers and providers are ill-equipped to understand and manage some of the information that is generated. The interpretation of test results is not simply clinical, but biosocial. Further, gendered and racialised meanings of motherhood and fatherhood are relevant to understanding the reproductive risks that arise, with particular consequences for women. Southern Ontario, where we conducted our research, is ethnically diverse. But the health system is universally accessible and of high quality, and extreme poverty is rare. Outside these privileged contexts, the implications of NBS are less certain, and warrant careful consideration.

## ABSTRACTS DAY THREE

### **Ethical issues in community study of severe mental disorders in India: the Thirthahalli experience**

*Jagadisha Thirthalli, Kudumallige Suresh, K V Suma, Basappa Venkatesh, Magadi Naveen, Ganesan Venkatasubramanian, Udupi Arunachala, Kengeri Kishorekumar, Bangalore Gangadhar*

The study of patients with severe mental disorders living in the community is an important area of research. However, ethical issues involved in conducting such research have not sufficiently been documented. This paper highlights the ethical dilemmas that the research team faced while conducting such a study in a rural Indian setting.

The community intervention in psychotic disorders (CoInPsyD) project entails the identification, treatment and follow-up of schizophrenia patients living in Thirthahalli Taluk, Karnataka. The primary aim of the project is to examine the effect of duration of untreated psychosis on the outcome of schizophrenia. Personnel from the existing public health care system were trained in the

identification and referral of patients. Mass media and public fora were used to publicise the project. Ethical dilemmas observed during the identification and treatment of patients were recorded anecdotally.

A number of ethical issues were noted: (1) difficulties in ensuring confidentiality in a rural community setting; (2) responsibilities of the research team regarding schizophrenia patients without caretakers; (3) the deliberate avoidance of treatment by family members; (4) the role of private psychiatrists practising in the region; and (5) the fate of the patients after the termination of the project.

Understanding of the socio-cultural background of the community is of utmost importance in understanding the ethical issues of community-based research in psychiatry. There are any unanswered questions that require systematic research in this area.

## **Ethical issues in treating pregnant women with severe mental illness**

*Geetha Desai, Prabha Chandra*

With advances in psychiatric treatment, more and more women with severe mental illness are considering pregnancy and are often at risk for unplanned pregnancies. The stage and severity of illnesses can variably affect the woman's decision-making capacity about management of pregnancy. While untreated illness may have adverse consequences on the pregnant woman as well the foetus, adverse consequences have also been reported with some psychopharmacological agents. This poses great ethical challenges for the treating psychiatrist who has to strike a balance between the woman's autonomy for wanting a child versus beneficence-based obligations. In addition, there is responsibility to protect the rights of the viable foetus.

The initial decision in the treatment process that the woman must make is whether to become pregnant and subsequently, if there is foetal exposure to psychotropics, whether to continue the pregnancy. The psychiatrist has to evaluate whether the illness has altered the woman's decision-making capacity and whether she can participate in the informed consent process. The next step is discussing treatment options, the impact on pregnancy outcomes, the effects of non-treatment on the pregnancy, the foetus and herself, and available support systems.

Involving the woman and her family as partners in decision making is important. The perinatal psychiatry clinic at NIMHANS has been involved in pre-pregnancy counseling and care of pregnant women with mental illness for the last two years. The paper will describe the ethical dilemmas it has faced in the form of case studies from the clinic and discuss a possible ethical approach to several of these challenging situations.

## **Should mental health assessments be integral to domestic violence research?**

*Veena A S, Prabha Chandra*

Research on sensitive issues such as abuse and violence in vulnerable populations poses several ethical dilemmas. An important aspect is the impact of such enquiries on one's mental health. The paper discusses specific ethical issues related to mental health, based on violence research conducted and reviewed by the authors.

Research on violence among women includes the possibility that some revelations are occurring for the first time and are likely to be emotionally charged. Further, the very act of disclosure may involve emotional risks for the respondent. Hence assessing mental health parameters becomes essential and integral to research of this nature. Several issues in methodology are also important in mitigating the level of distress. Obtaining informed consent in violence research should be a process rather than a one-time formality. Reports of adverse events are likely in violence research, hence such studies cannot be bereft of mental health intervention, ongoing follow up, documentation

and appropriate referral services. Some women may also report positive mental health consequences which should be documented. Finally, since the researcher and the researched are both affected in a study of this nature, adequate sensitisation, ongoing training and supervision of research staff are equally essential.

Based on findings from ongoing research on violence and from review of other studies done in India, the paper will focus on best practices in addressing mental health issues in domestic violence research.

## **Down's screening guideline: roles, values and the problematic ethical issue of autonomy**

*Evelyn Lacson*

The new American College of Obstetrics and Gynecology guideline for universal antenatal Down's screening has increased the number of women recruited into the screening network. This network brings people and technology together in a common language and practice. Embedded into the practice of screening are meanings, values and priorities which women may not be aware of. This paper brings into the ethical discourse three issues: the role of the guideline in the screening network, the values in the practice of screening and the problematic issue of autonomy when screening is made to appear routine.

An electronic and hand search was conducted of relevant literature written in English from 1990 to 2007 using keywords. It employed the explorative-descriptive method for the discussion and reflection of the research.

The research found that evidence based guidelines make screening appear as a routine standard of prenatal care. Under such circumstances more women are offered screening and possibly invasive diagnostic tests and intervention. Based on information they receive, women fail to carefully consider and understand the rationale of screening, the implications of its result and its embedded values. Therefore, they make uninformed decisions and consent for screening. When women understand information on risks for Down's, they decline screening.

## **Impact of bioethics on patents**

*Vishwas Devaiah*

Patents have played a vital role in encouraging innovations on new medicines. But this is often embroiled in controversies regarding access to new drugs and further research on improving drugs. In the past decade biotechnology has made significant advancements in developing new medicines. But issues of the morality and ethics of patenting new biotechnology-based medicines derived from human biological material has created uncertainty in various parts of the world. European countries have increasingly discouraged patents on medicines derived from biological materials. More recently, Germany has rejected patents on stem cells derived from embryos on similar grounds. While research involving the derivation of stem cells was conducted under strict protocols of bioethics, the patent claim was rejected. It is of significance that ethical practices in

research are increasingly invoked to reject claims on patents involving the use of biological material.

This paper looks at research ethics and their possible impact on patent claims. It explores the relation between morality, bioethics and patents in the context of stem cell research in India as it is an emerging technology which has assumed great importance in recent years. The paper will illustrate the importance of ethical research in securing patent protection for new technology. While links between bioethics and patents have never occurred in the Indian context, developments in this area in the European Union can influence patent laws in India.

### **Post TRIPS world: what next in public health and policies?**

*Nalin Bharti*

In the post TRIPS era public health is one of the most pressing issues for developing and least developed countries. Due to a collective approach by developing economies, the Doha and post Doha round talks considered the issue of public health seriously. But the matter does not end here because the trade concessions given to these countries are temporary. This paper argues that public health faces a crisis in the long run. It will present a summary of public health in the pre TRIPS era and then discuss the post TRIPS era in which, due to the product patent regime populations in developing and least developed economies face a "drug famine". The discussion calls for a mass awareness and an intervention in government policy.

