## **FORUM FOR MEDICAL ETHICS SOCIETY**

Trust registration No. F-17441 (Mumbai), 1995 Society registration No. Mumbai, 218, 1995, GBSD

# **Annual Report** 2015-16



INDIAN JOURNAL OF MEDICAL ETHICS JOURNAL OF THE FORUM FOR MEDICAL ETHICS SOCIETY SINCE 1993

ONLINE ISSN: 0975-5691 | PRINT ISSN: 0974-8466

INDIAN JOURNAL OF MEDICAL ETHICS national bioethics conterenc

## THE MANAGING COMMITTEE

The present Managing Committee was elected at the Annual General Meeting, September 19, 2015. The members elected were:

- Sanjay Nagral (Chair)
- Rakhi Ghoshal (Secretary)
- Lubna Duggal (Treasurer)
- Barun Mukhopadhyay (Member)
- Leni Chaudhuri (Member)
- Sarojini N (Member)
- Shyamala Nataraj (Member)
- Sunita S Bandewar (Member)
- Sunita Simon (Member)

## THE EDITORIAL BOARD, IJME -

#### **Editor Emeritus**

Sunil K Pandya

#### Editor

Amar Jesani

#### **Consulting Editor**

Sandhya Srinivasan

#### Working Editors

- Mala Ramanathan
- Sanjay A Pai
- Sunita V S Bandewar
- Vijayaprasad Gopichandran
- Aamir Jafarey, Pakistan
- Aasim Ahmad, Pakistan
- Abha Saxena, Switzerland
- Alok Sarin, Delhi
- Amit Sengupta, Delhi
- Angus Dawson, Australia
- Anurag Bhargava, Mangalore
- Bruno Rodolfo Schlemper Junior, Brazil
- Deepa Venkatachalam, Delhi
- Dhanwanti Nayak, Bengaluru
- Ehsan Shamsi Gooshki, Iran
- Fatima Castillo, The Philippines
- Geeta Vemuganti, Hyderabad
- George Thomas, Chennai

#### Editorial Board, **UME**

- Jacob Leveridge, UKJacob Puliyel, Delhi
- Jacqueline Chin Joon Lin, Singapore
- Jerome Amir Singh, South Africa
- Jing Bao Nie, New Zealand
- Akoijam Joy, Imphal
- Julian Sheather, UK
- Mario Vaz, Bengaluru
- Neha Madhiwalla, Mumbai
- Nithya Gogtay, Mumbai
- Nobhojit Roy, Mumbai
- Prathap Tharyan, Vellore
- Raffaella Ravinetto, Belgium
- Rakhi Ghoshal, Mumbai

- Ravindran GD, Bangalore
- Richard Cash, USA
- Ruth Macklin, USA
- Sabina Faiz Rashid, Bangladesh
- Sanjay Nagral, Mumbai
- Sisira Siribaddana, Sri Lanka
- Sreekumar N, Chennai
- Sridevi Seetharam, Mysore
- Subrata Chattopadhyay, Kolkata
- Sujith Chandy, Kottayam
- Vasantha Muthuswamy, Coimbatore
- Veena Johari, Mumbai
- Vikram Patel, Goa
- Xiaomei Zhai, China

#### **Editorial office**

The editorial office is run by Meenakshi D'Cruz, with Rakhi Ghoshal joining the team from April, 2016. Administrative tasks of both the journal and the FMES are handled by Santosh Tirlotkar.

#### New rented premises

FMES has recently rented premises at No 68, Flat No 2933, Gandhi Nagar, Bandra (East) Mumbai – 400 051. *IJME* hopes to hire more staff who will be required to work out of the office.

## FOREWORD

#### Struggle against odds

The Society and its journal were born after a failed attempt at entering the Maharashtra Medical Council in order to improve its functioning. (See http://www.ijme.in/index.php/ijme/article/view/1668/3600) We have travelled a great distance in the 24 years since they were founded, and the 12-page issue has grown.

The task has not been easy. The *milieu extérieur* in the medical profession was not conducive to discussions on medical ethics. The subject was of negative interest, scorned, and many preferred to ignore its principles or any consideration of them.

Efforts to popularise the journal by sending early issues *gratis* to medical college libraries throughout the country evoked no response. Funds were non-existent, with those working for the fledgling organisation and its journal, spending from their own meagre incomes and working in a purely honorary capacity. The journal was run on personal funds and donations and with voluntary labour.

We were fortunate in having well-wishers who produced the journal free of cost, got this done at their own expense, or provided money for printing, paper and postage. The services of Dr Rajeshwar Singh (of *Prescription*) and Mr Satish Kulkarni (of Parkar Arts) in the production of our earlier volumes were invaluable.

#### Our position today

In 2016, the *Indian Journal of Medical Ethics* is established as the authoritative platform for ethical discussions in India. A comprehensive, open access website gives the journal's content an international reach. The sections of this document after the foreword describe our current position and strengths.

#### Some thoughts on better usage of the journal by society

Over the last 24 years, our editors, their boards and our contributors have created a significant body of knowledge, information, statistics and debate in the volumes published from 1993 to date. The Society has also published separate volumes on selected topics. These could form a continuing source of important educational material on medical ethics, philosophy, medicine, and the law for teachers, students and society at large.

The journal also provides material on current topics with critiques of existing policies and suggested measures for correction where needed. Editors and reporters of our media could use these effectively. In doing so, they will provide their readers and viewers with expert comments and suggestions for improvement.

#### The future

The Forum for Medical Ethics Society needs further healthy growth. The illusion that it is only open to those connected to the medical profession must give way to enthusiastic participation in its activities by judges, eminent lawyers and educationists, concerned experts from the media and, above all, those with the means to effect change for the better. A wide-based group of proven integrity and a will to rectify the sad current state of our medical education and practice can make a big difference.

The journal has proven its merits nationally and internationally. Increasing contributions from other centres on medical ethics in our neighbouring countries and those further afield are encouraging signs.

We need to add to the journal's current strengths. Attempts by the FMES Managing Committee and the *IJME* Editorial Board need to be supplemented. A permanent, well-equipped office and a full range of staff as is commonplace in *Journal of Medical Ethics, Medical Humanities, BMJ, American Journal of Bioethics, Hastings Center Report, Journal of Medicine and Philosophy, Journal of Clinical Ethics* and others, are vital to long-term excellence and progress.

Despite considerable effort and some success and despite the utmost efforts at economy, the availability of funds remains below requirements. The journal has thus far refused advertisements from commercial organisations in order to retain its independence and credibility. Can it continue to do so and yet grow in strength?

The continuing series of National Bioethics Conferences augurs well for the future. University departments, institutions and organisations from different parts of India and abroad are now regular participants. The spread of venues at which these conferences are held – Mumbai, New Delhi, Bengaluru, Hyderabad and now Pune – ensure that local communities are also involved in deliberations. Much good is expected to follow.

Indian participation in the World Congress of Bioethics and the organisation of the event in India in 2018 will provide a much needed impetus to all those in our country working for bioethics. There will be much for us to learn and we hope foreign delegates will also find much that they can take home with profit, especially as regards countries where infrastructure is poor and administration substandard, and where large numbers of the poor must be helped.

#### Sunil K Pandya

Founder Editor, IJME, and Neurosurgeon, Jaslok Hospital and Research Centre, Mumbai.

### **EXECUTIVE SUMMARY**

This Annual Report of the Forum for Medical Ethics Society (FMES) and the *Indian Journal of Medical Ethics (IJME)* for the financial year 2015-16 is aimed at providing our readership and other constituencies insights into our achievements during the year, and the opportunities we optimised to further the bioethics discourse, especially in the context of the developing world.

It was in 1989 that a group of concerned activists and health professionals in Mumbai started to meet to discuss ethical challenges in healthcare. The group registered itself as the FMES in 1993. Over the past 24 years FMES has been able to establish and consolidate two platforms: *IJME* and, since 2005, the National Bioethics Conference.

