Towards a history of bioethics in India (1980-2010):

mapping the field

A Preliminary Report

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CENTRE FOR STUDIES IN ETHICS AND RIGHTS

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About CSER:

CENTRE FOR STUDIES IN ETHICS AND RIGHTS (CSER) is a research centre established by Anusandhan Trust in 2005. It was established with the view to promote ethics, human rights and social relevance in professional practice, research and training in health, education, law, media and social welfare and all other aspects of public life. CSER undertakes research and writing in the above disciplines. Currently, its main focus areas are ethics in reproductive health, ethics and rights aspects of social welfare policy and ethics in research in biomedicine as well as social sciences. CSER organizes various programmes for the education, training and mentoring students, academics and professionals in bioethics. Through its involvement in networks and forums, such as the Indian Journal of Medical Ethics (IJME), the National Bioethics Conferences, it provides an open space for public space for public discussion and debate on ethics and human rights.

Content:

1. Setting the stage

“Bioethics did not begin with a Big Bang,” writes Albert R Jonsen, delving into origin stories of bioethics (1998; 3). The stage was set against multiple backdrops. A landmark event was the Nuremberg Trial in Germany in 1947, where 23 Nazi physicians and medical administrators were charged with murder, torture and other atrocities committed in the name of medical science. The unethical war crimes captured public imagination. A few years later, the Tuskegee revelations in 1972 in the United States, where 600 poor and uneducated blacks were used as guinea pigs in a clinical trial to test syphilis, exposed by the *New York Times*, laid the stage for debates on the ethics of medical research across the developing world (Jonsen, 2000). 1947 onwards, were also marked by a series of biological and medical advances. Innovations like the dialysis machine and assisted reproductive technologies, developments in eugenics, advances in organ transplantations, debates on defining ‘death’, on abortion and a host of other issues. The engagement with the morality posed by some of these issues, the ethical dilemmas and the legal challenges they stood for, paved the way for a new engagement with medical ethics (Jonsen, 1998; 2000). The space provided by the media had a string role to play in taking the issues to the common people who got involved in it as well, and took stands, thereby leading to increased public consciousness. The war crimes, illegal clinical trials, medical advancements that invoked questions of justice, patients’ autonomy and informed consent, the re-emphasis for doctors to “first do no harm” – medical beneficence – all together prompted a review of the constituency of the term ‘medical ethics’. “Answers were needed for personal choices and for policy decisions. These events took place in a cultural, and a social environment that fostered”, explains Jonsen (2000; 115). And the traditional domain of philosophy, with its already existing theories on ethics, provided material for the discourses to shape up. This new theatre of bioethics thus had roles and opportunities for doctors, sociologists, lawyers, policy makers, and philosophers and theologists alike. The cast was large and the audience wide. The stage was set.

2. The present focus

However, bioethics in India has never captured the popular imagination, opines Dr Pravesh Jung Golay, Professor of Philosophy, Indian Institute of Technology (Bombay), who is also on the managing committee of the Forum for Medical Ethics Society, Mumbai and a faculty member on the board of a bioethics course offered by ICMR in collaboration with the Indira Gandhi National Open University (IGNOU) Medical issues such as organ transplantation, technologically assisted reproduction and euthanasia have now long been around, making noises and evoking debates, and sometimes effecting policy changes. For instance the case of forced narco-analysis on suspected criminals and antisocials: in response to consistent campaigns against this form of test, the Supreme Court of India, in 2010, declared the compulsory use of the test on suspects illegal. That it was considered a violation of human rights and had been taken up as an agenda by the National Human Rights Commission, is another matter to consider. But this is one of the many instances when an issue – at the interface of medicine and ethics – has been popularly understood as an issue of human rights and not bioethics.

In contrast, the West has seen a burgeoning academic interest in bioethics and has witnessed an active involvement of social scientists, especially philosophers in bioethics, even as 'applied ethics'[1] – as a branch of philosophy – provided their theoretical framework for understanding the biomedical dilemmas. But, as Golay rhetorically asks, "Where is the structure [in India] that will enable the engagement between medical practice and the profession of philosophers which is basically academic?" In the absence of an academic orientation and the scope to grow as a discipline or a situation prompted forth by philosophical principles, how does bioethics play itself out in India?

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[1] Golay traces the rise of 'applied ethics' to the last 4-5 decades. "Ethics is always applied …it is weird to have ethics that is not applied. The idea was that ethics *per se* is a very general engagement pertaining to the actions and behaviour of individuals, irrespective of the situatedness of these individuals." The need arose to apply the general theories of ethics to specific contexts like in the case of biomedical profession, where the demand was to address specific ethical questions over and above the general ethical theories and questions.