---

### **Biotechnology and intellectual property rights: ethical aspects for biomedical and theological scientists in Iran**

*Mansoorah Saniei, Ladan Naz Zahedi, Saeed Shahraz, Elnaz Jafari Mehr, Saye Sayar, Ala Melati Rad, Roya Sherafat, Mohammad Reza Zali*

Genetic engineering and biotechnology is considered to be amongst the most powerful and economically promising technologies in this millennium with potential economic and social benefits to all sections of society. Since the first steps were taken towards commercial exploitation of biotechnological inventions, tensions have been growing over intellectual property rights (IPRs) of the information contained in genetic material and biotechnological results. This study reports on what Iranian scholars in the field of medicine, genetics and theology think about the most important ethical issues on IPRs and biotechnology according to the four principles approach.

To investigate the attitude of Iranian scholars on this issue, a Likert scale questionnaire was developed that included a series of the most important ethical dilemmas about IPRs, human genetic material and biotechnological results. The research was conducted through face-to-face in-depth interviews

Thirty four geneticists, 136 physicians and 65 theologians responded to the survey. Forty three per cent of physicians and geneticists and 62% of theologians believed that genetic innovations should not belong to a particular person. Most theologians (58.1%) said that IPRs belong to the people. Most

biomedical participants disagreed. About 40% of participants believed that the right to use genetic innovations belonged to the researcher or company that supports the research project.

Participants showed a weak positive attitude towards IPRs of genetic material and biotechnological results. Most agreed that the benefit of society prevailed over the autonomy of researchers or companies.

---

### **E-medicine: an ethical evaluation**

*Sanghamitra Pati*

Information and communication technology have engendered many changes in our lives. Among the recent developments of information technology is cyber medicine. Seeking medical information, advice or even procuring drugs via the internet is gaining momentum among the urban population in India. Numerous websites claim to provide medical assistance to patients. There is no doubt that cyber medicine has the potential to transform medical practice in the Indian context. However, knowledge and capabilities, particularly of a new technology, tend to develop faster than the guidelines needed for ethical practice in the new arena. This is particularly true in e-medicine. The blending of medicine and health care with e-commerce and the internet raises many questions. What sort of ethical conduct should be expected by practitioners and developers of the medical internet? This research attempts to analyse the ethical issues surrounding the arena of cyber medicine and stimulate more discussion in the medical internet community towards a morally acceptable cyber medicine. Several key challenges were identified, the first being to determine the boundaries of "medical/healthcare internet ethics" in the Indian context. Care should be taken to make the best use of this emerging internet technology in medicine and health care without compromising the fundamentals of medical ethics.

---

### **Ethical dilemmas in the recruitment of volunteers in the first HIV vaccine trial in Pune, India**

*Seema Sahay, Sanjay Mehendale*

Protecting autonomy of volunteers and ensuring their informed participation in clinical research are basic ethical expectations from investigators. During the process of fair selection of volunteers in the first HIV vaccine trial in Pune, India, the trial team experienced ethical dilemmas and were made aware of the vulnerability of some potential participants.

Potential volunteers had to participate in a multi-level contact and education approach and then were critically assessed for ethical issues. In-depth analyses of issue based cases are presented.

Participation of unmarried young individuals posed the dilemma of legal maturity and protection of autonomy versus social dependency and family support in decision-making. The trial team involved family members, respected cultural norms and lost some eligible volunteers.

The trial team ruled out participation of an eligible female

participant after realising on probing that she wanted to win confidence of her husband with high-risk behaviour and her eagerness to participate was driven by a sense of security likely to be offered by the trial vaccine.

The enrolment of a volunteer with a lower socioeconomic background was carefully scrutinised to rule out participation for monetary benefit while also ensuring equitable opportunity. With a proven history of several altruistic tasks the volunteer was enrolled, respecting his autonomy.

The trial investigators succeeded in reaching the volunteers' enrolment target by strictly adhering to ethical norms. We applied a viable form of moral pluralism described as "negotiated universalism" by adapting a set of values most appropriate for the given socio-cultural context that would be close to wider expectations.

---

### **Standards of care in microbicide efficacy trials: a mapping exercise**

*Katharine Shapiro, Katie West, Lori Heise, Sean Philpott*

In 2006 the Global Campaign for Microbicides embarked on an exercise to map standards of care (SOC) and prevention in seven different Phase 2B and 3 international multi-site clinical trials being conducted to evaluate the effectiveness of vaginal microbicides or the diaphragm for prevention of HIV acquisition in women. The goal was to provide empirical evidence of progress made towards meeting ethical aspirations described by scientists, ethicists and communities regarding SOC; to compare challenges posed in various community settings; to describe the different care and prevention strategies utilised within different studies and trial sites; and to examine how strategies are locally operationalised. This presentation will compare findings from different trials in different settings, discuss issues common to the field and those unique to specific settings, look at progress made, and make recommendations that can be considered for implementation in second generation trials.

---

### **Changing facets of ethics in transfusion medicine**

*Shivaram Chandrashekar*

Historically it has been considered perfectly ethical and legal to buy blood for transfusion. Doctors recommended that relatives donated blood and fresh blood was always preferred. A simple VDRL test was considered sufficient to ensure safety of the blood. All this changed with the emphasis on HIV, quality, ethics and confidentiality.

Ethics in blood donation : A donor with sexual risk behavior doesn't realise that his donation is risky. A patient's relative is labelled as a "voluntary donor" and voluntary donors are given unscientific reasons to benefit, such as the benefits of donation. Blood banks are rewarded for this "noble effort".

Ethics in safe (testing) Blood: Blood is "priceless" but blood it comes at a price for testing. ELISA is the standard test but less sensitive rapid tests are legally acceptable. A follow-up of the rapid test with ELISA entails more cost. Who pays for it? If the

ELISA turns positive after the blood has been issued, will the blood bank be praised or penalised?

Ethics in safe transfusion: Use oldest blood first is the dictum but patients want the freshest. What is ethical: allowing someone to die for want of platelets or collecting surplus platelets and wasting some?

Patients, physicians, blood bankers and government want exactly the opposite of what scientific and ethical guidelines prescribe. The distinction between voluntary and relative donors is blurred, as is the incidence of infections. Giving the patient what he wants is a safer alternative to quality blood. Quality and cost contradict each other, as do law and ethics. Following law rather than ethics is a safer alternative.

---

### **Do condoms have us covered? Rethinking HIV/AIDS programmes in India**

*Sonia J Cheruvillil, Bhavana Nancherla*

Over the past decade, HIV/AIDS has gained enormous prominence in international health as one of the most pressing epidemics facing the global South. There has been much written about intervention successes and failures, as well as the critical relationship between HIV/AIDS and human rights. Less understood is how the whirlwind of action from multilateral, bilateral, and private funders, and both government and non-governmental organisations (NGOs) has altered the Indian landscape of HIV/AIDS programming. In order to take advantage of copious funding streams, many NGOs have rearranged infrastructure and resources to tackle this public health emergency - though accommodation often occurs with little attention to capacity-building, or at the cost of existing service provisions. Such intervention often has a split effect, enabling acknowledgement of traditionally marginalised communities hardest hit by the epidemic, but failing to address the persisting climate of social and legal discrimination faced by these populations. This phenomenon manifests a contradiction of increasing importance to practitioners, activists, and ethicists alike.

