

# INDIAN JOURNAL OF MEDICAL ETHICS

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Forum for Medical Ethics Society



## REFUSAL OF TREATMENT

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## FORUM FOR MEDICAL ETHICS SOCIETY

C/o CEHAT, Survey 2804-5, Aram Society Road, Vakola, Santacruz (E), Mumbai – 400 055

Trust registration.: No- F-17441 (Mumbai), 1995

Society registration.: No: Mumbai, 218, 1995, GBBSD

# THE FORUM FOR MEDICAL ETHICS SOCIETY

## - BACKGROUND -

Ethics is integral to the legitimacy of modern healthcare. It helps protect patients' rights, facilitates the conduct of transparent and humane research, and enables medical practitioners to deliver rational, patient-friendly and compassionate care. And yet it continues to be largely absent from the healthcare discourse in India.

## - INCEPTION -

The Forum for Medical Ethics Society (FMES) was founded by a group of Mumbai-based medical practitioners in 1989. The primary agenda of this group was to highlight issues in medical ethics and generate discussions around them. FMES was registered as a Trust and Society in 1995.

FMES contested the Maharashtra Medical Council (MMC) elections in 1992 with a panel of eight doctors under the name 'Forum for Medical Ethics'. The objective was to orient the MMC to strengthen the ethical voice of medical practitioners. Though the panel won a substantial number of votes and support from several members of the medical fraternity, it lost the elections. But this attempt was successful in bringing to light the corruption in the Medical Council election system. The same corrupt practices were documented by the Observers appointed by the Mumbai High Court during the 1997 MMC elections.

After more than a decade of struggle, including litigation in the High Court of Bombay, FMES was able to make the state government institute some radical changes, and at present, the MMC is the only state medical council in India to have shifted to a secret ballot system of voting.

## - BACKGROUND -

The *Indian Journal of Medical Ethics (IJME)* was founded by FMES in 1993. *IJME* has worked to highlight ethical principles in healthcare, draw attention to malpractices in the healthcare system, create awareness of the rights and responsibilities of patients and doctors, promote discussion with patients, and give importance to patients' perspectives. The journal has generated exchanges between non-medical experts, philosophers and social scientists, medical providers, health researchers, paramedical personnel and advocacy groups. *IJME* is, till date, the only journal on bioethics and medical ethics published from India.

## - SCOPE OF THE JOURNAL -

*IJME* has successfully combined the scope and potential of academics, advocacy, knowledge dissemination and public debates. It is a repository of case studies, commentaries, original viewpoints and research findings. For over two decades now, it has served as a platform for deliberating on and discussing a wide range of issues on healthcare ethics in the developing world.

## - INDEXING -

*IJME* is a peer-reviewed, quarterly journal indexed on MEDLINE, Google Scholar and The Philosopher's Index.

## - ACCESS -

*IJME* is digitally available ([www.ijme.in](http://www.ijme.in)) and all back issues and current issue are free access. The 'Online First' section carries topical articles ahead of print.

*IJME* is associated with several ethics activities, and it organizes the National Bioethics Conference as a biennial event.

# THE NATIONAL BIO-ETHICS CONFERENCE

## - BACKGROUND -

The primary objective of organizing a conference on bioethics in India was to set up a platform for direct interaction between the stakeholders in bioethics. The National Bioethics Conferences (NBC) are organized in collaboration with medical science, social science, and non-governmental institutions. The first NBC was held at Mumbai in 2005; since then, the NBCs have been a biennial event, organized in 2007, 2010, 2012 and 2014. The sixth NBC is scheduled for early 2017 in Pune.

## - THE CONFERENCES -

The NBCs are a meeting ground for delegates from India and abroad to report, debate and brainstorm on all kinds of ethical issues in health, healthcare, research and public health. Each NBC has witnessed the active participation of bioethicists from across the globe. A prime agenda of the conferences has been to contribute to bioethics in the context of a developing world.

The themes of the first five NBCs were:

- Ethical challenges in biomedical and social science research;
- Moral and ethical imperatives of healthcare technologies;
- Governance of healthcare: issues of ethics, equity and justice;
- Ethics and regulatory challenges in health research, and
- Integrity in medical care, public health and healthcare research.

The theme for the 6th NBC will be 'Healing and Dying with Dignity: Ethical Issues in Palliative Care, End of Life Care and Euthanasia'.

The 7th NBC and the 14th World Congress of Bioethics (WCB): The International Association of Bioethics (IAB) has awarded the organisation of the 14th WCB to the joint bid by FMES and Sama: Resource Group for Women and Health, New Delhi. The overarching theme of the conference is "Health for all in an unequal world: obligations of global bioethics". The WCB, a biennial activity, serves as a global platform in bioethics, and is organised by the IAB in collaboration with local key organising entities in different countries each time. In December 2018 the 7th NBC will be organised along with the 14th WCB, in New Delhi.

The scientific sessions of the NBCs encourage research and reflection on bioethics. The papers and plenary presentations have been published in many journals, including *IJME*.

As a result of the systematic efforts of FMES and the organizing role of *IJME* since 2005, today, the NBCs are an established platform for reporting, debating and discussing bioethics in this region.

# OTHER ACTIVITIES OF FMES

In addition to the publication of *IJME* and regular organization of the NBCs, FMES is involved in the following activities:

## **- CONTRIBUTIONS TO BIOETHICS -**

FMES has played a critical role in developing, and supporting the growth of bioethics in India. Curricula and modules developed by FMES have been adapted by other ethics training initiatives. Members of FMES serve as resource persons for courses in ethics at various institutions in India, Bangladesh and Pakistan. Some members serve on the ethics review boards of different research institutes.

