

# Strengthening Health Care Ethics: A Multi-Disciplinary Engagement with Diverse Constituencies Related to Health and Health Care

(August 2018 to July 2019)

Grant Ref No/Proposal Id: TEDT/MUM/HEA/FfMES/2018-2019/0048/sa

## Highlights of the Initiative and Achievements



Forum for Medical Ethics Society's  
Health, Ethics, and Law (HEaL) Institute for  
Training , Research and Advocacy  
Enabled and Seeded by Tata Trusts via this grant



Supported by

**TATA TRUSTS**

# About Us

Briefly about us before we present the achievements on the initiative supported by Tata Trusts

(You may watch the embedded video of one minute long about FMES shot in 2016)

# FMES at a glance

- ▶ Life span: Quarter century
- ▶ Overall goals: To work towards enhancing ethical practices in health and allied theme with regards to policy, research, clinical care, and public health
- ▶ Organisational Structure
  - ▶ Current: Registered Society, Managing Committee (MC), IJME Editorial staff and admin-finance human resource primarily governed by and overseen by the MC
  - ▶ Aspirational: Director/Coordinator, Project staff, expanded admin-finance unit wherein MC will be taking a backseat and work towards help strengthen this expanded organizational structure
- ▶ Present activities: IJME & NBC; advocacy and campaigns; bioethics trainings, public engagement on bioethics matters
- ◉ Future plans: Further strengthening of current activities; expanding FMES scope of work to research, advocacy, intervention-research, institutionalizing bioethics training program, innovative e-platforms for health news analysis, critique

# Do we matter?: Salience & shifting landscape

## FMES

Essential for the existence of IJME and NBC

Increasingly involved in active advocacy initiatives independently or collaboratively

Aspires to respond to issues by undertaking research , policy analysis & shaping ethics related regulatory frameworks

Aspires to institutionalise bioethics training

Preparation on for 6<sup>th</sup> NBC in Pune in Jan 2017

Won the bid to host 14<sup>th</sup> World Congress of Bioethics in Dec 2018 jointly with 7<sup>th</sup> NBC

## IJME

Platform for critical reflections, debate, self & peer learning,

When no players were there we initiated ethics training activities in research and clinical care

Scholarship in bioethics in systematic form was not available, we made significant contribution

It serves as a bridge between academia and advocacy initiatives informed by grassroots players & their work

Impact on practice & policy

## NBC

A response to the need for a more active and inclusive platform

Enabled direct dialogue across disciplines

Attracts younger practitioners, scholars and advocates

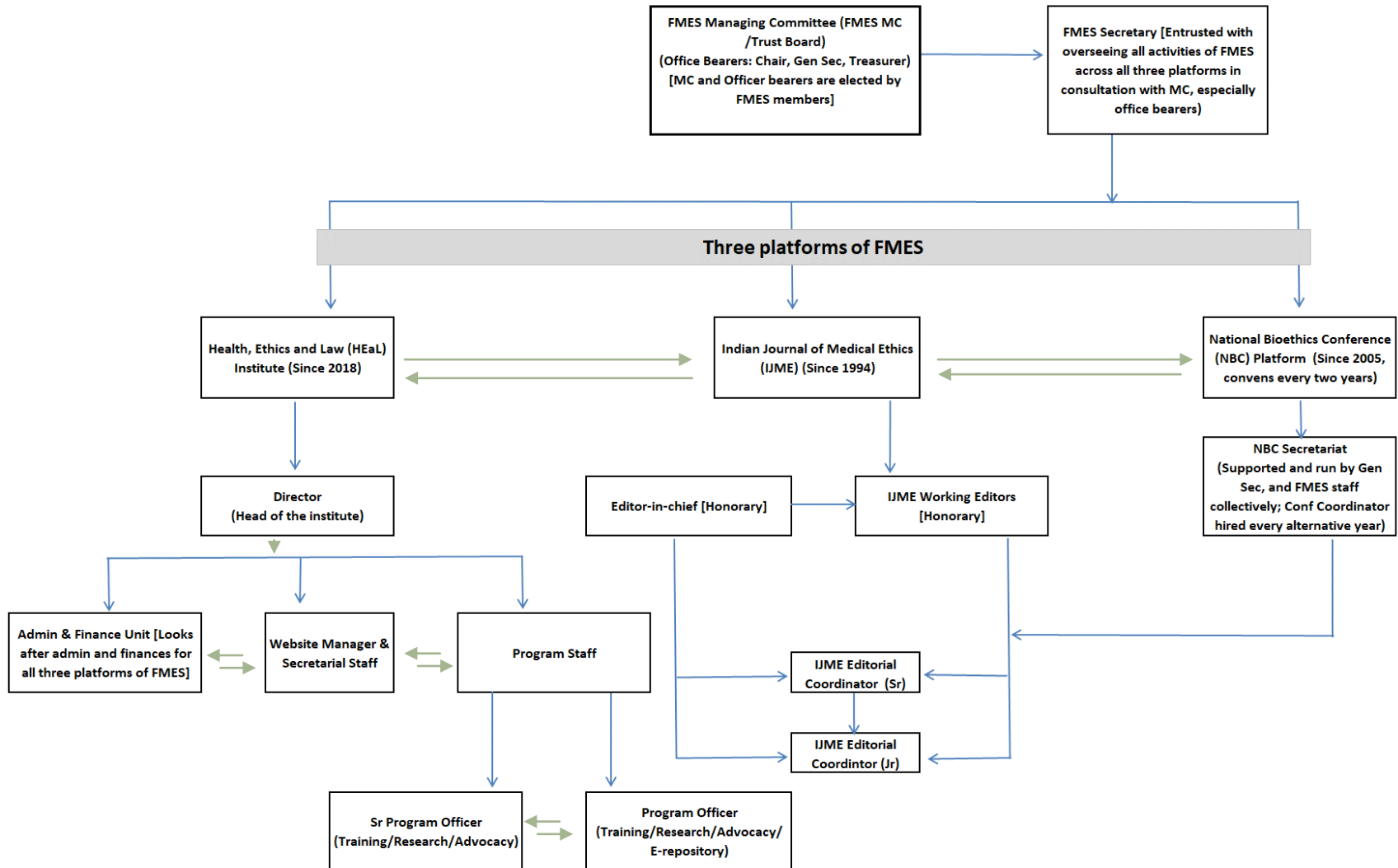
Enabled networking

Enabled exploration of newer areas and focused debate on contemporary pressing issues in bioethics