We report the significant progress made by the journal across several parameters. These include the efforts at *IJME* for upgradation of infrastructure, human resources and the website. Efforts are on to fully utilise and extend the use of available technological resources. We are planning to regularly publish accepted papers in the section 'Online First' towards minimising the waiting time between issues. Two of the four issues published during the year have been theme-based special issues, on the themes 'Trust in healthcare' and 'Healing and dying with dignity'. The profile of readership, contributors and reviewers is increasingly becoming multidisciplinary and global. *IJME* is a peer reviewed and indexed journal.

Going beyond running *IJME*, FMES also felt the need for a more active and inclusive platform, where stakeholders could come together to deliberate, debate and share ideas on ethical issues relating to health, healthcare systems and health research. The result was the biennial National Bioethics Conference (NBC), organised five times between 2005 and 2014, by the FMES-*IJME*, along with collaborating partners. We are poised to organise the 6<sup>th</sup> NBC from January 12 to 15, 2017, on the theme of 'Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia' in Pune, India.

FMES-*IJME* will be co-hosting the 14th World Congress of Bioethics (WCB) in December 2018 in Delhi, in collaboration with Sama – Resource Group for Women and Health, New Delhi. The WCB platform was established by the International Association of Bioethics (IAB) in 1992. The overarching theme of the 14th WCB will be 'Health for all in an unequal world: obligations of global bioethics'. We chose this theme against the backdrop of the colossal global inequities in health and healthcare.

As a collective we have contributed to the bioethics discourse by publishing on various themes in different peerreviewed national and international journals; by presenting our work at conferences and colloquiums; by serving on ethics review boards in India and abroad; by serving as faculty on teaching and training programmes in bioethics; and by participating or leading in relevant campaigns towards strengthening professional integrity amongst the peer community of healthcare professionals, health researchers and biomedical scientists, and others interested in equitable access to quality healthcare.

The report touches upon the ongoing challenges that we confront in sustaining our efforts and maintaining quality with limited human resources and finances. However, we have been able to keep ourselves afloat for over 24 years and have attempted to grow and to enhance the quality of the journal in terms of scope, scale, contributors and reviewers, and timely coverage of time-sensitive matters.

This report is intended to offer the current readership of *IJME* and associates of FMES and the NBC platform critical insights into our activities over the year, and help expand this network towards further enriching the bioethics discourse.

The financial report of FMES-*IJME* for 2015-16 will be published after it has been audited and approved at the FMES Annual General Meeting.

## INTRODUCTION

On behalf of the Managing Committee of the FMES, we are pleased to present this annual report. The report is evidence of the fact that in spite of the tremendous odds it has faced, the Society has managed to endure and expand its sphere of activity.

Over the years, the main focus and energies of the FMES have been engaged in producing and nurturing *IJME*, now a leading journal on bioethics in India and South Asia. However, simultaneously, the Society has been actively pursuing work in the area of bioethics documentation, research and education. Its members have been active participants in various committees including Institutional Review Boards. It has been collaborating with a large number of other groups on areas of joint concern.

One of the major difficulties faced by the Society and its journal has been to find a sustainable funding model. With the substantial and ever increasing costs of producing a high quality print journal and website it has not been easy to ensure a steady source of funds. Most publications dealing with healthcare have easy access to funding from the pharmaceutical and medical equipment industries. FMES/*IJME* has, as a matter of principle, kept away from this source of funds as there is an obvious conflict of interest. Beyond a few staunch well wishers, the healthcare and medical community has also not been very forthcoming with financial support. We feel that this is partly because of our stands on various issues some of which hurt vested interests.

In spite of such limitations, the FMES has managed to make forays into various areas. The years 2015 to 2016 have been particularly significant in terms of a certain revitalisation of the organisation, as well the involvement of many new individuals from diverse backgrounds. We have also been fortunate in receiving substantive funding support for our activities. We could not have survived without the generous grants received from Ms Rohini Nilekani, the noted philanthropist, and from Orient Blackswan Pvt Ltd under its Corporate Social Responsibility policy. We hope that they will continue to support us as they believe in supporting independent and socially committed publications.

We hope and believe that, given this base, we are poised to increase our strength and spectrum of activity in an area which is crying out for intervention.

#### Sanjay Nagral

Chairperson, Forum for Medical Ethics Society, and Consultant Surgeon, Department of Surgical Gastroenterology, Jaslok Hospital and Research Centre, Mumbai.

#### **History of the FMES**

In 1989, a group of concerned activists and health professionals started meeting sporadically, in Mumbai, to discuss ethical challenges in healthcare. Disturbed by the gross erosion of medical ethics and patients' rights; the dysfunctional medical councils; inequities in access to healthcare and the rapid decline in the public health system, the members initially assisted aggrieved patients in their complaints against doctors and supported them in public interest litigation (PIL). The group took an organised first step in 1992, by contesting elections to the Maharashtra Medical Council (MMC). To their surprise, though they lost the election, the group was able to gain more votes than expected and expose the rank corruption in the Council. In the 1998-99 MMC elections, the group revived its old PIL and got the High Court to appoint two independent observers of the elections. The observers' documenting of the malpractices led to the MMC's dissolution.

These successes spurred the group to intervene in many other issues: (a) It provided support to activists protesting (and pursuing a PIL) against the involuntary hysterectomies on mentally challenged women in a public institution in Pune by formulating ethical guidelines; and thus bringing ethics and reproductive health on to its priority agenda; (b) It documented discriminatory practices indulged in by healthcare professionals and institutions during and after the post-Babri Mosque demolition violence in Mumbai. Some of its members also provided testimonies to the People's Commission inquiring into the riots; (c) It brought to the fore in the healthcare discourse corrupt practices in private healthcare, particularly the so-called cut practice in referrals, with laboratories etc. (see: http://www ijme. in/index.php/ijme/article/view/1668/3600); (d) It also helped organise an annual meet of the Medico Friend Circle on ethics in healthcare; contributed to the debate on the need for universal access to healthcare; and so on.

Such activism did not produce immediate results in changing the system except for getting some minor relief, but it made the group stronger. It became clear that achieving reforms in the system was a long-term task which must combine activism with education and sensitisation of health professionals and society. At the same time, the group felt it ought to work for the development of bioethics as a discipline in the medical and humanities curricula.

Thus, from the latter part of the 1990s, while continuing with its intervention in critical health issues, the group committed itself to building a peer-reviewed bioethics journal, encouraging publication of research in the neglected areas of healthcare ethics and human rights. From 2005, it also established a platform for reflection, debate and the coming together of people interested in the improvement of the healthcare system in the form of the National Bioethics Conferences held every two years. So far five such conferences (2005, 2007, 2010, 2012, 2014) have taken

## FORUM FOR MEDICAL ETHICS SOCIETY

place, each attracting between 300 to 700 participants.

## INDIAN JOURNAL OF MEDICAL ETHICS

The Indian Journal of Medical Ethics website makeover, started in 2014, is being expanded. Efforts are on to fully utilise and extend the use of available technological resources. There has been significant progress in the journal across several parameters. The earlier shortage of human resources is being addressed with an additional editorial coordinator joining the editorial office, part-time from April 2016. This is expected to go a long way towards improving the efficiency of the journal.

#### Contents of the journal

Between April 2015 and March 2016, the journal received 198 submissions. Of these, 65 were accepted, 67 were rejected, 19 are with the authors for revision, and 43 are at various stages of the review process. Four submissions were withdrawn by the authors.

All submissions are subject to external peer review, except for editorials which are invited and internally reviewed. The journal has also started to publish fiction and poetry which deal with issues in ethics in healthcare, experiences of healthcare, and related themes.



These are internally reviewed. The time taken to process a submission varies from three days (for cases of obvious rejections) to, in a few cases, up to six months. The gap between first review and publication time has been significantly reduced because of the introduction of the segment 'Online First' which now publishes accepted pieces every 10 days between the regular quarterly issues.