This paper attempts to untangle the effects that HIV/AIDS has exerted on India's public service and activist spaces. It begins with an overview of HIV/AIDS work in India and the roles that various sectors have historically played. The paper defines a continuum of service-based versus rights-based approaches and discusses significant models for HIV/AIDS prevention and management within this framework. The authors critically examine India's "NGO culture" to demonstrate how shifting funding trends simultaneously nurture and undermine commitment to the principles of autonomy and justice.

---

### **Establishing a clinical ethics committee: five years of experience in Pakistan**

*Rehana S Kamal*

In spite of all the problems and the unequal distribution of health care in developing countries there are no guidelines

available for the application of ethical principle in health care.

The need for a hospital ethics committee (HEC) was felt at the Aga Khan University Hospital. The committee's mandate is to facilitate the establishment of a community of health professionals who are sensitive to issues of ethics in health care. The committee was to provide two specific services; ethics consults and education. An outline of the goals of the committee was drawn up. These included developing terms of reference (TOR), education, awareness in the hospital regarding the existence and functions of the committee and developing and initiating an ethics consultation process. After three months of deliberations a final draft for the TOR was prepared and approved by the Hospital Board. A programme of continuing self-education of committee members through journals, case discussions and by attending workshops and conferences was drawn up.

The consultation will be provided by HEC to serve as an important mechanism for resolving moral and ethical dilemmas in patient care. Awareness regarding the existence and functions of the HEC was achieved by making presentations in different departments of the hospital, by distributing flyers and publishing a three monthly newsletter, and by conducting workshops.

In the past five years a total number of 60 consults have been held. The majority were related to end-of-life issues. Others related to the lack of resources, conflicts within families, social and cultural background and issues relating to autonomy.

---

### **Profile of members of ethics committees in hospitals and research organisations in Pune city**

*Sanjay Mehendale*

The appropriate constitution of ethics committees (ECs) might ensure high quality review of research proposals. We studied the profile of EC members of Pune-based health and research organisations.

55 ethics committee members representing 12 health and bio-medical research institutions in Pune city completed the structured questionnaires. Their profiles were analysed.

Among the respondents, 9(16%) were EC chairpersons, 4(7%) were member secretaries and 42(77%) were members. They represented ECs of hospitals (64%), research organisations (25%) or NGOs (11%). The majority of them (80%) had become EC members on their own interest. The majority were men (73%) and above 40 years of age (87%). Nearly 55% had more than 20 years of research experience. The average affiliation with the EC was four years (range 1-15 years) with backgrounds from medicine (51%), social science/ social work (25%), biological sciences (14%), law, (4%) and others (6%). Ethical principles were correctly known to 42% members. Chairpersons/ secretaries were more likely to have a medical background (10/13 Vs. 18/42,  $p=0.032$ ) and formal training in ethics (8/13 Vs. 9/42,  $p=0.011$ ) compared to others. None of the chairpersons/secretaries were

either stakeholders or community representatives. EC members were well-educated; 62% with MD/ PhD and 33% postgraduates. Long-term EC members were more likely to attend meetings ( $p=0.0058$ ).

Most ECs had appropriate constitutions and members were generally senior by age, highly educated, interested and well-experienced in research. The representation of lawyers, ethicists, women and common people needs to be increased. EC members had less than desired clarity on ethical issues and ethical principles. Formal training of EC members on ethical principles and practices is crucial.

### **Concerns of potential participants: are the ICMR Guidelines 2000 adequate?**

*Mala Ramanathan*

In the Indian context, the ICMR guidelines for biomedical research are used to guide the ethical review of biomedical research. This paper describes an attempt to examine the perceptions of one of the stakeholders in the research process -potential participants. Their concerns regarding the required safeguards in a research process are usually not considered, even though the ultimate requirement for the study is their informed consent and participation. The aim of this paper is to identify the concerns of potential participants in biomedical research in view of the kind of protections offered under the ICMR guidelines.

The perceptions of these key persons were obtained using focus group discussions (FGDs). As most community members were not aware of ethics committees, discussions were initiated with a video coverage of a hypothetical ethics committee meeting. Four FGDs were conducted in the state of Kerala in India, which has the highest levels of literacy (above 90%) in the country. Understandings of informed consent processes, spreading of risk, fairness and justice, review processes for research involving human subjects, etc were explored in the FGDs.

The participants felt that most of the principles outlined in the ICMR guidelines were adequate for protecting human subjects in biomedical research. However, their understanding of the risk of participation included unanticipated health consequences of participation. A need for compensation for such problems was identified.

The study extends the understanding of risk-benefit analysis to include the unforeseen risks involved in participation.

### **Time to plug the holes in the National Blood Policy**

*Shailaja Tetali, C Balagopal*

In 1997 the Supreme Court of India passed a ruling banning paid blood donations. The National Blood Policy, 2002, strongly advocates non-remunerated voluntary blood donation (VBD) and unambiguously rejects replacement donation. But the ground reality is different.

Patients advised to undergo surgery must often travel to far-off cities for treatment. The onus for arranging blood for the patient

is on his poor relative, who must find a replacement for every unit of blood required for the surgery. Outside the hospital gates, he finds "relatives" who are only too willing to donate blood for a large fee. It is difficult to check if this contact is indeed the patient's relative.

What is the use of having a ruling from the highest court of law, and a policy on paper, if it is not implemented? In 39 countries, which include developing countries with much smaller human resources, 100% of blood collected is from VBD, as opposed to 50% in India.

The safest blood comes from healthy altruistic volunteers who take pride in being regular donors, not from people who sell their blood to mitigate their financial problems. One of the great roadblocks preventing the development of an effective VBD service is a lack of sufficient forward planning by the relevant political authorities. It has been documented that the most important factor for good VBD service is commitment from the government.

It is imperative that the government bans replacement donation with immediate effect, and actively promote VBD.

## PARTICIPANTS

**Aamir Jafarey:** assistant professor, Centre of Biomedical Ethics and Culture (CBEC), Sind Institute for Urology and Transplantation, editor of *Bioethics Links*, the quarterly newsletter of CBEC, and lecturer and consultant general surgeon, Aga Khan University, Karachi, Pakistan.

**Abdul Jameel Shareef:** assistant professor, department of orthopaedics, Medical College, Pariyaram, Kannur Kerala.

**Abhay Bang:** director, Society of Education, Action and Research in Community Health, Gadchiroli, Maharashtra.

**Abhijit Das:** director, Centre for Health and Social Justice and clinical assistant professor of the School of Public Health and Community Medicine at the University of Washington, Seattle, USA.

**Abraham Thomas:** formerly with Community Health Cell, Bangalore, and the department of informatics, St John's Medical College, Bangalore, currently with the Secretariat of the Second National Bioethics Conference.