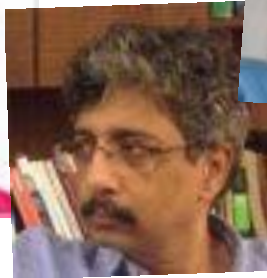
**Added a third platform to FMES - HEaL**  
**Institute for Training, Research and Ethics**  
**Enabled and seeded by Tata Trusts**

## FMES (HEaL, NBC and IJME platforms) ORGANOGRAM



# FMES' HEaL Institute: MC & Lead & Team

## Managing Committee



## Managing Committee

1. Dr Sanjay Nagral (Chair)
2. Dr Sunita Bandewar (Gen Sec)
3. Lubna Duggal (Tresurer)
4. Barun Mukhopadhyaya
5. Sunita Simon
6. Shamim Modi

## Lead



## Lead

Dr Sunita Bandewar

## Team



## Team

1. Mahendra Shinde
2. Navneet Wadkar
3. Nikita Surani
4. Shahnawaz Islam
5. Vijay Sawant

# Strengthening Health Care Ethics: A Multi-Disciplinary Engagement with Diverse Constituencies Related to Health and Health Care

(August 2018 to July 2019)

Located at  
FMES' Health, Law, and Ethics Institute for  
Training, Research and Advocacy  
Enabled and Seeded by Tata Trusts



# Goal and Specific Objectives

## Goal

To build and strengthen the ethical fabric of healthcare systems and health professionals for a patient-centered healthcare system, through strategic networking, and public engagement with constituencies related to health care service provision via the two established platforms of FMES - IJME and NBC.

## Specific Objectives

**Objective 1:** To set up bioethics training program (certificate and diploma) in three major streams - clinical ethics, biomedical research ethics, and public health and social sciences research ethics - in collaboration with one or two academic entities/universities.

**Objective 2:** Public engagement with individuals and the leadership of associations of the health professions (doctors, nurses, chemists etc); other wide ranging allied fields, such as, biomedical sciences including environmental sciences, law, social sciences, humanities; and civil society organizations (NGOs) who have a significant role to play in strengthening medical and healthcare ethics and influence related policies in India.

**Objective 3:** To create a systematically organised repository of material on medical, healthcare ethics and bioethics in the form of books, guidelines, manuals, case studies as well as papers from other journals as part of the ongoing effort for awareness and consciousness building.

**Objective 4:** To further strengthen the digital marketing of *IJME*.

# Objective 1

## Commitments | Deliverables

- To set up bioethics training program (certificate and diploma) in three major streams - clinical ethics, biomedical research ethics, and public health and social sciences research ethics - in collaboration with one or two academic entities/universities.
- Four trainings committed in collaboration with other institutes/organizations

## Status on July 31, 2019

- Organized three of four
- In collaboration with five collaborating institutes
- Three curriculs developed and implemented
- One draft curricula developed, require further work
- Clinical Ethics case studies booklet developed (**not committed**)
- Case studies in public health ethics materials developed; require more work (**not committed**)

## Forthcoming beyond July 31, 2019 (being conceptualized)

- Two deemed to be universities expressed willingness to introduce some of these trainings as university recognized certificate programs
- Research ethics in social sciences and public health training (5 days) with Centre for Policy studies, IITB, Mumbai early 2010
- Ethics of Implementation Research Training in collaboration with WHO, Geneva for South-Asia and/or South-East Asia with involvement of other govt institutions in India - early 2010
- Request for developing curriculum for nursing ethics
- Request for developing curriculum for ethics for staticians

# BIOETHICS TRAINING PROGRAMS

## Three Short-Duration Intensive Training Programs Concluded

(Aug 2018-July 2019)



32  
Trained

### SOCIAL SCIENCE AND PUBLIC HEALTH RESEARCH ETHICS

*Bhubaneswar - June 2019*

*Collaborators: ICSSR-Nabakrushna Choudhury Centre for Development Studies, Bhubaneswar*

19  
Trained

### BIOMEDICAL RESEARCH ETHICS

*Kolkata - June 2019*

*Collaborators: Calcutta School of Tropical Medicine, Kolkata  
ICSSR-Nabakrushna Choudhury Centre for Development Studies,  
Bhubaneswar*

23  
Trained

### PUBLIC HEALTH ETHICS

*Mumbai - July 2019*

*Collaborators: ICMR-National Institute of Epidemiology, Chennai  
Centre for Public Health, Tata Institute of Social Sciences, Mumbai  
Centre for Policy Studies, Indian Institute of Technology Bombay, Mumbai*

# Glimpses into course participants' views

“It was a wholesome learning experience.”

“I gained a new perspective on research ethics.”

“Large number of case studies and discussions are very useful. If more numbers are included than it will be very beneficial for us.”

“It has been helpful to me as an individual to understand that how to deal with theory and practical aspects of ethics in public health.”

“The knowledge will be helpful to design a research protocol, and assess risk-benefit factors in a particular research.”

“Learnt better about composition and functioning of ethics committees.”

“As a newly inducted ethics committee member I learnt how the meetings should be held and how the decision is arrived at.”