#### **Online First**

The resolution to publish accepted pieces 'Online First' ahead of print was adopted in April 2014. In the year 2014-15, we published nine articles in Online First. In 2015-16, the number went up to 22. We have now decided to publish accepted pieces in Online First thrice a month. Facilitating faster publication would be more author-friendly and also sustain reader interest. This is expected to encourage established authors to submit good quality papers to the journal as they would be confident that an accepted article would be published promptly.

#### What we published

In 2015-16, the journal published a total of 68 items, which included six editorials, 13 articles, 12 comments, two reports, nine book and film reviews, eight letters, three obituaries, two case studies and one item each in the following sections: Students' Corner, Law and Bioethics, Fiction, Ethics of Ethics Committees, and Commentary. Eight pieces were published as part of two theme-based special issues.

*IJME* publishes one or two theme-based issues a year, in which between 20 and 30 pages focus on a specific important theme. Theme-based issues are usually edited by invited guest editors. In the past few years, the journal has published theme issues with a focus on ethics committees; medical humanities; corruption in healthcare and ethical challenges in organ transplantation. The guest editor of an issue is expected to commission papers from authors involved in the theme area. However, all papers, even in theme-based issues, and even those commissioned, undergo the same stringent peer review as do regular submissions.

We published two theme-based issues during the year 2015-2016, on trust in healthcare and on healing and dying with dignity.

a. **Trust in Healthcare** [12(3): 2015]: This issue had three papers that examined the concept of 'trust' in the medical/ healthcare set-up from different vantage points: one interrogated 'trust' in the patient-physician relationship; a second paper developed a scale to measure trust in public health services; and a third discussed the providers' perspective on trust.

b. **Healing and Dying with Dignity** [1(1) NS: 2016]: This theme issue encompassed the range of palliative care, euthanasia and end-of-life care. Five papers examined the caregivers' point of view; access to palliative care in India; passive euthanasia in India; the right to die with dignity, from a legal perspective; and a physician's perspective which focused on recognising medical futility and improving quality of death.

Apart from the specific theme-based issues, other subjects explored in 2015-16 include:

- making medical care rational and affordable;
- palliative care;
- ethics education;
- corruption in healthcare in India;
- assisted reproductive technologies;
- analyses of the 2014 amendment to the Juvenile Justice Act;
- the proposed Medical Termination of Pregnancy Bill, 2014;
- the Allied and Healthcare Professionals Central Council Bill, 2015;
- conflict of interest in public healthcare;
- how provisions of the Right to Information Act may be in conflict with medical ethics;
- prevention of TB among healthcare workers;
- the ethics of carrying out community-based randomised clinical trials among severely malnourished infants;
- the quality of medicines;
- the experience of an ethics committee of the accreditation process of these committees in India;
- the unethical isolation of patients recovered from Ebola infection;
- the Medical Council of India's recent policy shift in the requirements for promotion of medical teachers;
- spirituality and medical practice; and how to handle patients' requests for faith healing;
- workplace safety for women in the medical profession in the context of Aruna Shanbaug's case;
- the development of a system to do away with ragging in a medical college;
- public health perspectives in cross-system practice;
- the duty of a physician in dealing with cases of domestic abuse; and
- misrepresentation of psychiatrists in mainstream Indian cinema.

Some of the subjects covered in research studies are:

- plagiarism and the need to educate medical students about it;
- the best ways of disclosing a diagnosis of severe illness;
- the views of research participants on clinical trials;
- ethical dilemmas faced by dentists, nurses, and trainee psychological therapists, and the awareness of ethics among these professionals;
- perceptions of stigma regarding certain medical conditions among healthcare workers;
- poor doctor-patient communication; and
- medical error during internship.

TABLE 1: AFFILIATIONS OF AUTHORS IN 2015/16												
Issue	Clinicians	Medical instns	Other acad instns	Health NGOs	Students	Govt officials	Research instns	Law	Ethics Instns	IJME / other Jnls	Journalists	Total
Apr-Jun 2015	2	16	1	4	1	_	12	-	-	1	-	37
Jul-Sept 2015	1	12	3	3	1			3	-	-		23
Oct-Dec 2015	3	20	2		8		7		2	2		44
Jan-Mar 2016	10	6	1	3	1	1	2	1		6	1	32
Total	16	54	07	10	11	1	21	4	2	09	01	136

#### Our contributors

We had contributions from authors from all over India and several other countries, including Australia, Belgium, Cameroon, Canada, China, Iran, Italy, Japan, Nepal, the Netherlands, Nigeria, New Zealand, Pakistan, Sri Lanka, Saudi Arabia, Thailand, the UK, the USA and the West Indies. The authors are healthcare professionals, including those from the medical, dental and nursing fields, health researchers, students of medicine, law and the humanities, lawyers, health activists, and government officials.

Apart from medical and research writing, *IJME* has started to encourage authors to submit fiction, fictionalised writing, personal narratives, poetry, views of students (both medical and non-medical). Besides, artists are invited to send in work to be used as cover images. While the journal is not able to pay, it sincerely acknowledges the contribution of the artists. Most of the cover images used in the past year have been contributed by medical doctors and are their original work.

#### **Our reviewers**

We were fortunate in having the support of the following external peer reviewers, including editorial board members, who gave their time and expertise generously through 2015-16: Aarti Prasad, Akoijam Joy, Ali Asghar Lanewala, Alison Thompson, Alok Sarin, Amit Dias, Amit Sengupta, Angus Dawson, Anindita Majumdar, Anoop Thekkuveetil, Asha George, Astrid Lobo Gajiwala, Barbara Klugman, Benson Igboin, Chinu Srinivasan, Deepa Venkatachalam, Divya Bhagianadh, Faisal Khan, GD Ravindran, George Thomas, Gracy Andrew, Harikumar Sivanandan, Hemalata More, Irfan Engineer, Jacob Leveridge, Jamshed Akhtar, Jissa VT, Joe Varghese, Kavita Bhatia, Ketaki Rege, Keymanthri Moodley, K Srinivasan, Lopa Mehta, Mani Kalliath, Manjulika Vaz, Monica Sakhrani, Nabil Mohsin, Nagmani Rao, Nancy Fernandes, Neha Madhiwala, Nilangi Nanal, Nithya Gogtay, Nobhojit Roy, Padmaja Mawani, P Manickam, Paulina Tindana, Priya Ranganathan, Priya Satalkar, Raffaella Ravinetto, Rakesh PS, Rana Muzaffar, Ravikant Singh, Ravi Prasad Varma, Ravi Shankar, Renu Addlakha, RR Kishore, Sana Contractor, Sangeeta Rege, Sangita Patel, Saima Iqbal, Sanish Davis, Santhosh Kumar M, Seetharaman Hariharan, Shyamala Nataraj, Shubha Ranganathan, Siddharth David, Sreedevi Seetharam, Sreelekha Nair, Subrata Mukherjee, Sumit Kane, Suresh Bada Math, Udayan Mishra, Veena Johari, V Raman Kutty, V Sujatha, William Joe, and Zamrooda Khanday.

#### **Our readers**

The *IJME* Facebook page has continued to grow, with a membership of 5,771 (in March 2016), which is a sizeable increase from 2,301 in January 2014. This page has acted as a platform for resources as several members continue to post links to important events, and news updates; and discussion threads are generated on a variety of topical health issues.

The print issue of *IJME* has been an expensive proposition in terms of both printing costs and postage, which is barely covered by the subscription charges. The question of discontinuing the print issue has been considered several times, but the eventual decision has been to continue with it for the time being. Since a substantial proportion of subscribers are medical college libraries and health NGOs working in remote areas with scarce access to power supply and the Internet. If the journal is to reach them, a print issue is necessary, though the situation may have to be reconsidered in future.