**Achintya Mitra:** Central Research Institute, Ayurveda, Central Council for Research in Ayurveda and Siddha, department of Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy, ministry of health and family welfare, government of India.

**Adarsh Gangadhar:** fifth year student at the NALSAR University of Law, Hyderabad.

**R K Agarwala:** professor and head, department of psychiatry, Subharti Medical College, Meerut, Uttar Pradesh.

**Ajay Radhakrishna:** assistant professor, department of orthopaedics, Medical College, Kannur, Kerala.

**Ajith Kumar:** assistant professor of dermatology and venereology and member secretary of the institutional ethics committee, Government Medical College, Trichur, Kerala.

**Ala Melati Rad:** Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

**Aliya Naheed:** researcher, International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B), member of the ethical review committee and coordinator of the bioethics workshop of ICDDR,B and part-time faculty in the MPH programme of the James P Grant School of Public Health, BRAC University, Bangladesh.

**Amar Jesani:** trustee of Anusandhan Trust, former coordinator of the Centre for Studies in Ethics and Rights, Mumbai, founding member of the Forum for Medical Ethics Society, Mumbai, and editorial board member of the *Indian*

*Journal of Medical Ethics.*

**Amit Nirmalkar:** division of epidemiology and biostatistics, National AIDS Research Institute, Pune.

**Amita Singh:** Centre for the Study of Law and Governance, Jawaharlal Nehru University, Delhi.

**Ammu Joseph:** independent journalist, author and media analyst, Bangalore.

**Anand Grover:** lawyer, co-founder of the Lawyers Collective, and director of the Lawyers Collective HIV/AIDS Unit.

**Anandi Yuvaraj:** programme manager for HIV and Sexual Reproductive Health, PATH India, member of the national advisory board of the Indian chapter of the International AIDS Vaccine Initiative and steering committee member for phase III of the National AIDS Control Programme in India.

**Anant Bhan:** independent researcher in public health and bioethics, Pune.

**Anant Phadke:** coordinator of Support for Advocacy and Training to Health Initiatives (SATHI)-CEHAT, Pune.

**Ananthy Thambinayagam:** programme advisor, Global Campaign for Microbicides, India.

**Angus Dawson:** senior lecturer in ethics and philosophy, Centre for Professional Ethics, Keele University, UK, joint coordinator of the Public Health Ethics Network and joint editor-in-chief of *Public Health Ethics*.

**Anjani Jani:** women's activist, Old Age Project, Mumbai.

**Annie Hasan:** consultant and head of the department of genetics and molecular medicine, Kamineni Hospitals, and senior scientific officer, Bhagawan Mahaveer Hospital and Research Centre, Bangalore.

**Anoop Kumar Thekkuveetil:** biotechnologist, Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala.

**Armida Fernandez:** neonatologist and founder member of the Sneha Urban Health Centre, Mumbai.

**Arockiam Thaddeus:** reader in zoology, Jayaraj Annapackiam College for Women, Periyakulam, Kerala.

**Arjun Rajagopalan:** trustee and medical director, Sundaram Medical Foundation, Chennai.

**Arun Kumar Khanna:** Emcure Bio, and member of the Supply Chain Management Committee of the US government



for paediatric HIV/AIDS patients in developing countries, member of the Technical Education Board,

---

**BYT Arya:** chief of radiology, Manipal Hospital, Bangalore.

---

**Arun Risbud:** division of basic sciences, National AIDS Research Institute, Pune.

---

**Asha Kilaru:** head of research, Belaku Trust, Bangalore.

---

**Ashish Goel:** department of medicine, All India Institute of Medical Sciences, New Delhi.

---

**Athula Sumathipala:** Institute of Psychiatry, King's College, London, UK.

---

**Baiju Julian:** doctorate in moral theology from the Alfonsianum, Rome, Italy.

---

**C Balagopal:** chief executive officer of Terumo Penpol Ltd, manufacturer of medical products and equipment for blood transfusion services.

---

**Balaji Sampath:** Association for India's Development, Chennai.

---

**Balasubramanian Dorairaja:** director, Hyderabad Eye Research Foundation, L V Prasad Eye Institute, Hyderabad.

---

**Baneen Karachiwala:** Belaku Trust, Bangalore.

---

**Beryl Primrose Gladstone:** department of community health, Christian Medical College, Vellore.

---

**Bernard Lo:** professor of medicine and director, programme in medical ethics, University of California-San Francisco, member, data and safety monitoring committees for diabetes prevention trials and an HIV vaccine trial at NIAID, member, ethics working group, HIV Prevention Trials Network, and co-director of the policy and ethics core of the Center for AIDS Prevention Studies at UCSF.

---

**P M Bhargava:** founding director (retired), Centre for Cellular and Molecular Biology, Hyderabad, and former member of the Knowledge Commission, Government of India, New Delhi.

---

**Bhargavi Rao:** Environment Support Group, Bangalore.

---

**MG Bhat:** consultant surgeon, informatics and medico-legal expert, Bangalore

---

**Bhavana Nancherla:** LEPR Society, Andhra Pradesh.

---

**Bopanna PP:** retired high court judge, Karnataka, and chairperson of the institutional review board of Manipal Hospital, Bangalore.

---

**Brad Crammond:** research fellow, human rights and bioethics unit in the department of epidemiology and preventive medicine at Monash University, Melbourne, Australia.

---

**Chanda Kulkarni:** head of pharmacology, St John's Medical College, Bangalore.

---

**Chitra Kannabiran:** Kallam Anji Reddy Molecular Genetics Laboratory, LV Prasad Eye Institute, Hyderabad.

---

**S Choudhary:** assistant professor in the department of psychiatry, Subharti Medical College, Meerut, Uttar Pradesh.

---

**Christiane Fischer:** public health physician, BUKO Pharma-Kampagne, Germany.

---

**Daphne Viveka Furtado:** Society of the Sacred Heart of Jesus, Bihar.

---

**Deepa V:** SAMA: Resource Group for Women and Health, Delhi.

---

**Devadass PK:** professor in the department of forensic medicine, Bangalore Medical College and Research Institute, Bangalore.

---

**Dharmanand BG:** consultant rheumatologist at Manipal Hospital, Bangalore.

---

**Edward Wilson Grandin:** School of Medicine, Tufts University, Boston, MA, USA.

---

**Elnaz Jafari Mehr:** Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

---

**Evelyn Lacson:** physician and chairperson of the research ethics evaluation board at the University of St La Salle, Bacolod City, Philippines.

---

**Evita Fernandez:** gynaecologist and managing director, Fernandez Hospitals, Hyderabad.

---

**Farida Akhtar:** Unnayan Bikalper Nitinirdharoni Gobeshona (UBINIG), Bangladesh

---

**Farhat Moazam:** professor and founding chairperson of the Centre of Biomedical Ethics and Culture of the Sind Institute of Urology and Transplantation in Karachi, fellow at the Institute of Practical Ethics, and visiting professor, Centre for Humanism in Medicine, at the University of Virginia, USA.

---

**Fiona Miller:** assistant professor and holder of the Senator William McMaster Chair in Health Policy in the department of health, aging and society at McMaster University, Ontario, Canada, member of McMaster's Centre for Health Economics and Policy Analysis, and associate member of the department of clinical epidemiology and biostatistics.