“Learnt about epidemiology and its approaches about which I did not have much exposures earlier.”

# Learnings from trainings conducted

- A couple of course participants expected some more support regarding logistics
- More videos and film screening
- More small group based learning using case studies
- Duration of training program could be increased

# Objective 2

## Commitments | Deliverables

- Public engagement with individuals and the leadership of associations of the health professions (doctors, nurses, chemists etc); other wide ranging allied fields, such as, biomedical sciences including environmental sciences, law, social sciences, humanities; and civil society organizations (NGOs) who have a significant role to play in strengthening medical and healthcare ethics and influence related policies in India.
- **Six grand rounds**
- **Two round tables**
- **One essay competition**

## Status on July 31, 2019

- Five grand rounds organised
- Four round tables organized
- One essay competition concluded

## Forthcoming beyond July 31, 2019

- Three grand rounds
- Will continue essay competition
- Round table on ethics of sport medicine being discussed

# PUBLIC ENGAGEMENT

## Round Tables

Organised so far: **Four** (February (1), June(2), & July 2019 (1))

## Grand Rounds

Organised so far: Five (Mumbai)

Upcoming: Sept 2019 (Chennai); Sept 2019 (Mumbai);  
June 2020 (Delhi)

## Essay Competition

All India level; April to July 2019

Internship of awardees completed. Was well received  
Awardees were mentored by members of the selection  
committee. Revised manuscripts (4) are being copy  
edited to put on website.

## 4 Round Tables

122  
Participated

- ▶ Death Penalty in India: Legal, Ethical, and Health Issues
- ▶ Indian Philosophical Traditions
- ▶ Publication Ethics Governance and Policies for Academic Journals
- ▶ Emerging AI Technology in Health Care in India, Health Equity, and Justice: Critical Reflections and Charting Out Way Forward

## 5 Grand Rounds

378  
Participated

- ▶ Grant Medical College and Sir Jamsetjee Jeejeebhoy Hospital: Foundation, Renown, and Decline
- ▶ Response of Bioethics Community to #metoo Movement and History and Evolution of International Association of Bioethics (IAB)
- ▶ Emerging Infectious Diseases and the Impact of Behaviour on Amplification and Spread of Diseases during Outbreaks
- ▶ The Case of the Spurious Drug Kingpin: Shifting Pills in Chennai
- ▶ 127<sup>th</sup> WHO Global Health Histories Seminar - Towards Universal Health Care: History of 'Health for All' Struggles in India





# Round tables supported by research pieces (not committed)

- ▶ **Death Penalty in India: Legal, Ethical, and Health Issues:**
  - ▶ Was essential to undertake both desk work to conceptualize the round table; of relevance but almost no work in Indian context
  - ▶ Complemented by designing an online survey
  - ▶ Will be completing the work and publishing the same
  - ▶ A manuscript based on proceedings of the round table drafted
- ▶ **Emerging AI Technology in Health Care in India, Health Equity, and Justice: Critical Reflections and Charting Out Way Forward:**
  - ▶ Relevant and requires more work to be done in this area
  - ▶ A manuscript developed and will be submitted to peer reviewed journal. This was done as part of the preparation for the grand round.
  - ▶ Wrote two grants on this topic. Outcome awaited
  - ▶ Will be included in our new grant to Tata Trust that is being conceptualized
  - ▶ Round Table proceedings report being finalized
- ▶ **Ethics of Health Journalism (could not take place):**
  - ▶ Relevant, requires more work and training of health journalists
  - ▶ Both desk work and small scale qualitative research was conceptualized
  - ▶ Will be writing it up and publishing
  - ▶ Will be included in our new grant to Tata Trust that is being conceptualized

# Public Engagement Success and Learnings

*“Good content and good delivery.”*

*“The lecture was very engaging.”*

*“Very informative.”*

*“A bigger space should be a better option.”*

*“After lecture gained more knowledge in bioethics.”*

*“Can be videographed as a story.”*

*“Learned more about politics of drug quality.”*

*“Interesting series of more such lectures are required.”*

*“An interesting take on legal aspects.”*

# Essay Competition

35  
Essays

**4** Winners

**3** Runners-Ups

- ▶ Theme 1: Artificial Intelligence in Health Care
- ▶ Theme 2 : Role of Health Professionals in Death Penalty
- ▶ Theme 3: Health Journalism

3 Winners of Essay  
Competition  
completed one-  
week internship  
with Jan Swasthya  
Sahyog

Essays of 2  
Winners and 1  
Runner-Up  
submitted as  
manuscript to  
IJME

# Objective 3

## Commitment | Deliverable

To create a systematically organised repository of material on medical, healthcare ethics and bioethics in the form of books, guidelines, manuals, case studies as well as papers from other journals as part of the ongoing effort for awareness and consciousness building.

## Status on July 31, 2019

- Tech partner contribution
  - E-repository platform technical work completed by tech partners
- In-house contribution
  - 1555 sources slated for posting on the repository
  - This involved searching, screening, classifying, and organizing them to be posted on the e-repository
  - 100+ pieces posted
  - Will be completing these in-house work in the coming times

# E-Repository (1555 resources)

Type of resources	Number
Documentaries	50
Books	25
Journal articles	25



FMES[E-repository - navneet.wad] x eRepository (under construction) x

Not secure | erepository.fmesinstitute.org

Apps ★ Bookmarks 🔍 Big Data, Data Mini... Social Network Ana... Statistics: Making S... Library Genesis Resources to help y... Committee Report... Purpose of Guide ...

Home Browse Help Search DSpace Sign on to: -

## eRepository

eRepository (under construction)

### Communities in DSpace

Choose a community to browse its collections.