#### Analysis of our website usage

The number of sessions in which the *IJME* website was engaged with increased from 17,763 sessions in May-July 2014 to 63,564 sessions for February-April 2016. This represents a three-fold growth in traffic to the website. The number of users (both new and returning) increased from 15,152 in May-July 2014 to 50,168 in February -April 2016. The page views per session have remained a steady 1.8 pages per session. Perhaps users are making use of targeted searches.

During the most recent three-month period, the number of new users has been more or less stable, but the return user component has been steadily rising. This is a desirable trend, indicating that the number of visits tends to increase; both first timers and frequent ones tend to be focused around the publishing of a new issue.

Most of the searches were a result of organic searchers (about 70 percent) in the recent period. Direct searchers were responsible for a major portion of the searches. The most frequently used browser is Chrome, with Android-based searches accounting for less than 2 percent of the searches. However, this could also be reflective of the audience base for the journal, perhaps academics and others who are operating desktops. This is borne out by data, which indicate that 64.1 percent of users are doing so from a desk top. But mobile and tablet-based use is strong and this segment is likely to get more active in the future. The multiple modes of access will improve accessibility to the journal online.

#### Indexing





*IJME* is indexed in PubMed (this began in 2002, but was applied retrospectively to cover all issues going back to 1993). In 2015, The Philosopher's Index (TPI) approached the journal expressing an interest in indexing its data, given the journal's focus areas which closely overlap with concerns in philosophy. Citation data has been sent to TPI beginning from October 2015. They have also agreed to include articles retrospectively from 2011.

#### Editorial team meeting

On June 20 and 21, 2015, the Editorial team of Editor, Consulting Editor, Working Editors and Editorial Coordinator had a two-day long meeting at Mumbai University, Kalina Campus. The costs of the meeting, including travel costs of out-station members, were borne by the participants themselves. All issues pertaining to the running of the journal and related administrative matters were discussed, followed by a discussion of financial and related matters along with the Managing Committee of the FMES, the publisher of the journal.

This meeting helped to formalise and systematise the processes involved in review, correspondence and acceptance of submissions. The institution of the Working Editors' team has helped to decentralise work, increase efficiency, evolve policies collectively, and democratise decision-making in the production of *IJME*. The Working Editors are all

experienced and dedicated ethicists and professionals in their own right, giving their time and expertise on a purely voluntary basis

#### **Conference** participation

*IJME* presented two posters at the International Conference of the World Association of Medical Journal Editors (WAME) organised in New Delhi, from October 1 to 4, 2015. They were on the subjects:

The *Indian Journal of Medical Ethics*. Compiled by Meenakshi D'Cruz and Rakhi Ghoshal, the poster showcased the journal's history since its inception; with tables and charts displaying the highlights of the journal, affiliations of all editors, the country-wise break-up of authors who published in 2015, and break-up of the journal's content.

*Editorial challenges in practice: case studies from the Indian Journal of Medical Ethics.* This poster, coauthored by Meenakshi D'Cruz, Mala Ramanathan, Sandhya Srinivasan, Sunita S Bandewar, Amar Jesani and Sanjay A Pai reflected on some of the key ethical challenges in editorial decision-making, using the case study method. Discussing three cases, the poster also presented the decisions arrived at by the editors in each case, concluding that such dilemmas will help the journal evolve its own guidelines to address similar problems in the future.

## NATIONAL BIOETHICS CONFERENCES

#### An overview

Bioethics has been a dynamic discipline, facing serious challenges due to the slack regulatory environment in India and to the increasing commercialisation of healthcare. Hence, while FMES has published the journal continuously for over two decades, it also felt the need for a more active and inclusive platform, where stakeholders could come together to deliberate, debate and share ideas on ethical issues relating to health, healthcare systems and health research. The result was the biennial National Bioethics Conference (NBC), which will be held for the sixth time in January 2017. This collaborative platform has encouraged new thinking, generated discussion, and actively sought and received feedback from the community of those interested in the ethical practice of healthcare The FMES-*IJME* strives to publish materials presented at the NBCs after peer review, and to involve the participants in its work. For example, 58 of the participants at NBC-1, 73 at NBC-2, 99 at NBC-3, 48 at NBC-4 and 53 at NBC-5 have contributed to *IJME* either as authors or as reviewers. These are participants from several countries including our neighbours Pakistan, Sri Lanka, Bangladesh and Nepal.

#### The first five NBCs

Between 2005 and 2014, the FMES-*IJME*, along with collaborating partners, organised five National Bioethics Conferences<sup>1</sup> as shown in Table 2:

NBC	YEAR	ТНЕМЕ	VENUE	NO. OF COLLABORATING INSTITUTIONS	NO. OF PARTICIPANTS	
1	2005	Ethical challenges in biomedical and social science research	Mumbai	20	317	
2	2007	Moral/ethical imperatives of healthcare technologies	NIMHANS, Bengaluru	38	500	
3	2010	Governance in healthcare	AIIMS, New Delhi	38	350	
4.	2012	Ethics and regulatory challenges in health research	University of Hyderabad, Hyderabad	03*	370	
5.	2014	Integrity in healthcare and research	St John's Medical College, Bengaluru	03	695	
6	2017	Healing and dying with dignity: ethical issues in palliative care, end of life care, and euthanasia	Pune	-	-	

8

<sup>1</sup>All details of past National Bioethics Conferences are available on the IJME website (under the 'Archives menu at http://ijme.in/nbc-20140321/index.php/ nbc-5/index/pages/view/ijme-fifth-national-bioethics-conference-report#)

#### The 6th NBC

The 6th NBC, scheduled for January 13-15, 2017, is on the theme 'Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia'. It will be held at the Management Development Centre, Yashwantrao Chavan Academy of Development Administration (YASHDA), Pune, India. Pre-conference satellite meetings will take place on January 12, 2017. This conference will bring together key stakeholders to examine important and controversial facets of the conference theme.

Palliative care and end-of-life care are two neglected areas, where the extremely inequitable distribution of facilities across the country leaves a large number of patients and their families in tremendous distress. With over a million estimated new cases per year of cancer alone, palliation is becoming increasingly relevant to the larger population with a range of health conditions. While ongoing advances in health technologies offer opportunities for a fresh lease of life to those who can afford them, some new healthcare interventions seem aggressive and unjustified. These create a host of ethical dilemmas regarding when to extend curative care; how to combine it with palliative care; when futility is to be considered and discussed with families and patients; and when to prepare them for end-of-life related matters. The healthcare system and service providers need to be equipped and willing to engage with these areas which are essential for healing and dying with dignity.

The bioethics discourse on end-of-life care and euthanasia is inseparable from right to die and right to life debates and closely intertwined with cultural norms, religious practices/teachings, and the social and legal environment in any specific population. The need to adopt culturally sensitive approaches during end-of-life care in alignment with local philosophical traditions and values is increasingly being acknowledged and advocated for. The existing body of literature from within India and outside, and the existing guidelines developed by professional associations will form the foundation for taking this discourse forward. The contributions to this debate have so far come mostly from practising medical professionals, especially those engaged in palliative care and critical care service provision, who are confronted daily with end-of-life situations. The discussions on these issues should lead to the formulation of appropriate guidelines, policies and laws at the national level, complemented by appropriate implementation and redress systems. This discourse should involve all those concerned and ensure that the ensuing policies and laws are robustly informed by ethics, human and constitutional rights, and insights into religious and community values. The 6th NBC will offer a platform to discuss these themes in healthcare ethics.

#### Co-hosting the 14th World Congress of Bioethics, 2018

The International Association of Bioethics (IAB) has been organising biennial international conferences in bioethics since 1992. Past Congresses have been held in Mexico City (2014), Rotterdam (2012), Singapore (2010), Croatia (2008), China (2006), Australia (2004), Brazil (2002), the United Kingdom (2000), Japan (1998), the United States (1996), Argentina (1994), and Amsterdam (1992). The 13th World Congress of Bioethics is scheduled to be held in Edinburgh in June, 2016 (http://iab2016.com/).