---

**Gangadeep Kang:** department of gastrointestinal sciences, Christian Medical College, Vellore.

---

**Geeta Kashyap:** LV Prasad Eye Institute, Hyderabad.

---

**Geeta Vemuganti:** director of the ophthalmic pathology service, head of the Sudhakar and Srikant Stem Cell Laboratory, and member-secretary, ethics committee of the institutional

review board, L V Prasad Eye Institute, Hyderabad.

---

**Geetha Desai:** assistant professor in department of psychiatry, National Institute of Mental Health and Neurosciences, Bangalore.

---

**George Swamy:** member, community advisory board, National AIDS Research Institute, Pune.

---

**George Thomas:** orthopaedic surgeon, head of emergency services, St Isabel's Hospital, Chennai, and editor of the *Indian Journal of Medical Ethics*.

---

**Gigi Chandy:** faculty of the reproductive medicine unit at the Christian Medical College Vellore, Tamil Nadu.

---

**Girish Menon:** Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram.

---

**Girish N Rao:** assistant professor in the department of epidemiology, National Institute of Mental Health and Neurosciences, Bangalore.

---

**MR Hariharan Nair:** retired high court judge and chairperson, institutional ethics committee, Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram.

---

**Helen E Sheehan:** lecturer in health and sociology, department of South Asia studies, University of Pennsylvania, USA.

---

**Hemlata Pisal:** Mahila Sarvangeen Utkarsha Mandal (MASUM), Pune.

---

**Hewage Suwin:** fellow at the Institute for Research and Development, Colombo, Sri Lanka.

---

**Ilias Mahmud:** faculty of the James P Grant School of Public Health, BRAC University, Bangladesh.

---

**Jacob Sijtsma:** economist specialising in environment and development issues, and planning, monitoring and evaluation officer at the Wemos Foundation, Amsterdam, The Netherlands.

---

**Jagadisha Thirthalli:** associate professor of psychiatry in the department of psychiatry, National Institute of Mental Health and Neurosciences, Bangalore.

---

**Jagadeesh N Reddy:** faculty of the department of forensics, Vydehi Institute of Medical Sciences, Bangalore.

---

**Jameela George:** Emmanuel Health Association, New Delhi.

---

**Jayaprakash Muliyl:** principal, Christian Medical College, Vellore.

---

**T Jayashree:** documentary film maker, Bangalore, India.

---

**Jayna Kothari:** lawyer with Ashira Law: Advocates and Solicitors, Bangalore.

---

**Joanna Murray:** Institute of Psychiatry, King's College, London.

---

**S V Joga Rao:** senior advocate and health care consultant, Bangalore.

---

**P D Jose:** professor in the corporate strategy and policy area at the Indian Institute of Management, Bangalore.

---

**M A Jothi Rajan:** lecturer in physics at the Arul Anadar College, Karumathur, Tamil Nadu.

---

**SP Kalantri:** department of medicine, Mahatma Gandhi Institute of Medical Sciences, Sewagram, Wardha, Maharashtra.

---

**Kalpana Kannibirani:** faculty at the NALSAR University of Law, Hyderabad, India.

---

**V N Karandikar:** chairperson, community advisory board, National AIDS Research Institute, Pune.

---

**G K Karanth:** professor and chairperson of the Centre for Study of Social Change and Development at the Institute for Social and Economic Change, Bangalore.

---

**Karthik Nagesh:** consultant neonatologist and paediatrician at Manipal Hospital, Bangalore.

---

**D S Nagesh:** Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala.

---

**Katharine Shapiro:** Global Campaign for Microbicides.

---

**Katie West:** Global Campaign for Microbicides.

---

**Kavita Sivaramakrishnan:** senior programme manager, academic and research programmes, at the Public Health Foundation of India.

---

**C B Keshavamurthy:** interventional cardiologist at the Vikram Hospital and Heart Care, Mysore.

---

**Kishore Phadke:** paediatric nephrologist and secretary, Zonal Coordination Committee for Transplantation for Karnataka.

---

**Kshama Devi:** pharmacologist, Al Ameen College of Pharmacy, Bangalore.

---

**Ladan Naz Zahedi:** Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

---

**Latha Jagannathan:** founder and managing trustee, Bangalore Medical Services Trust India.

---

**Latika Karve:** division of epidemiology and biostatistics, National AIDS Research Institute, Pune.

---

**Lekamwattage Manura:** Institute for Research and Development, Colombo, Sri Lanka.

---

**Leni Chaudhuri:** Centre for Enquiry in Health and Allied Themes, Mumbai.

**Liontjen Laterveer:** Wemos Foundation, Amsterdam, The Netherlands.

**Lori Heise:** director, Global Campaign for Microbicides.

**Madhava Menon:** founder director of the National Law School of India University, Bangalore, and the West Bengal National University of Juridical Sciences, Kolkata, and director of the National Judicial Academy, Bhopal.

**Mahesh Kharat:** division of epidemiology and biostatistics, National AIDS Research Institute, Pune.

**Mala Ramanathan:** Achutha Menon Centre for Health Science Studies, Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala.

**Mala Srivastava:** head, business strategy, Clinigene International Ltd, Bangalore.

**Manjula Athukorale:** Institute for Research and Development, Colombo, Sri Lanka.

**Mansoor Saniei:** secretary of the biomedical ethics committee at the Research Center for Gastroenterology and Liver Diseases, Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

**Manur Lekamwattage:** Institute for Research and Development, Colombo, Sri Lanka.

**Martin Prince:** Institute of Psychiatry, King's College, London.

**K Mathiharan:** practising consultant in legal medicine, assistant professor with the Institute of Forensic Medicine, Madras Medical College.

**Meena Satale:** division of social and behavioural sciences, National AIDS Research Institute, Pune.

**Meera Pillai:** independent consultant, Bangalore.

**Meera Purushottam:** molecular genetics laboratory, department of psychiatry, National Institute of Mental Health and Neurosciences, Bangalore.

**Mohammad Reza Zali:** Research Center for Gastroenterology and Liver Diseases, Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

**Mufid Baig:** research assistant and community worker at the National AIDS Research Institute, Pune.

**Muraleedharan CV:** Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala.

**Muraleedharan V R:** professor of economics at the Indian Institute of Technology-Madras, Chennai.

**Nabeel M K:** lecturer in the department of orthopaedics, Centre for Tele-Health and Medical Informatics at the Academy

of Medical Sciences, and nodal officer of the Indian Space Research Organisation-supported Kerala Tele-Health and Medical Education Project.

**V Nagaraj:** professor at the National Law School of India University, Bangalore.

**S Nagasubramaniam:** consultant urologist and member-secretary of the institutional review board of Manipal Hospital, Bangalore.

**S C Nagendraswamy:** medical director, Manipal Health Services.

**Nageshwar Rao Gullapalli:** founder director and chairperson of the LV Prasad Eye Institute, Hyderabad, and president of the International Agency for Prevention of Blindness.