- Books**
- Documentaries**  
This documentary collection contain documentaries on clinical ethics, research ethics and public health ethics
- Journal Articles**

### Discover

Author	Subject	Date issued
Caplan, Arthur L. 4	Ethics 12	2010 - 2017 11
Archard, David 2	Euthanasia 10	2000 - 2009 16
Emanuel, Ezekiel J. 2	Doctor and Patients Relationship 8	1990 - 1999 9
Grady, Christine 2	End of Life 8	1980 - 1989 15
Gross, Michael 2	Dignity of Patients 7	
Holmes, Helen B. 2	Medical Practice 7	

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# Objective 4

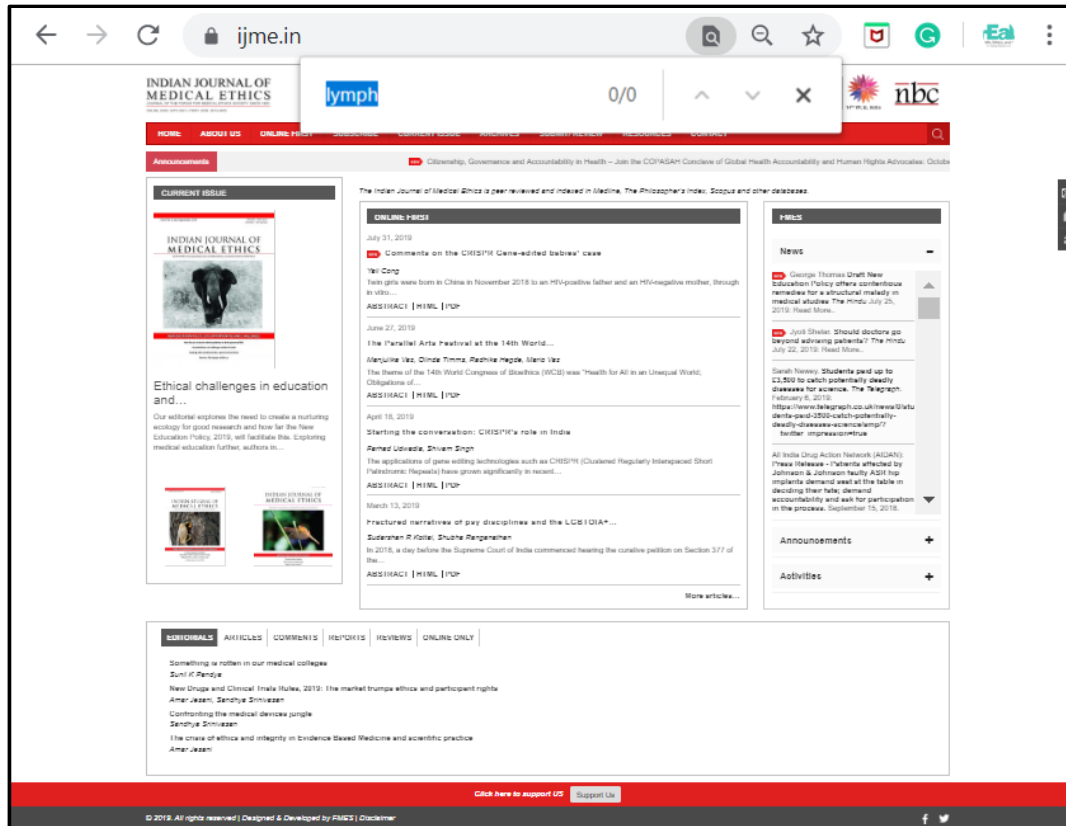
## Commitments | Deliverables

To further strengthen the digital marketing of *IJME*.

## Status on July 31, 2019

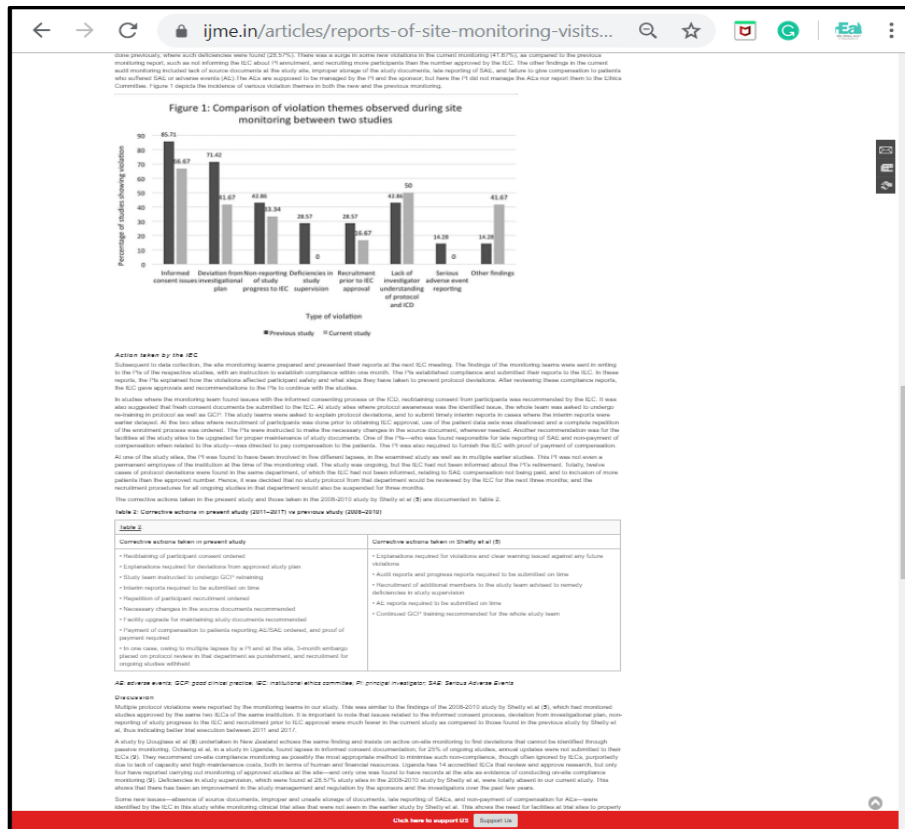
- Work by technical partner is done
- Involved extensive backend technical work by the tech partners
- In-house work continues
- Dedicated website for HEaL (not committed)