In 2015, the IAB invited proposals from interested organisations across the globe to co-host the 14th World Congress of Bioethics. The overarching theme of the 14th WCB will be 'Health for all in an unequal world: obligations of global bioethics'. This theme was chosen against the backdrop of colossal inequities in health and healthcare. Despite gains in health research, and new discoveries in healthcare , the global community is far from achieving equitable healthcare systems so far. Situating the WCB in the developing world should provide scope for raising philosophical and political issues related to the developing world and its relationship with the developed countries

FMES-*IJME*, jointly with Sama – Resource Group for Women and Health (http://www.samawomenshealth.org/), participated in the bidding process, and were duly intimated by the IAB that they had won the bid. The 14th WCB will be contiguous with the 7th NBC and will be organised in New Delhi, in December 2018. The dates will be finalised later and posted on the *IJME* website.

As the formal co-hosts of the 14th WCB, FMES-*IJME* and Sama have been invited to participate at the upcoming 13th WCB. The following members will attend the 2016 Edinburgh conference:

#### FMES

Sanjay Nagral, Chairperson, Leni Chaudhuri, Member, Managing Committee

#### IJME

■ Mala Ramanathan, Working Editor, Vijayaprasad Gopichandran, Working Editor

#### Sama

Sarojini N, Executive Director, Deepa V, Executive Coordinator

These members will participate in the 13th WCB and formally announce the 14th WCB in the capacity of joint hosts.

## - INITIATIVES TOWARDS FURTHER STRENGTHENING FMES-*UME* -

Starting from December 2014, the newly constituted Managing Committee, along with the core editorial team of *IJME*, undertook activities towards further strengthening the presence of FMES in select campaigns in the domain of health and healthcare. The Managing Committee focused on certain strategic matters to strengthen both FMES and *IJME*. These include enhancing staff strength, strengthening infrastructure, and bolstering its e-platform which is critical to *IJME* given the fact that it is open access and available both in print and digital formats. We were able to implement these with the support of the grants we secured. Below we describe them briefly.

#### The FMES-IJME TechAugment Initiative: strengthening the digital platform

We implemented the TechAugment Initiative to strengthen FMES-*IJME*'s technology platform, one of our priority areas for the next five years. This has been necessitated by important changes in the context of healthcare delivery and health research needs on the one hand, and the ever growing importance of a digital platform on the other.

In May 2015, the FMES Managing Committee submitted an application for funding to Ms. Rohini Nilekani, the noted philanthropist, for continuation of a previous grant received by FMES for the period 2013-14; this second application was also considered favourably and FMES received another grant for the period June 01, 2015 – May 31, 2016. The specific mandate of this grant was to develop the online portal of the journal.

Amongst other tasks, we refurbished and achieved modest modernisation of the website, while keeping it a free, open access journal. This has led to a stable website with improved access for users; a better organised online journal; and the customisation of an open software online manuscript management system. Currently, we are in the process of operationalising a fully functional electronic manuscript submission and tracking system. Building on the existing platform will enable fuller utilisation of the relevant features from within the Open Journal System and the existing FMES-*IJME* e-platform. It will also expand the online user base by promoting the journal via further optimal utilisation of the existing technology tools like Search Engine Optimisation and Search Engine Marketing.

Towards enhancing the e-presence of *IJME*, we have also initiated the assigning to each published manuscript a unique Digital Object Identifier (DOI). Publishing houses, across the globe, are resorting to DOI assignments to ensure that each published piece is available in the web-space permanently, without the risk of losing access in case of migration of the material. The necessary ground work has been completed. This includes acquiring membership to CrossRef who provide the services necessary for DOI assignment; and organising backend work with our web service providers. By the end of 2016, we will be able to start assigning DOI to published work in *IJME* on an ongoing basis for the entire body of materials published over the 24 years of the journal's existence.

We will migrate the front end of the FMES-*IJME* portal to WordPress to further enhance its user-friendly character, leaving OJS only for back-end purposes to optimise its robustness. WordPress is considered to be simpler to use, have more options for improving the appearance of a website, and be more flexible than OJS. It allows for precise search engine optimisation (SEO), lends itself to almost 100 percent customisation of the portal; and allows the organisation team to work independently with the portal without having to be dependent on the web service provider. The necessary work towards this has begun, and we are hopeful of launching . the WordPress front end by December 2016.

In coming times we hope to raise funds to develop a bioethics repository and make it accessible at the FMES-*IJME* portal. Such a repository will contain scholarly contributions on wide ranging topics in bioethics relevant to both global and local issues. We will also create space for blogs, updates on ongoing campaigns and documentation of campaigns from the past. Ideally speaking, we would like the FMES-*IJME* portal to serve as a 'go to' place for the peer community in bioethics and allied fields. Work on collection of resources has already begun.

#### Strengthening of organisational capabilities

The mainstay of FMES and *IJME* has been the sustained voluntary contributions of time, effort and intellectual leadership provided by both members of FMES' Managing Committee and *IJME*'s core editorial team. Although voluntary work has an important place in the organisation's and the journal's activity, their growth has remained somewhat slow paced and limited. Full-time staff are needed to respond to the growing volume of work at *IJME* and for FMES to get involved more actively in research and advocacy in bioethics. Towards this, in this past year, we have been able to raise funds to appoint additional salaried staff. We hope to further increase and enhance human resources for FMES-*IJME*. Currently we have four salaried staff members.

Also, as part of strengthening infrastructure, we have been able to hire office space in Mumbai which will be used as an administrative office and meeting place for FMES-*IJME*; although many will also continue working in virtual spaces to complement office-based staff.

## - CAMPAIGNS, ADVOCACY AND PUBLIC EVENTS

#### Co-organiser of the 8th Krishna Raj Memorial Lecture of the Anusandhan Trust

FMES was a collaborator in organising the 2015-16 Krishna Raj Memorial Lecture on Contemporary Issues in Health and Social Sciences. The lecture was delivered on February 4, 2016 by Dr Eric Suba, Director, Clinical Laboratories, at the Kaiser Permanente Medical Center, USA. Dr Suba also leads the Viet/American Cervical Cancer Prevention Project, a non-profit organisation. Dr Suba spoke on randomised control trials on cancer screening conducted on women from economically marginalised communities in villages and urban slums, in which effective screening techniques were not provided to women in the control arms of the trials. Dr Suba's articles in *IJME* have stimulated extensive debates on the ethical concerns in these trials (http://ijme.in/index.php/ijme/article/view/2072/4511) (http://ijme.in/ index.php/ijme/article/view/2092/4512 and http://ijme.in/index.php/ijme/article/view/2112/4587).

The talk was followed by a discussion on the scientific and ethical issues concerned.

The event was co-organised by Centre for Enquiry into Health and Allied Themes (CEHAT), Mahila Sarvangeen Utkarsh Mandal (MASUM), e-Social Sciences, University of Mumbai, Shreemati Nathibai Damodar Thackersey Women's University, Mumbai, Tata Institute of Social Sciences, Deonar, Mumbai, Seth GS Medical College and King Edward Memorial Hospital, and FMES.

#### CIOMS guidelines: comments by FMES-IJME

The Council for International Organisations of Medical Sciences (CIOMS) 2002 'International Ethical Guidelines for Biomedical Research Involving Human Subjects' was revised by its Working Group, and the revised draft was opened to a public consultation. FMES-*IJME* prepared a section-wise critique and shared it with the CIOMS Working Group.