**M D Nair:** Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram.

**Nalin Bharti:** lecturer in economics at the NALSAR University of Law, Hyderabad.

**Nancy Padian:** executive director of the Women's Global Health Imperative, currently based at Research Triangle Institute, and faculty at the University of California San Francisco and at the School of Public Health at the University of California, Berkeley.

**Naveen C Balan:** assistant professor, department of orthopaedics, Medical College, Pariyaram, Kannur, Kerala.

**Neha Madhiwalla:** coordinator of the Centre for Studies in Ethics and Rights, Mumbai, and managing trustee of Chehak Trust which runs Sahyog, a community-based initiative for primary health and education for women and girls.

**S N Pal:** HSCC (India) Ltd

**G Parameshwaram:** consultant anaesthesiologist, Manipal Hospital, Bangalore.

**Padmini Swaminathan:** professor and director, Madras Institute of Development Studies, holder of the Reserve Bank of India Chair in regional studies at the Institute and member of the research institute committee of the Indian Council for Social Science Research.

**Padmaja Udaykumar:** member of the institutional ethics committee, Kasturba Medical College and Hospital, Mangalore.

**Paramita Kundu:** programme associate, Global Campaign for Microbicides, PATH in India, New Delhi.

**Prabha Chandra:** professor of psychiatry in the department of psychiatry, National Institute of Mental Health and Neurosciences, Bangalore.

**Prabha Desikan:** head of the department of microbiology

and secretary of the institutional review board, Bhopal Memorial Hospital and Research Centre, Bhopal.

---

**R Prajeesh:** consultant, Integrated Health Care Group, Sobha Renaissance Information Technology, and additional secretary, Indian Association of Medical Informatics, New Delhi.

---

**Pramod Vhadge:** division of social and behavioural sciences, National AIDS Research Institute, Pune.

---

**Pranoti Chirmuley:** senior programme officer, Centre for Studies in Ethics and Rights, Mumbai.

---

**Prashant Raymus:** Centre for Enquiry in Health and Allied Themes, Mumbai.

---

**Prathap Tharyan:** professor of psychiatry and additional vice-principal (research), Christian Medical College, Vellore, coordinator of the South Asian Cochrane Network, member of the institution's ethics and research committees and a founder member of the institution's clinical ethics committee.

---

**Preeti Gedam:** division of epidemiology and biostatistics, National AIDS Research Institute, Pune.

---

**Preeti Nayak:** SAMA: Resource Group for Women and Health, Delhi.

---

**Prem Pais:** dean, St John's Medical College, Bangalore.

---

**Radhika Brahme:** research officer at the National AIDS Research Institute, Pune.

---

**Rajendiran Duraiswamy:** lecturer in pathophysiology and clinical and hospital pharmacy, KMCH College of Pharmacy, Coimbatore.

---

**Rajesh Kumar Sinha:** assistant professor in the department of health information management, Manipal College of Allied Health Sciences, Manipal, Karnataka.

---

**Rajiv Sarkar:** senior research fellow in the department of gastrointestinal sciences, Christian Medical College, Vellore..

---

**Rama Baru:** associate professor at the Centre of Social Medicine and Community Health at the Jawaharlal Nehru University, New Delhi, member of the editorial board of *Global Social Policy* published by Sage.

---

**S Ramalingam:** principal of the PSG Institute of Medical Sciences and Research, Coimbatore.

---

**Ramesh Awasthi:** co-convenor of Mahila Sarvangeen Utkarsha Mandal, Pune.

---

**Rangarajan T N C:** retired judge of the Andhra Pradesh High Court and chairperson of the ethics committee of the institutional review board of LV Prasad Eye Institute, Hyderabad.

---

**B C Rao:** primary care physician, Bangalore.

---

**Ravi Narayan:** community health physician and co-founder of the Community Health Cell, later the Society for Community Health Awareness Research and Action, Bangalore.

---

**G D Ravindran:** professor in the department of medicine at St John's National Academy of Medical Sciences, Bangalore.

---

**Reginald Watts:** Sangama (a human rights organisation working for individuals oppressed due to their sexual preference), Bangalore.

---

**Rehana S Kamal:** professor in the department of anaesthesia and chairperson of the hospital ethics committee at the Aga Khan University, Karachi, Pakistan.

---

**Reidar Lie:** professor of philosophy and senior investigator in the department of bioethics, University of Bergen, Norway, adjunct professor of research ethics at Thammasat University, Bangkok, Thailand.

---

**Renzo Zanotti:** associate professor of nursing faculty of medicine, University of Padova, Italy, director, International Institute of Nursing Research, Padova, and fellow of the European Academy of Nursing Science.

---

**Richard Cash:** director of the Program on Ethical Issues in International Health Research at the Harvard School of Public Health, faculty of research ethics and infectious disease epidemiology, Achutha Menon Centre for Health Science Studies, Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala, and the James P Grant School of Public Health at BRAC University, Bangladesh.

---

**Ritu Mathur:** MBA in health management working on women's health and rights issues.

---

**Ritu Priya:** professor and researcher in the School of Community and Social Medicine at Jawaharlal Nehru University, Delhi.

---

**Roya Sherafat:** Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

---

**Ruth Macklin:** professor of biomedical ethics at Albert Einstein College of Medicine in the Bronx, New York, USA, chairperson of the external ethics committee of the Centers for Disease Control and Prevention, adviser to the HIV Vaccine Initiative and the department of reproductive health and research, World Health Organisation, member of the Global Reference Group on HIV and Human Rights of the Joint United Nations Programme on HIV/AIDS and director of an NIH training programme in research ethics in Latin America.

---

**Sachin Sharma:** assistant professor, department of psychiatry, Subharti Medical College, Meerut, Uttar Pradesh.

---

**Sadath Sayeed:** faculty member in the division of medical ethics, department of social medicine, Harvard Medical School, attending neonatologist and member of the hospital ethics committee at Children's Hospital Boston, USA.

**Saeed Shahraz:** Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

**Sandhya Srinivasan:** freelance health writer and executive editor of the *Indian Journal of Medical Ethics*.

**Sangameshwar B M:** Karnataka Health Promotion Trust.

**Sangeeta Rege:** Dilaasa Crisis Centre for Women, Centre for Enquiry in Health and Allied Themes, Mumbai.

**Sanghamitra Pati:** assistant professor in the department of biochemistry at SCB Medical College, Cuttack, Orissa.

**Sanjay Mehendale:** deputy director (senior grade) at the National AIDS Research Institute, Pune.

**Sanjay Nagral:** hepatobiliary surgeon, Jaslok Hospital and Research Center, Mumbai, and member of the editorial advisory board of the *Indian Journal of Medical Ethics*.

**Sanjay A Pai:** consultant pathologist and head of the department at Manipal Hospital, Bangalore, editorial board member of the *Indian Journal of Medical Ethics*, working committee member of *The National Medical Journal of India* and member of the institutional review board of Manipal Hospital, Bangalore.

**Sanjeev Jain:** professor in the Molecular Genetics Laboratory, Department of Psychiatry at the National Institute of Mental Health and Neurosciences, Bangalore.