# Strengthening IJME Platform



- Improvements in the design and layouts of the IJME website.
- Improve responsiveness and user experience of IJME for small screen devices.
- XTML generation automated
- Article metrics
- Capacity building of FMES colleagues enabling transitioning to in-house operations of IJME, HEaL Website and eRepository platform

# Strengthening IJME Platform

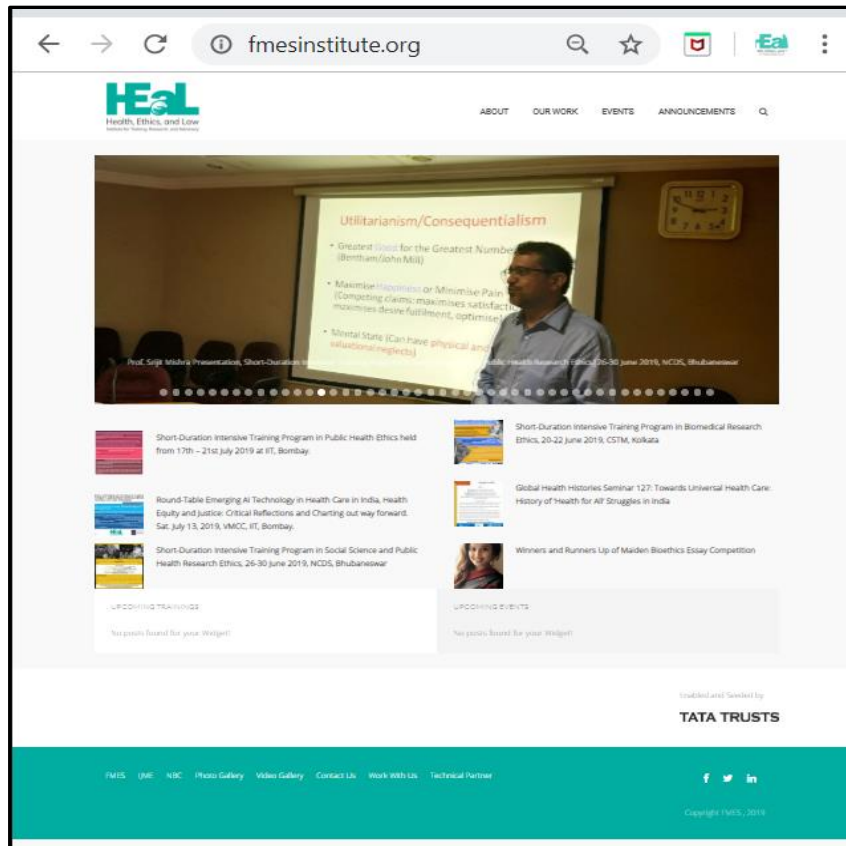


- Improvement in marketing of IJME website to increase the number of users and page views.

Indicator	2016-17	2017-18	2018-19
Users	133207	156659	288962
Page views	324073	377224	554739



# New Dedicated Website for HEaL Institute (1)



- Separate website for FMES' HEaL Institute enabled and seeded by Tata Trusts via this grant (Aig 1, 2018 - July 31, 2019).
- Helps establish HEaL's own identity independent of FMES' two other established platform, namely, IJME, and National Bioethics Conference platform

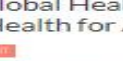
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[Health, Ethics and, Law / Posts / Page / Public Engagement / Global Health Histories Seminar 127: Towards Universal Health Care: History of 'Health for All' Struggles in India](#)

## Global Health Histories Seminar 127: Towards Universal Health Care: History of 'Health for All' Struggles in India

RDH



On June 18, 2019, Forum for Medical Ethics Society (FMES), Mumbai organized the 127th WHO Global Health Histories seminar in collaboration with Centre for Global Health Histories (CGHH), University of York, United Kingdom, the Centre for Law and Society, School of Law, rights and Constitutional Governance & the Centre for Public Health, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai, and Centre for Policy Studies, IIT Mumbai.

The seminar was addressed the theme 'Towards Universal Health Care: History of 'Health for All' Struggles in India'. It was divided into three sessions with presentations and Q&A rounds, wherein the attendees could get informed about the various topics by the presenters, and then ask pertinent questions regarding the topics.

In the first session Arun Joshi, Editor, Indian Journal of Medical Ethics gave a presentation on 'From Committee to Action Declaration: Towards 'Health for All' wherein he presented the history of the movement towards the goal of 'Health for All'. He began by speaking about the community health plans that had been a success at the local project level but could not be a success at a national program level because of lack of support at the federal level. He stated that the issue was often about providing of care at the secondary and tertiary level, and that a view had been articulated that primary care could be provided by public health while secondary and tertiary care could be provided by private health sector. This led to private sector growing stronger while the public health system stagnated. He also spoke about the recommendations of the Shree Committee (1946), the Alma-Ata (1978) and Astana (2018) declarations. Arun Joshi, National Convener, Peoples Health Movement-India, Pune, spoke on 'History of Peoples Health Movement-India and PMs Peoples Health Manifesto'. He spoke about the trend of the governmental budget of the primary health services going down. He spoke about 'Social Medicine' that centered around the idea of going to the poor without taking from anyone, steering it to making medicines without breaking eggs. He also discussed the need to educate people about their rights when taking private health care while maintaining that it was necessary to develop the public health sector. The presentations were followed by a Q&A round. During the Q&A, in response to a question on how to engage with CSR and the funding that came with it, Arun Joshi touched upon CSR actually means services, what it is doing done in the name of CSR, in response to a question on health insurance, Arun Joshi shared the relationship of health insurance and the terrible state of public health care in villages, funded some and publicly available top notch whereas an individual solved a problem in response to a public medical problem that allowed the individual to cope with the societal problem without solving it.