#### **Expressions of solidarity**

FMES has been a signatory to various statements issued during this period. This includes a protest at the arrest of Dr Saibal Jana, an open letter to the *BMJ* on data sharing, and a joint editorial on the Medical Council of India circular. Links to all these statements are available at: http://www.ijme.in/index.php/ijme

- 1. Editorial on the MCI circular regarding performance assessment: *IJME* along with a number of journals simultaneously published an editorial (Aggarwal R, Gogtay N, Kumar R, Sahni P, Indian Association of Medical Journal Editors. 'The revised guidelines of the Medical Council of India for academic promotions: Need for a rethink'; *Indian J Pharmacol.* 2016 Mar-Apr; 48(2): 111–113. Also available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4825424/)
- 2. BMJ Open letter on data sharing: In November 2015, *IJME* signed an open letter, thereby joining international bioethicists, bioethics journal editors and medical researchers, in making an appeal to presidential candidates in the US, calling for "a statement by all US presidential candidates on whether they support access to clinical trial data held by federal agencies, irrespective of topic, sponsor, country in which the trial was run or results." The letter also asked the candidates about "what measures they would put forward, if elected, to address the scandal of invisible and distorted clinical trials." The open letter was published in the *BMJ* (http://www.bmj.com/content/348/bmj.g2263/rr).

#### Council on Health Research for Development

In 2015, the Council on Health Research for Development (COHRED), Geneva, was working towards developing a protocol to ensure fair, equitable and transparent health research across the globe, named the Research Fairness Initiative. The FMES endorsed this initiative. *IJME* also published a write up, 'Ethics of health research: developing the COHRED Fairness Index' (http://ijme.in/index.php/ijme/announcement/view/7) on the collaborative possibilities of COHRED.

## – CONTRIBUTIONS TO THE BIOETHICS DISCOURSE (2015-16) ——

#### Guest faculty in research ethics training programmes

- Amar Jesani March 28, 2016: training session on "Ethics and abortion: Conscientious objection and sex selection", at a workshop organised by the Asia Safe Abortion Partnership, West End Hotel, Mumbai, India.
- Amar Jesani February 16, 2016: training session on "Police ethics: Ethics in law enforcement and policing" at workshop for senior police persons, organised by the School of Law, Rights and Constitutional Governance, Tata Institute of Social Sciences, Mumbai, India.
- Amar Jesani January 24, 2016: training workshop/lectures for post-graduate diploma students on "Ethics in Social Science Research" at the Department of Civics and Political Science, Mumbai University, Kalina, Mumbai, India.
- Amar Jesani, Sunita Bandewar, Veena Johari, Sandhya Srinivasan January 08-09, 2016: training workshop on "Ethics and regulation of clinical trials in India", organised by the Sama Resource Group for Women and Health at the YWCA, Colaba, Mumbai, India.
- Amar Jesani, Mala Ramanathan December 07- 08, 2015: training workshop on "Ethics in public health intervention research" and "Public health and social science writing skills" for researchers and programme staff at the Narotam Sekhsaria Foundation, Mumbai, India.
- Amar Jesani September 12-13, 2015: presentation on "Ethics, conscience and being pro-choice" at the 3rd Youth Refresher Training Institute, and a presentation in a panel discussion on "Role of healthcare providers in ensuring safe abortion as a human right" organised by the Asia Safe Abortion Partnership, at the Mirage Hotel, Colombo, Sri Lanka.
- Amar Jesani August 12 -13, 2015: presentation on "Ethical dimensions of mentoring", at the Training workshop for mentoring skills for AIIMS faculty members", organised by the Centre for Research and Education for Social Transformation, Calicut, Kerala at the All India Institute of Medical Sciences, New Delhi, India.
- Amar Jesani July 25-26, 2015: presentation on "Publication ethics: Authorship, plagiarism, and scientific fraud", at the "BMJ medical writing workshop", organised by the BMJ at the Bangalore Baptist Hospital, Bengaluru, India.
- Amar Jesani, Mala Ramanathan May 11 15, 2015: "Five day intensive short training course in Ethical Issues in Biomedical Research", organised by the Centre for Ethics, Yenepoya University, Mangalore, India.
- Barun Mukhopadhayay December 2015: presentation on "Ethical issues in biomedical and anthropological research", at a workshop on research methodology, organised by the Department of Anthropology, West Bengal State University, Barasat, India.
- Sanjay Nagral December 11, 2015: talk on End of life care in South Asia' in plenary session on Bioethics in the International Symposium on Transplantation : organised by the Centre for Biomedical Ethics and Culture at the Sindh Institute for Urology and Transplantation, in Karachi, Pakistan
- Shyamala Nataraj December 10-11, 2015: in a Indo US Joint Committee workshop for junior researchers in New Delhi, organised by the ICMR, New Delhi.
- Sunita V S Bandewar September 11, 2015: half-day research ethics workshop for MA students at the Maniben Nanavati Women's College, Mumbai, India.
- Sunita V S Bandewar August 3, 2015: coordinator for a one day research ethics training workshop for research staff of Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai, India.
- Sunita V S Bandewar June 15, 2015: orientation session for members of the Ethics Review Board, Vishwanand Kendra for integrated health research and care (ayurveda, naturopathy, yoga and modern medicine), Pune, India.
- Sunita V S Bandewar February 27, 2015: one-day "Research ethics and regulatory training programme" for members of the research ethics review board members of the Foundation for Medical Research, Mumbai, India.
- Sunita V S Bandewar May 10 and 16, 2016 training programme in Research Methods and Research Ethics for doctoral and post graduate students organised by Political Sciences and Public Administration, Savitri Bai Phule Pune University, Pune, India.

#### Members of committees appointed by the Government of India and allied bodies

- Amar Jesani and Sarojini N January 2016: reconstituted Central Ethics Committee on Human Research of Indian Council of Medical Research, New Delhi, India.
- Amar Jesani and Sarojini N March 29, 2016: third mission meeting of mission steering group of the National Health Mission, Ministry of Health and Family Planning, Government of India, New Delhi, India.
- Sarojini N November- March 2015: sub-committee on Inclusion of Women in Biomedical Research, Indian Council of Medical Research (ICMR), New Delhi, India, as part of its initiative to revise the ICMR Guidelines for biomedical research involving human subjects.

## ANNUAL REPORT: APRIL 2015 – MARCH 2016

Sunita S Bandewar – November – March 2015: sub-committee on research ethics matters in social and behavioural sciences, Indian Council of Medical Research (ICMR), New Delhi, India as part of its initiative to revise the ICMR Guidelines for Biomedical Research involving Human Subjects.

#### Members of Ethics Review Boards

- Amar Jesani serves on
  - ~ The Central Ethics Committee of the Indian Council of Medical Research, New Delhi, since 2016;
  - The Institutional Review Board of the Tata Institute of Social Sciences, Mumbai, since 2015; and
  - ~ The International Ethics Review Board of Medicins Sans Frontieres, since 2010.
- Barun Mukhopadhyay serves as
  - ~ Chairperson, Institutional Ethics Committee, National Institute of Biomedical Genomics, Kalyani, India;
  - Member, Institutional Ethics Committee, Anthropological Survey of India, Kolkata, India; and
  - ~ Member, Institutional Ethics Committee, Indian Statistical Institute, Kolkata, India.
- Mala Ramanathan serves as
  - Member Secretary, IEC-Sree Chitra Institute for Medical Sciences and Research, SCTIMST, Thiruvananthapuram, Kerala, India; and
  - ~ Member, IEC, Health Action by People, Thiruvananthapuram, Kerala, India.
- Sanjay A Pai serves as
  - ~ Member, ICMR Cancer Atlas, Bengaluru, India, since 2016;
  - Deputy Chairman, IRB, Karunashraya Hospice, Bengaluru, India (2010 2015); Member, new committee, now registered, since 2015.
  - ~ Chairman, Institute of Ayurveda and Integrative Medicine [FRLHT], India since 2012;
  - ~ Member, Hindustan Unilever Independent Ethics Committee since 2012;
  - ~ Member, ICMR Regional Occupational Health Centre, Bengaluru, India, since July 2009;
  - Member, IRB, Columbia Asia Hospitals, India (2010 2016); and
  - Member, NU Trust Hospitals, Bengaluru, India (2007 2013); Chairman, (2013 2016);
- **Shyamala Nataraj** serves as
  - ~ Member, Institutional Ethics Committee, National Institute for Research in Tuberculosis, Chennai, India.
- Sunita S Bandewar serves on
  - Foundation for Research and Community Health , Pune-Mumbai, MH, India, since June 2013;
  - European Research Council, European Union, as remote reviewer for its Horizon 2020 program, since 2013;
  - Data Monitoring and Safety Committee for the PREMIUM (PRogram for Effective Mental health Interventions in Under-resourced health systeMs), a partnership between Sangath, Goa, India, and the Centre for Global Mental Health, London School of Hygiene & Tropical Medicine, since March 2013;
  - Data Monitoring and Safety Committee for 'Prevention of depression in later life: A model for low and middle income countries (DIL)'project, Sangath, Goa and Goa Medical College Goa as part of a collaborative international multi-site intervention research, since December 2014;
  - ~ International Ethics Review Board for Medecins Sans Frontieres, Geneva, Switzerland, since November 2006.
- **Vijayaprasad Gopichandran** serves as
  - ~ Member, IRB of Foundation for Research on Health Systems in Bengaluru, India, since 2014.