**Sanjeev Rai:** Father Mueller Medical College, Mangalore, Karnataka.

**Sankara Sarma:** biostatistician and faculty member of the Achutha Menon Centre for Health Science Studies, Sree Chitra Thirunal Institute for Medical Sciences and Technology, Thiruvananthapuram.

**N B Sarojini:** founder of SAMA Resource Group for Women and Health, New Delhi.

**Saye Sayar:** Shaheed Beheshti University of Medical Sciences, Tehran, Iran.

**Sean Philpott:** Global Campaign for Microbicides.

**Seema Sahay:** assistant director, division of social and behavioural science at National AIDS Research Institute, working in the field of physical and social anthropology.

**Shalini Bharat:** professor and dean, school of health systems studies, Tata Institute of Social Sciences, Mumbai.

**Shailaja Tetali:** physician in clinical medicine and public health, working on issues related to HIV prevention and blood safety.

**Shirin Shikalgar:** division of epidemiology and biostatistics,

National AIDS Research Institute, Pune

**Shivaram Chandrashekar:** chief, transfusion medicine, Manipal Hospital, Bangalore, and secretary, Indian Society of Blood Transfusion and Immunohematology.

**Shobana Kubendran:** department of psychiatry at the National Institute of Mental Health and Neurosciences, Bangalore.

**Sunil Shroff:** consultant urologist, managing trustee, MOHAN Foundation, and president, Medical Computer Society.

**Shubhangi Sapkal:** division of epidemiology and biostatistics at the National AIDS Research Institute, Pune.

**Simble Susan Thomas:** graduate of the Erasmias Mundus Advance Master of Bioethics.

**Siribaddana Sisira:** Institute for Research and Development, Colombo, Sri Lanka.

**Siriwardhana Chesmal:** Institute for Research and Development, Colombo, Sri Lanka.

**Sivakami M:** faculty at the Institute for Social and Economic Change, Bangalore.

**Sonia J Cheruvillil:** service corps fellow in Bangalore with Sangama, a human rights organisation working with sexual minorities and HIV/AIDS.

**C V Sowmini:** medical research officer at the Human Reproduction Research Centre, Indian Council of Medical Research, SAT Hospital, department of obstetrics and gynaecology, Medical College, Thiruvananthapuram, Kerala.

**M G Sreekumar:** Fulbright scholar and currently visiting professor at the faculty of computer science and information technology, University of Malaya, Kuala Lumpur, Malaysia, and librarian and head, Center for Development of Digital Libraries, Indian Institute of Management Kozhikode.

**Sreekumar N:** assistant professor of philosophy in the department of humanities and social sciences, Indian Institute of Technology-Madras, Chennai.

**Sridevi Seetharam:** medical doctor and consultant pathologist at the Swami Vivekananda Youth Movement, Mysore, involved in research related to HIV/AIDS, diabetes and hypertension, sickle cell anaemia.

**S Srinivasan:** managing trustee of the LOCOST, Baroda, currently editor of the *Medico Friend Circle Bulletin*.

**Sriram Rajagopal:** department of cardiology at the Railway Hospital, Perambur.

**Stephen Fernandez:** FIAMC Biomedical Ethics Centre, St Pius College, Mumbai.

**Sten Vermund:** director, Institute for Global Health and professor, Vanderbilt University School of Medicine.

**Subadrata Chakrabarti:** scientist at the Kallam Anji

Reddy Molecular Genetics Laboratory, LV Prasad Eye Institute, Hyderabad.

---

**V N Subba Rao:** chairperson, Karnataka Media Academy.

---

**Sucheta Kadam:** division of epidemiology and biostatistics, National AIDS Research Institute, Pune.

---

**H Sudarshan:** doctor, social worker and tribal rights activist in Karnataka, and former chairperson, Health Task Force, ministry of health and family welfare, government of Karnataka.

---

**Sukanya Rangamani:** Community Health Cell, Bangalore.

---

**Suneeta Krishnan:** social epidemiologist working at Research Triangle Institute, International, in San Francisco, with adjunct/visiting faculty appointments at the School of Public Health, University of California, Berkeley and the Centre for Public Policy, Indian Institute of Management, Bangalore.

---

**Sunil K Pandya:** consultant neurosurgeon at the Jaslok Hospital, Mumbai, and editor emeritus, the *Indian Journal Medical Ethics*.

---

**Sunita Puri:** fourth year medical student at the University of California, San Francisco, domestic violence counsellor in the South Asian immigrant community and PACCTR clinical research fellow at UC-SF.

---

**Supriya Bijlwan:** lawyer at a corporate law firm in New Delhi.

---

**Suresh Kumar:** director of the pain and palliative care centre at the Calicut Medical College, Kerala.

---

**Sushma Kapoor:** International AIDS Vaccine Initiative, New Delhi

---

**Swarnalakshmi S:** member of the institutional review board, community advisory board and regulatory coordinator at YRG CARE, Chennai.

---

**Swatija Manorama:** women's and health activist, Mumbai.

---

**Sweta Das:** International AIDS Vaccine Initiative, New Delhi.

---

**Tarun Kumar:** faculty of the Bapuji Dental College and Hospital, Davangere, Karnataka.

---

**Tejaswini:** Belaku Trust, Bangalore.

---

**Thelma Narayan:** epidemiologist and co-founder of the Community Health Cell, Bangalore.

---

**Thomas Kalam:** director, St John's National Academy of Health Sciences, Bangalore.

---

**Thomas Xavier:** creative director at Orchard India Advertising Ltd, Bangalore, and former external member of the institutional review board of Manipal Hospital, Bangalore.

---

**Tine Abraham:** third year student of law at the NALSAR University of Law, Hyderabad.

---

**Usha Raman:** science writer, communications consultant and member of the ethics committee at L V Prasad Eye Institute, Hyderabad.

---

**M S Valiathan:** cardiac surgeon, Fellow of the Royal College of Surgeons, former director of the Sri Chitra Thirunal Institute of Medical Sciences, Thiruvananthapuram, former vice chancellor of Manipal Academy of Higher Education, and Fellow of the Indian National Academy of Engineering.

---

**Vandana Gupta:** founder of the cancer patient support group V-Care, member of the ethics committee of the Tata Memorial Hospital as a patient representative, and vice president of Cancer Care India.

---

**Vasantha Muthuswamy:** senior deputy director general, Indian Council of Medical Research, New Delhi, heading the division of basic medical sciences, traditional medicine and biomedical ethics, and member of the editorial advisory board of the *Indian Journal of Medical Ethics*.

---

**Venkatesh Krishnamoorthy:** Nephrology-Urology Trust, Bangalore.

---

**Veena A S:** doctoral scholar in the department of clinical psychology, National Institute of Mental Health and Neurosciences, Bangalore, currently project coordinator of a World AIDS Foundation-funded Indo-US research project on HIV prevention among at-risk women in Bangalore.

---

**Victoria Loblay:** department of anthropology, Macquarie University, Sydney, Australia.

---

**Vijay:** Swasti Health Resource Center, Bangalore.

---

**N Vijaya Raaghavan:** student of the master's programme in health administration, Tata Institute of Social Sciences, Mumbai.