In the second session, Ron Guggel, independent researcher and Health Activist, Mumbai gave a presentation on 'The Political Economy of Healthcare Financing in India: Saying No to Insurance, which included the historical antecedents of health financing in India. He articulated about the historical antecedents of health financing in India, and compared the state of private health care in the 1970s to the current political economy of health care. He shared strongly against young people taking health insurance while pointing out that the elderly who needed it were not given it or had to pay high premiums for it. He gave the example of the US where the prevalence of health insurance had slowed the cost of health care because the health companies could successfully charge the patient based on how much money the policy could pay the practitioners or institute. Following his presentation, Sakshana Kishor presented on 'Data on Equity, access and utilization in the state funded universal health insurance schemes: implications on tribal groups. She gave examples of tribal tribal who had not been able to take advantage of the publicly funded health insurance, and how out-of-pocket expenditures will increase. Meanwhile, those who did manage to avail of the PM-JAY considered it to be a form of discounting of costs rather than an complete doing away of the financial burden of illness.

**Activities:**

1. Flyer
2. Program schedule
3. Photo Gallery
4. GHHS Seminar 127: History of 'Health for All' Struggles in India - Video (Part 1), (Part 2)

Supported by Tata Trusts

[READ PREVIOUS:](#)
[List of Participants for the Short Duration Intensive Training Program in Public Health Ethics to be held from 17th to 21st July 2019 at IIT Bombay.](#)

[READ NEXT:](#)
[Short-Duration Intensive Training Program in Public Health Ethics held from 17th-21st July 2019 at VHHS, IIT Bombay.](#)

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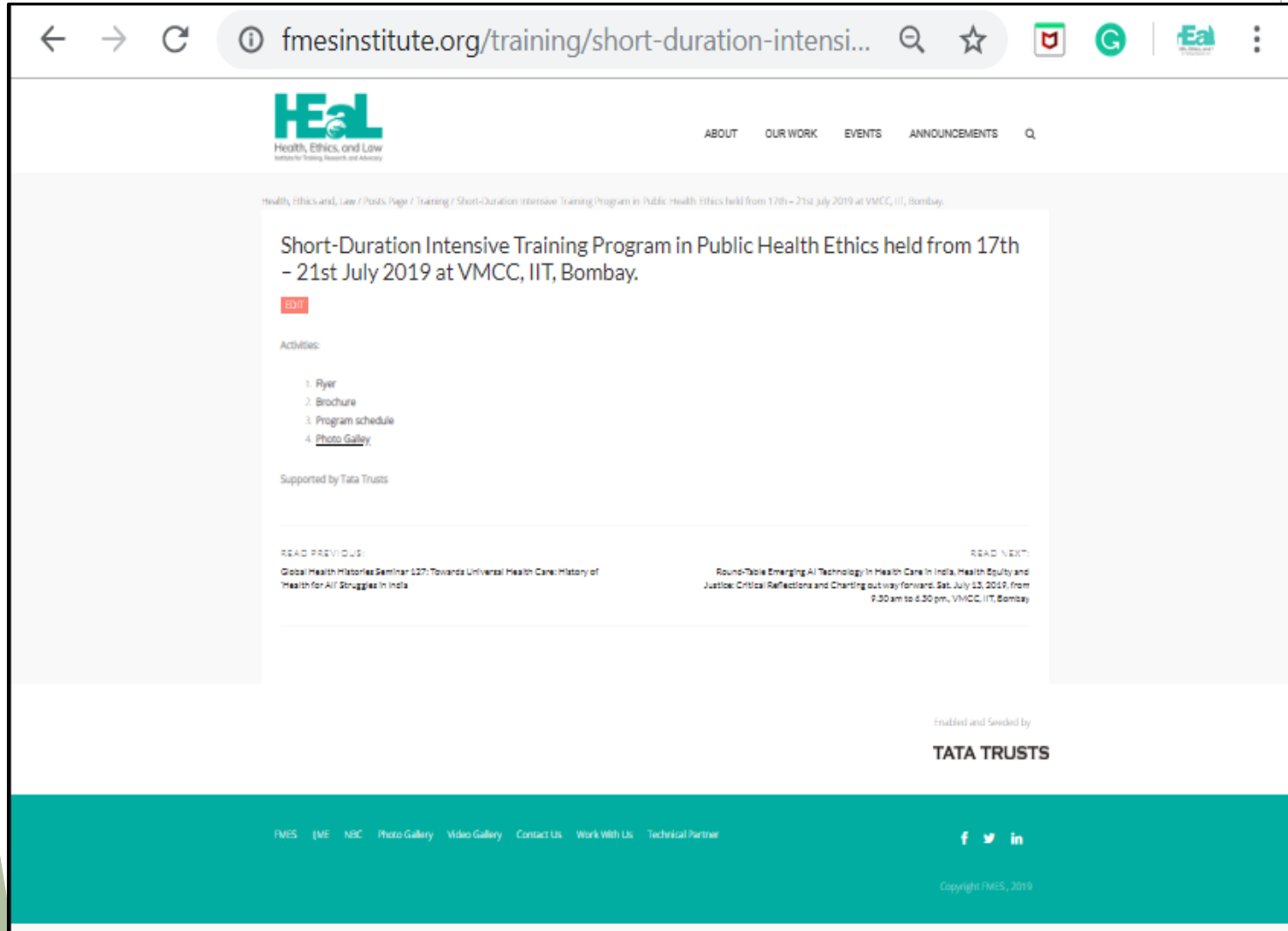
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# New Dedicated Website for HEaL Institute (3)