## **- SEMINARS AND TRAINING PROGRAMMES -**

FMES has organised many training programmes over the years. Participants of these programmes have included post-graduate students, research scholars, professionals and NGO staff. It has organized seminars on medical ethics and research, and research ethics with private associations and government institutions. In 2001, FMES organized a seminar on Medical Ethics (conducted by the Academy of Medical Sciences) at Nagpur; in 2002 it organized a seminar on Ethics in Research at the Medical College, Trivandrum; in 2009 FMES collaborated to organise the Krishna Raj Memorial seminar on Clinical Trials and Healthcare Regulations in Mumbai.

FMES has facilitated meetings of visiting ethics experts at hospitals as well as medical and social science institutions. It has initiated the development of ethics curricula and e-repositories of case studies from the Indian context.

## **- INTERVENTIONS -**

FMES has participated in the debates on the application of the Consumer Protection Act to the medical profession, and in meetings of the Indian Medical Association. It has raised issues of patients' rights and the need to integrate ethics in medical education; questioned the involvement of medical professionals in human rights violations; and fought medical malpractice, irrational and unnecessary medical care and corruption in medical associations and councils.

# OTHER ACTIVITIES OF FMES

## - ENGAGEMENT WITH REGULATORY BODIES -

FMES has been part of the struggle that led to the formulation of legislation, such as the law to regulate use of medical technologies (The PC-PNDT Act, 1994) and the law to regulate healthcare services (The Clinical Establishments Registration and Regulation Act, 2010).

## - RESEARCH PROJECTS -

Among the research projects FMES has worked on are:

- An online survey of sexual harassment. Conducted in collaboration with AMCHSS, SCTIMST (2004-05)  
<http://www.issuesinmedicalethics.org/index.php/ijme/article/view/722/1749>;
- A study of promotional practices of pharmaceutical firms in Mumbai (2003). Supported by the WHO  
<http://www.issuesinmedicalethics.org/index.php/ijme/article/view/168/1380>

## - PUBLICATIONS –

- Indian Journal of Medical Ethics: selected readings 1993-2003*. FMES and CSER, 2005.
- Technology in healthcare: current controversies*. FMES and CSER, 2007.
- "*Physicians, Heal Thy System!*" *Economic & Political Weekly*, Vol47, No 25, p 5, Executive Committee, Medico Friend Circle and Managing Committee, FMES, June 23, 2012.
- "*National Health Policy 2015: Mapping the Gaps*," *Economic & Political Weekly*, Vol 50, No 36, pp 21—23, FMES, September 5, 2015.

# COLLABORATORS OF FMES

FMES has organised several activities, trainings, workshops and conferences both independently, and in collaboration with other organizations, institutions and associations.

The NBCs are always a collaborative enterprise.

NBC 1, 2005, was hosted by the FMES in collaboration with 20 institutions from India, in Mumbai.

NBC 2, 2007, was organized at the National Institute of Mental Health and Neuro-Sciences (NIMHANS), Bengaluru, in collaboration with 38 institutions from all over India.

NBC 3, 2010, was organized at the All India Institute of Medical Sciences (AIIMS), Delhi, in collaboration with 40 medical, social science, legal and NGO institutions from all over India.

NBC 4, 2012, was organized at the University of Hyderabad (UoH) in collaboration with several departments of the UoH and the Council for Social Development, Hyderabad.

NBC 5, 2014, was organized at St John's Academy of Health Sciences, Bengaluru, in collaboration with St John's Academy and with the Society for Community Health Awareness and Research and Action (SOCHARA), Bengaluru.

Collaborators for the training programmes offered by FMES–*IJME* include the Tata Institute of Social Sciences, Mumbai; Centre for Social Studies, Surat; and Sree Chitra Tirunal Institute of Medical Sciences and Technology, Thiruvananthapuram.

SAMA – Resource Group for Women and Health, Delhi, and Centre for Studies in Ethics and Rights, Mumbai, have provided consistent support to FMES–*IJME*, and the former continues to be associated with it in various capacities. FMES–*IJME* has also received support from the Anusandhan Trust, Mumbai on numerous occasions.

# HOW YOU CAN BE PART OF THIS

## - BECOME A MEMBER -

Those interested in the larger vision and cause of the FMES are invited to join FMES as members. An FMES member is expected to participate in the annual meetings, contribute towards the further growth of the Forum and its activities. For details write to [fmesmumbai@gmail.com](mailto:fmesmumbai@gmail.com)

## - SUBSCRIBE TO IJME -

Individuals and institutions in India and abroad can subscribe to the journal. For subscription details, please write to [ijmemumbai@gmail.com](mailto:ijmemumbai@gmail.com) or visit <http://ijme.in/index.php/ijme/pages/view/subscribe>

## - DONATE TO FMES -

FMES is a non-profit organization registered as a society under the Societies Registration Act. On ethical grounds, it does not accept funds from healthcare, tobacco and alcohol companies. It is run on individual donations, journal subscriptions and occasional funds from philanthropic organizations.

FMES welcomes financial aid from individuals and institutions invested in the idea of ethical and just healthcare.

**Donations to FMES are eligible for tax benefits under Section 80G of the Income Tax Act;** details of online and cheque/DD donations are available at <http://ijme.in/index.php/ijme/pages/view/donate>.