#### Workshops, seminars, conferences, colloquiums, international visits

- Amar Jesani March 12, 2016: moderated a seminar on 'Controversial cervical screening studies in India', organised by the Papanicolaou Society as a Companion Meeting to the 105th Annual Meeting of the United State and Canadian Academy of Pathology, at Washington State Convention Centre, Seattle, USA.
- Amar Jesani February 06, 2016: was a panellist in a public conversation with Elizabeth Pisani, UK, on the theme, 'Healthy nations: Challenges of global health policies and public health in developing countries', at the David Sassoon Library, the Kala Ghoda Arts Festival, Mumbai, India.
- Amar Jesani February 01, 2016: delivered a public lecture titled. 'Ethics at the time of epidemic and pandemic of communicable diseases: Understanding principles', organised by the Jamshetji Tata School of Disaster Studies at the TISS, Mumbai, India.

## FORUM FOR MEDICAL ETHICS SOCIETY

- Amar Jesani January 27, 2016: presented on 'Introducing new contraceptives in India: Problems, pitfall and ethical challenges', in a parallel group panel discussion titled 'Ethical aspects of introducing new contraceptives in low resource settings', at the International Conference on Family Planning, Nusa Dua, Bali, Indonesia.
- Amar Jesani January 07, 2016: presented a paper titled 'Role of state medical councils in protecting and ensuring rights of patients: Maharashtra Medical Council', at the Western Region Public Hearing on Right to Healthcare, organised by the National Human Rights Commission and Jan Swasthya Abhiyan.
- Amar Jesani November 22-24, 2015: participated and moderated a session at a 'Meeting to develop WHO Guidance on Ethics and Epidemics', organised by the Global Health Ethics Unit, World Health Organisation, Geneva, in Prato, Italy.
- Amar Jesani November 04-06, 2015: participated and presented on '(Un)ethics of inequities: Social and health system determinants of neglect' (on Sickle Cell Disease in India) at a workshop titled '(En)countering invisibility: Critical perspectives of disease, health advocacy and equity', organised by the Department of Health Sciences, University of York, UK, at the Brocher Foundation, Switzerland.
- Amar Jesani September 04, 2015: participated and presented on the 'Ethics in public health research and practice' at the 'Consultative meet on ethics in public health research and practice', organised by Azim Premji University, Bengaluru, India.
- Barun Mukhopadhyay March 5, 2016 and October 5-7, 2015: participated in workshops on 'Promoting Ethics in Medical Practice and Professionalism' jointly organised by the British Deputy High Commission, Kolkata, and the Institute of Health and Family Welfare, Government of West Bengal, India.
- Rakhi Ghoshal June 01-05, 2015: participated at a workshop titled 'Ethical, Legal and Social Issues (ELSI) in Assisted Reproductive Technologies', organised by the Brocher Summer Academy, Geneva, Switzerland.
- Rakhi Ghoshal, Sarojini N and Sunita V S Bandewar February 10, 2016: participated in a workshop titled 'Funding Horizon, India', organised by the Wellcome Trust, New Delhi, India.
- Sandhya Srinivasan March 2016: delivered a talk on ethical concerns in cervical cancer screening research, at a meeting of the International Relations Committee of the Papanicolou Society of Cytopathology, at Washington State Convention Centre, Seattle, USA.
- Sandhya Srinivasan October 01-04, 2015: participated at the WAME International Conference for Medical Journal Editors, New Delhi, India.
- Sanjay Nagral and Sunita V S Bandewar March 15, 2016: delivered talks on end-of-life care at the Dr R N Cooper Municipal Medical College and General Hospital, Mumbai, India, at the Bioethics Unit set up under a Maharashtra University of Health Sciences UNESCO initiative at all medical colleges.
- Sarojini N January 07, 2016: invited to speak on 'Concerns during research on women', at the Annual Institutional Ethics Review Board of Jawaharlal Nehru University, New Delhi, India.
- Shyamala Nataraj April 06-08, 2015: participated at a three-day capacity building workshop for Institutional Ethics Committee members, organised by CReATE in Puduchiry, India.
- Sunita V S Bandewar March 2016: participated and contributed by writing case studies in research ethics for a workshop entitled "Creating and enhancing trustworthy responsible and equitable partnerships in International research (TRUST)", co-hosted by The Forum for Ethics Review Committees in India (FERCI) and The University of Central Lancashire, UK.
- Sunita V S Bandewar February 23-24, 2016: presented a paper at the International Colloquium hosted by Asian Bioethics Review located at the Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore.
- Sunita V S Bandewar May 29-30, 2015: moderated a session titled 'Ethics, Law, and Regulations' in the international seminar 'Bio(medical) economies today: Understanding issues of ethics, markets and labour', organised by Sama Resource Group for Women and Health, New Delhi, India.

#### Publications by members, related to bioethics

- **Bandewar SVS.** Mandatory sex selection test: Constitutionally and ethically unviable. *Girls Count Newsletter*. 2016 Jan-March; Qtr 1(8): 4-5.
- Bandewar SVS, Nagral S. Healing and dying with dignity: Where does India stand? Indian J Med Ethics. 2016 Jan-Mar;1(1) NS: 5-7. Available from: http://ijme.in/index.php/ijme/issue/view/137 (Guest editorial for a theme issue entitled 'Healing and dying with dignity: Ethical issues in palliative care, end-of-life-care and euthanasia'. Part of the preparatory work leading up to the Sixth National Bioethics Conference to be held in Jan 2017 on the same theme).
- Bandewar SVS, Bharat S, Kongelf A, Pisal H, and Collumbien M. Considering risk contexts in large scale HIV prevention: the case of female sex workers in Mumbai and Thane, India. BMC Public Health. 2016 Jan 28;16(1):85. doi: 10.1186/s12889-016-2737-2.