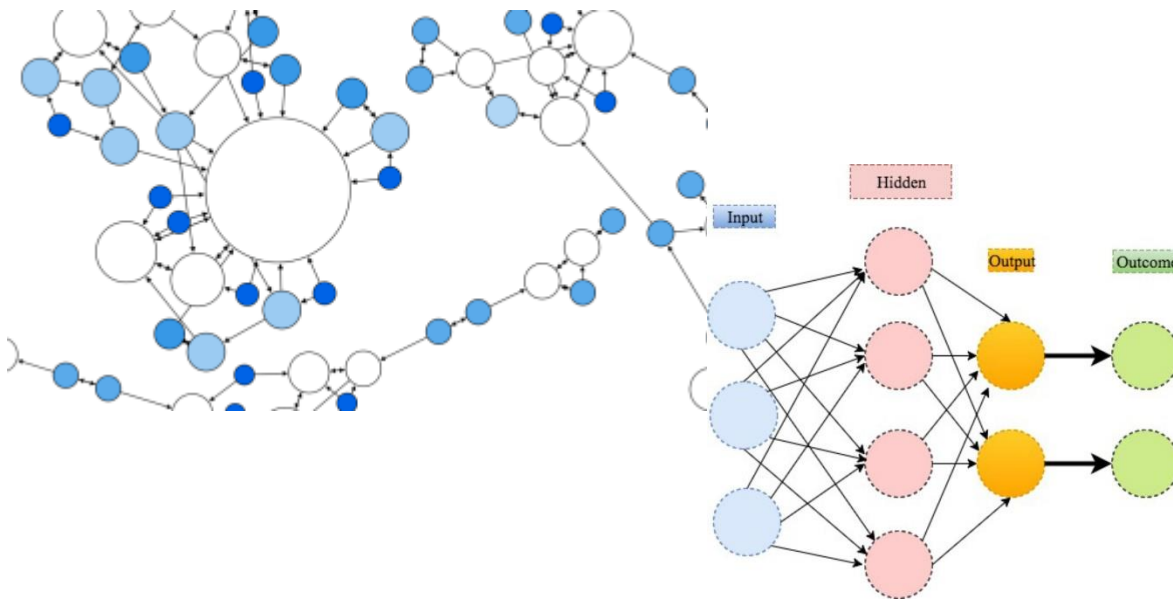
# Utilization of funds

(Aug 2018 - July 2019)

# Strengthening Healthcare Ethics Initiative Supported by Tata Trusts

Grant Period: August 1, 2018 to July 31, 2019

Sr. No	Budget Head	Total Trust	Actual	% Out of Total Trust	Variance till date in %
1	PERSONNEL	38,16,000	34,40,800	45.77	9.83
2	CAPITAL	12,60,000	9,35,146	15.11	25.78
3	PROGRAM COST	25,06,300	17,97,208	30.07	28.29
4	Total Budget	75,82,300	61,73,154		
5	Overhead 10 %	7,54,130	7,46,809	9.05	0.97
6	GRAND TOTAL	83,36,430	69,19,963	100.00	16.99



# Building Network: Institutions, Experts, Peers



# Collaborating Entities

1. Calcutta School of Tropical Medicine (CSTM), Kolkata, WB
2. Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai, MH
3. Centre for Law and Society (CLS), Tata Institute of Social Sciences, Mumbai, MH
4. Centre for Mental Health Law and Policy (CMHLP), Indian Law Society, Pune, MH
5. Centre for Policy Studies (CPS), Indian Institute of Technology Bombay, Mumbai, MH
6. Centre for Public Health (CPH), Tata Institute of Social Sciences, Mumbai, MH
7. Department of Humanities and Social Sciences (D-HSS), Indian Institute of Technology Bombay, Mumbai, MH
8. eSocial Sciences, Mumbai, MH
9. Indian Council for Medical Research - National Institute of Epidemiology (ICMR-NIE), Chennai, TN
10. Indian Law Society (ILS) Law College, Pune, MH
11. Jan Swasthya Sahayog (JSS), Ganiyari, Bilaspur, Chhattisgarh
12. Nabakrushna Choudhury Centre for Development Studies (NCDS), an Indian Council of Social Sciences Research (ICSSR), Bhubaneswar, Odisha