---

**Vikrant Sahasrabuddhe:** Institute of Global Health and assistant research professor at the Vanderbilt University School of Medicine.

---

**Vinay Chandran:** executive director of the Swabhava Trust, a support organisation for lesbian, gay, bisexual and transgender populations, Bangalore.

---

**Virender Sangwan:** corneal surgeon and associate director of L V Prasad Eye Institute, Hyderabad, and head, Cornea and Anterior Segment Service.

---

**Vishwas Devaiah:** doctoral student based in Bangalore, working at the Alternative Law Forum on intellectual property issues.

---

**Young-Gyung Paik:** Korean WomenLink, a feminist nongovernmental organisation in Seoul, Korea, coordinator of the International Forum on Biotechnology and Human Rights of Women, and doctoral candidate in anthropology at Johns Hopkins University.

---

**Zafrullah Chowdhary:** director of Gonoshastaya Kendra, Bangladesh.

---

**Zulfiker Ali:** lecturer in the department of paediatrics and neonatology at the Medical College under the Academy of Medical Sciences, Pariyaram, Kannur, Kerala.



## NOTES

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---





## CONFERENCE ORGANISERS, NATIONAL BIOETHICS CONFERENCE, 2007

### National organising committee

(01) AID India (**Balaji Sampath**), (02) Bangalore Medical Services Trust and Research Institute, (**Latha Jagannath**) (03) Bapuji Dental College and Hospital (**Barun Tarun Kumar**), (04) Belaku Trust (**Asha Kilaru**), (05) Centre for Enquiry in Health and Allied Themes (**Sangeeta Rege**), (06) Centre for Public Policy, Indian Institute of Management, Bangalore (**P D Jose**), (07) Centre for Studies in Ethics and Rights (**Pranoti Chirmuley**), (08) Christian Medical College and Hospital, Vellore (**Gigi Chandy**), (09) Community Health Cell (**Thelma Narayan**), (10) Department of Humanities and Social Sciences, Indian Institute of Technology, Madras (**VR Muraleedharan**), (11) Department of Forensic Medicine, Bangalore Medical College and Research Institute (**Devadass PK**), (12) Emmanuel Hospital Association (**Jameela George**), (13) Environment Support Group (**Bhargavi Rao/Leo Saldhana**), (14) Father Mueller Medical College (**B Sanjeev Rai**), (15) FIAMC Biomedical Ethics Centre (**Stephen Fernandez**), (16) Forum for Medical Ethics Society (**Sanjay Nagral**), (17) Institute for Social and Economic Change (**Sivakami M**), (18) Institute of Law and Ethics, National Law School of India University (**V Nagaraj**), (19) Institute of Legal Medicine (**K Mathiharan**), (20) Karnataka Health Promotion Trust (**Sangameshwar BM**), (21) Kasturba Medical College and Hospital Institutional Ethics Committee (**Padmaja Udaykumar**), (22) L V Prasad Eye Institute (**Geeta Kashyap**), (23) LOCOST Standard Therapeutics (**S Srinivasan**), (24) Mahila Sarvangeen Utkarsha Mandal (**Ramesh Awasthy/Hemlata Pisal**), (25) Manipal Health Services (**Sanjay A Pai**), (26) NALSAR University of Law (**Kalpana Kannabiran**), (27) National AIDS Research Institute (**Sanjay Mehendale**), (28) Nephrology-Urology Trust (**Venkatesh Krishnamoorthy**), (29) PSG Institute of Medical Sciences and Research (**S Ramalingam**), (30) Public Health Foundation of India (**Kavita Sivaramakrishnan**), (31) SAMA: Resource Group for Women and Health (**Preeti Nayak**), (32) Jawaharlal Nehru University Bioethics Forum (**Uttam Pati/ Amita Singh**), (33) Sree Chitra Tirunal Institute of Medical Sciences and Technology (**Anoop Kumar Thekkuveetil**), (34) St Johns National Academy of Medical Sciences (**G D Ravindran**), (35) SWASTI - Health Resource Centre (**Vijay**), (36) Tata Institute of Social Sciences (**Shalini Bharat**), (37) Tele Health and Medical Informatics, Academy of Medical Sciences (**Nabeel MK**), (38) Vydehi Institute of Medical Sciences (**Jagadeesh Narayana Reddy**)

---

#### National advisory committee

**Dr M S Valiathan:** Scientific advisor to the prime minister, former vice chancellor, Manipal Academy of Higher Education and former director, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram

**Prof Madhava Menon:** Member, Commission on Centre-State Relations, government of India, and former director, National Judicial Academy, former director, National Law School University, Bangalore

**Dr Vasantha Muthuswamy:** Senior deputy director general, Indian Council of Medical Research, New Delhi

**Dr Armida Fernandez:** Former dean, Lokmanya Tilak Medical College and Hospital, Mumbai

---

**Coordinating team :** **Amar Jesani:** Trustee, Centre for Studies in Ethics and Rights, Mumbai. **Prabha S Chandra:** Professor, department of psychiatry, National Institute of Mental Health and Neurosciences, Bangalore. **Suneeta Krishnan:** Visiting faculty, Centre for Public Policy, Indian Institute of Management, Bangalore. **Neha Madhiwalla:** Coordinator, Centre for Studies in Ethics and Rights, Mumbai.

---

**Local organising committee :** **Asha Kilaru:** Belaku Trust, Bangalore • **Girish N Rao:** NIMHANS, Bangalore • **Latha Jagannath:** Bangalore Medical Services Trust • **Meera Pillai:** Institute of Social Studies Trust, Bangalore • **Sanjay A Pai:** Department of pathology, Manipal Hospital, Bangalore, • **Sanjeev Jain:** Department of psychiatry, NIMHANS, Bangalore • **Sivakami M:** Institute for Social and Economic Change, Bangalore • **Sreedevi Seetharaman:** SVYM, Saragur, Mysore District • **Sukanya Rangamani:** Community Health Cell, Bangalore • **Vijay :** SWASTI - Health Resource Centre, Bangalore • **Vinay Chandran:** Swabhava, Bangalore.

---

**Conference secretariat:** Abraham Thomas, Jayanthi Bhat, Padma Ramaiah (Bangalore), Mahendra Shinde, Smita More (Mumbai)

---

**Review committee:** All members of the national organising committee and the *IJME* editorial board (Meenal Mamdani, Bashir Mamdani, Sanjay A Pai, Nobhojit Roy, Sandhya Srinivasan, George Thomas)

#### The *IJME* National Bioethics Conference 2007 is financially supported by:

International Development Research Centre (IDRC), Canada • ICICI Centre for Child Health and Nutrition • HIVOS - Netherlands • Wellcome Trust, UK • Sir Dorabji Tata Trust, Mumbai • The Ethics Training Project of the Centre for Public Policy, Indian Institute of Management, Bangalore - University of California, Berkeley-San Francisco AIDS International Training and Research Program (TW00003-15) • Action Aid India, New Delhi/Bangalore • Indian Council of Medical Research, New Delhi • PSG Institute of Medical Sciences and Research, Coimbatore • International AIDS Vaccine Initiative • Public Health Institute, New Delhi.