- Bandewar SVS, Pai SA. Regressive trend: MCI's approach to assessment of medical teachers' performance (Editorial). *Indian J Med Ethics*. 2015 Oct-Dec; 12(4): 192-5.
- Bandewar SVS. Access to controlled medicines for pain management and palliative care in India: Gains so far and challenges ahead. *Indian J Med Ethics*. 2015 Apr-Jun; 12(2):77-82. Epub 2015 Mar 23. Available from: http://ijme.in/index.php/ijme/article/view/2197
- **Bandewar SVS.** The draft National Health Policy 2015: Hype, hope and despairs. *eSocial Sciences*. 2015 Feb 01.
- D'Cruz M, Ramanathan M, Srinivasan S, Bandewar SS, Jesani A, Pai SA. Editorial challenges in practice: case studies from the *Indian Journal of Medical Ethics*. Poster at the WAME International Conference for Medical Journal Editors. 2015 Oct 2-4: New Delhi.
- Forum for Medical Ethics Society (Ghoshal R, Bandewar SVS, Sarojini N, Nagral S, Duggal L, Chaudhuri L, Mukhopadhyay B.) National Health Policy 2015: Mapping the Gaps. Econ Pol Wkly. 2015 Sep 5; 50(36):21-23.
- Gaitonde R, **Gopichandran V.** The Chennai floods of 2015 and the health system response. *Indian J Med Ethics*. 2016 Apr-Jun;1(2) NS:71-5.
- **Ghoshal R.** To believe or not to believe: the onlooker's role in cases of sexual boundary violations. *Indian J Med Ethics*. 2016 Jan-Mar; 1(1) NS:60-61.
- Ghoshal R. Economising desire with assisted reproduction in India. Open democracy, free thinking for the world. 2015 Dec 14. Available from: https://www.opendemocracy.net/rakhi-ghoshal/economising-desire-with-assisted-reproduction-in-India
- Ghoshal R. Regularising the fertility market in India. Girls Count Newsletter. 2015 Oct-Dec; Qtr 4(7):7-8.
- Ghoshal R. Bade logon ki tarah: pregnant and poor in the city. Inter-Asia Cultural Studies. 2015: 16(2):160-73.
- **Gopichandran V.** Dawson A. Ethics and the impact of climate change in South Asia. In: Macpherson C, ed. *Bioethical insights into values and policy: Climate change and health.* Springer; 2016.
- Gopichandran V. Faith healing and faith in healing. Indian J Med Ethics. 2015 Oct-Dec;12(4):238-40.
- **Gopichandran V.** Chetlapalli SK. Trust in the physician–patient relationship in developing healthcare settings a quantitative exploration. *Indian J Med Ethics*. 2015 Jul-Sep; 12(3):141-8.
- Gopichandran V. Wouters E, Chetlapalli SK. Development and validation of a socioculturally competent trust in physician scale for a developing country setting. *BMJ Open*. 2015 May 3;5(4):e007305
- **Gopichandran V.** Ethical guidelines for public health in developing countries a review. *Indian J Comm Fam Med.* 2015;1(2):22-7.
- Mariaselvam S, Gopichandran V. The Chennai floods of 2015: urgent need for ethical disaster management guidelines. *Indian J Med Ethics*. 2016 Apr–Jun; 1(2) NS:91-5.
- Nagral S. Medical Council of India under parliament scrutiny symptoms documented, but what about the disease? *Econ Pol Wkly*. April 2, 2016
- Nagral S, Jain A, Nundy S. A radical prescription for the Medical Council of India. BMJ. 2016 Mar 31;352:i1731. doi: 10.1136/bmj.i1731.
- **Nagral S.** Why do Indian medical institutions produce so few research papers? *Scroll.in.* May 2016.
- Nagral S. Ethics in Surgery; In Mishra PK, editor. *Textbook of Surgical Gastroenterology*, New Delhi: Jaypee; 2016.
- Nagral S. Prescription from Pakistan: How one hospital is a model for Asia. *Rediff.com* 2015 Dec 24.
- Nagral S, Nanavati A, Nagral A. Liver transplantation in India: At the crossroads. J Clin Exp Hepatol. 2015 Dec;5(4):329-40.
- Nagral S. The mob versus the doctor. *Mumbai Mirror*. 2015 Jul 23.
- Nagral S. The Indian Medical Association should stop playing victim Wire.in 2015 Jul 20,
- Nagral S. MLK. Indian J Med Ethics. 2015 Jan-Mar;12(1):61-2.
- Nagral S. We need to discuss India's reliance on private medical colleges.BMJ. 2015 Jan 21;350:h237.
- **Srinivasan S.** Ethical challenges in public health research. *Econ Pol Wkly.* 2016 Feb 27; 51(9):23-5.

## National Advisory Committee, *IJME* 6th National Bioethics Conference

#### Dr Raj K Mani,

CEO, Medical Services,

Chairman, Critical Care, Pulmonology and Sleep Medicine, Nayati Healthcare and Research Pvt Ltd, Gurgaon- 122 002 Haryana. India

#### Dr Vasantha Muthuswamy,

President, Forum for Ethics Review Committees, India (FERCI), Former Senior Deputy Director General, and Chief, Division of Basic Medical Sciences, Traditional Medicine and Bioethics, Indian Council for Medical Research, New Delhi, India

#### Dr Thelma Narayan

Director, School of Public Health, Equity and Action, Secretary, Society for Community Health, Awareness, Research and Action, Koramangala, Bengaluru – 560 034 Karnataka, India

#### Prof Dr Sundar Sarukkai,

Professor, Manipal Centre for Philosophy and Humanities, Manipal University, Manipal, Karnataka 576 104 India

#### Ms Vidya Bal,

Founder member, Nari Samata Manch Founder member, *Miloon Saryajani* magazine on women's issues, Pune 411 004 India

#### Dr Soumya Swaminathan

Secretary, Department of Health Research, Ministry of Health and Family Welfare, Govt of India. Director General, Indian Council for Medical Research, New Delhi, 110 029 India

#### Dr M R Rajagopal,

Chairman, Pallium India Director, Trivandrum Institute of Palliative Sciences, Thiruvananthapuram – 695 008 Kerala, India

## Conference Organisers

The 6th National Bioethics Conference to be held in Pune, Maharashtra, has been jointly organised by FMES / IJME and MASUM.

#### FMES-IJME

**The Forum for Medical Ethics Society (FMES)** was founded in 1989 and registered as a Trust and a Society in 1995. FMES seeks to highlight issues in medical ethics and bioethics, and generate discussion around them.

*Indian Journal of Medical Ethics (IJME)*(www.ijme.in/) has been published by FMES since 1993. IJME is the only indexed, peer-reviewed open access journal on bioethics and medical ethics published from India.

#### Mahila Sarvangeen Utkarsh Mandal (MASUM)

MASUM (http://www.masum-india.org.in/) founded in 1987 and based in Pune, is committed to women's rights within and outside the home. It works with a feminist perspective and a human rights approach, on the understanding that people can resolve their own problems collectively. MASUM focuses on advocacy for women's rights and physical and mental health, and on strengthening people's perspectives on democracy, equality, secularism and social justice.

## **Conference Organising Committee**

The Conference Organising Committee of the Sixth National Bioethics Conference consists of the following representatives from FMES-*IJME* and MASUM:

Dr Hema Pisal, Project Coordinator, Health, MASUM

**Ms Leni Chaudhuri**, Member, FMES managing committee, and Programme Manager, Health, Narotam Sekhsaria Foundation

Dr Ramesh Awasthi, Co-convener, MASUM

Dr Sanjay Nagral, Gastrointestinal Surgeon, Chairperson, FMES,

Dr Sunita V S Bandewar, Independent Research and Ethics Consultant, Working Editor, IJME, Member, FMES Managing Committee

**FIRST ANNOUNCEMENT: Block the dates** 



Indian Journal of Medical Ethics (www.ijme.in)

## 6<sup>th</sup> National Bioethics Conference 2017

- THEME -

## Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia

DATES AND VENUE -

Pre-conference satellite meetings: Thursday, January 12, 2017 Main Conference: Friday-Sunday, January 13-15, 2017 YASHADA, Baner Road, Pune, Maharashtra, INDIA

- CONFERENCE HOSTS AND COLLABORATORS



INDIAN JOURNAL OF MEDICAL ETHICS JOURNAL OF THE FORUM FOR MEDICAL ETHICS SINCE 1993

ONLINE ISSN 0975-5691 PRINT ISSN 0974-8466



Forum for Medical Ethics Society (FMES), Indian Journal of Medical Ethics (IJME) (www.ijme.in)

&

Mahila Sarvangeen Utkarsh Mandal (MASUM), Pune (www.masum-pune.org.in)

Five plenaries will be woven around the sub-themes – Palliative care, End-of-life care and Euthanasia - of the conference. However, oral presentation of papers, poster presentation, workshops, and symposia will be open to topics from within the broader discipline of bioethics, including the conference sub-themes. More information on the conference will be soon available on the website of the journal (www.ijme.in)



www.ijme.in A platform for informed discussion on healthcare