# Scientific and Ethics Advisory Group(SAG) and Affiliates/Subject Experts

Tejal Barai



Dr Anant Bhan

## SAG

1. Tejal Barai
2. Dr Anant Bhan

## Affiliates

1. Supriya Subramani
2. Amita Pitre
3. Dilnaz Boga
4. Olinda Timms

Dilnaz Boga

Supriya Subramani



Amita Pitre



Olinda Timms





# Bioethics Trainings

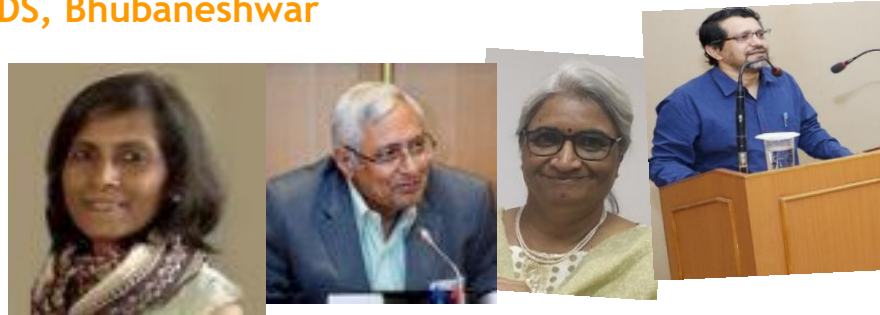


# Bioethics Training Programs: Faculty

## Social Science and Public Health Research Ethics, NCDS, Bhubaneswar

1. Amar Jesani
2. Mala Ramanathan
3. Sreejit Mishra
4. Sunita VSB

## Social Science and Public Health Research Ethics, NCDS, Bhubaneswar



## Biomedical Research Ethics, CSTM, Kolkata

1. Anant Bhan
2. Amar Jesani
3. Shantanu Tripathy
4. Subrata Chattopadhyay
5. Sunita VSB

## Biomedical Research Ethics, CSTM, Kolkata



## Public Health Ethics, IITB Mumbai

1. Amar Jesani
2. Anant Bhan
3. Kajal Bhardwaj
4. Kaustubh Joag
5. P. Manickam
6. Mathew George
7. Nilangi Nanal
8. Nilesch Gawade
9. Ravi Duggal
10. Sunita VSB
11. Tarun Bhatnagar

## Public Health Ethics, IITB, Mumbai





# Public Engagement in Bioethics

1. Grand Rounds
2. Round Tables
3. Essay competition

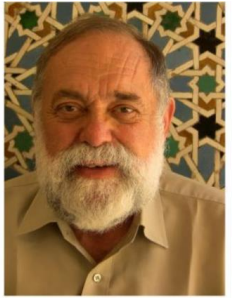




# Grand Rounds (Speakers and Chairs)



**Sarah Hodges**



**Dr. Richard A. Cash**

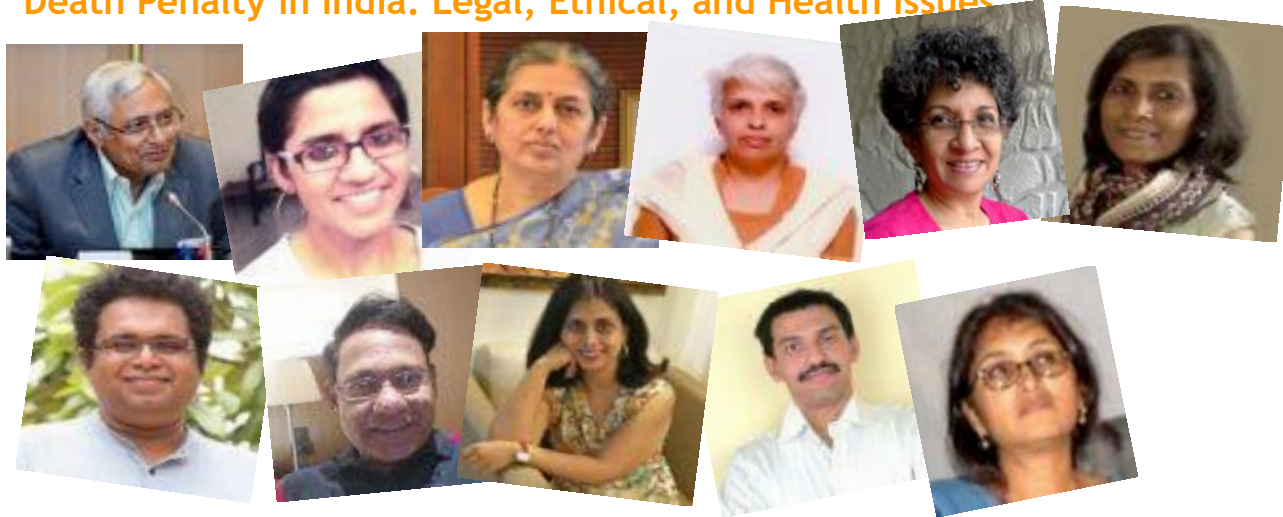


## Grand Rounds (speakers & Chairs)

1. Amar Jesani
2. Lopa Mehta
3. Mathew George
4. Nilesh Gawde
5. Richard Cash
6. Ritu Priya
7. Ruth Macklin
8. Sanjay Nagral
9. Sarah Hodges
10. S P Kalantri
11. Sulakshna Nandi
12. Sunil Pandya
13. Sunita VSB

# Round tables: Speakers & Chairs

## Death Penalty in India: Legal, Ethical, and Health Issues



### Round Tables

#### Death Penalty in India: Legal, Ethical, and Health Issues

1. Amar Jesani
2. Amita Pitre
3. Anup Surendranath
4. Maitreyi Mishra
5. Vaijayanti Joshi
6. Sandhya Srinivasan
7. Sandeep Mahamuni
8. Sunita VSB
9. Shamim Modi
10. Soumitra Pathare

#### Emerging AI Technology in Health Care in India, Health Equity, and Justice

## Emerging AI Technology in Health Care in India



1. Anant Bhan
2. Ashwini K.
3. Denny John
4. Navneet Wadkar
5. Radhika Ramkrishnan
6. Shivkumar S
7. Shishir Jha
8. Shashant S.
9. Sunita VSB
10. Surjit Nundy
11. Usha Ramanathan

#### Indian Philosophical Traditions

1. Meera Baindur
2. CD Sebastian



## Indian Philosophical Traditions

# IJME Young Bioethicist and Change Maker awards - Essay competition and Selection Committee



## Winners

1. Cheryl Ann Thomas
2. Migita D'cruz
3. Saibal Das
4. Sayali Tiwari



## Runners Up

1. Sharon Pradeeptha
2. Sreejith H. Das
3. Kamal Suna



## Selection Committee

1. Anant Bhan
2. Rema Nagarajan
3. Vijay Hiremath



Thank you

The background features abstract geometric shapes in shades of orange and green. A large, dark orange shape is prominent on the right side, with a green shape partially visible behind it. On the left, a green shape is partially visible. The overall design is minimalist and modern.