3. Rationale for the study

When asked about his views on bioethics in India, one of the respondents of the study said: “Honestly, bioethics is one word that I am not familiar with … if you want to discuss euthanasia or related subjects, I am there for it. I don’t know what bioethics really stands for.” This respondent is a member of a Mumbai based Society that defends euthanasia and who has participated in a number of television debates on the right to die, on the right to die with dignity. But his observation that he has nothing to do with bioethics *per se*, goes a long way towards highlighting the non-visibility of bioethics in India. While there has been considerable public attention to issues including foetal-sex determination tests, narco-analysis and organ transplant to name a few, they have almost never been discussed as issues *in* bioethics. Even in departments and organizations, there are no positions for a bioethicist. There are no government bioethics commissions like in the United States, where they have the U.S. Presidential Commission for the Study of Bioethical Issues. We could suffice it to say that the presence of bioethics in India as a field of study is still fragmentary and in a nascent stage.

Infact, a significant thrust for bioethics dissemination in India has come from programmes running in the U.S, the U.K, and in Australia. However, for bioethics to grow as a relevant field in India and respond to the given societal needs, it cannot merely re-echo the ethical concerns of other countries but must necessarily draw from internal experiences, from its own context. The present study tries to delve into these experiences and contexts by tracing the entry points of various individuals into the field of bioethics, both intentionally and incidentally.

3.1 Thinking through the objectives

How should a doctor behave with a patient? What is the decorum to be followed inside the clinic? How long should the doctor remain responsible for the patient? These ethical inquiries, irrespective of their origins in traditions in the West or in the oriental world, uphold a set of moral beliefs as being intrinsic to the form of practice (Jonsen, 2000). These beliefs, whether encased in the 5th century BC Hippocratic Oath or in the image of Sushruta – the ancient Indian surgeon operating on a patient somewhere in 6th century BC – which adorns the walls of most Indian hospitals, are also part of popular imagination.

Some of the oldest medical institutions in the country like Christian Medical College (CMC), Vellore, St. John's National Academy of Health Sciences (SJNAHS), Bangalore, have for long included medical ethics as part of their medical training curriculum. As a subject in the curriculum, medical ethics figures in some other institutions across the country but continues to languish as a sub-text in forensic medicine (Ravindran, 2008). The Medical Council of India (MCI), a statutory body set up in 1934, elaborately covers a doctor's ethical obligations to the profession. The MCI established the Code of Ethics Regulations in 2002. With codes of conduct being laid down and monitored by such statutory bodies, the need for bioethics has been not felt strongly enough. Even as late in the day as in 2012, bioethics as a term does not have much currency and concerns that actually come within its purview (like euthanasia or unethical clinical trials) become pivotal issues for other groups and individuals in the country and define agendas outside of bioethics. To put it shortly, in present day India, bioethics is mostly played out as medical ethics, public health ethics, bio-medical ethics or even consumer and human rights.

Against this backdrop, the present work sets out to do the following:

1. Locate the actors – both groups and individuals – who participated in ushering bioethics into the country;
2. Delve into the possible reasons that triggered an interest in bioethics; and,
3. Examine the manner in which bioethics permeates medical research and practice in present day India.

4. Methodology

4.1 Study design

There are many routes to history. However, the route I have adopted for the study is the one offered by oral history (Blatz, 1990). There is very little standardised data which trace the trajectory of bioethics in India or of institutionalised structures that lend a visible identity for bioethics. At the same time, bioethics as an ethical inquiry into issues in medical and biological research and practice lends itself to individuals interested in the question of wrongs perpetrated on them and others, and of their rights as individuals and collectives. It was important for the study to assume that there are different actors in bioethics and learn how their actions have shaped the field. It thus seemed crucial that the history got mapped primarily through their narratives. It also ensured that the study remain open-ended while drawing from the several formal and informal in-depth interviews, email exchanges, notes, campaign materials and records (including government reports) that were analysed.

Data collection

Respondents for the study were identified essentially through snowballing.[2] Moving through contacts, the study was able to cover 38 respondents from across disciplines and professions. A brief overview of the respondent profile would include:

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[2] This is a sampling method where one individual or interest group leads onto others in the field. An 'interest group' according to the *Encyclopaedia Britannica* means "any association of individuals or organizations, usually formally organized, that, on the basis of one or more shared concerns, attempts to influence public policy to benefit themselves or their causes."

Doctors – in active practice, doctors turned full-time activist, social scientist, teachers, researchers, and retired professionals	20
Lawyers (one of them retired from practice)	2
Journalists	2
Social scientists	10
Theologist	1
Zoologist (retired)	1

Many of these individuals – including those who have retired from active service – continue to function with multiple job profiles and roles, notwithstanding their primary identity and affiliation.

The tool was an in-depth interview schedule that focused on the respondent's basic biography details and his/her views on bioethics and the future of bioethics in India. Questions were occasionally altered to suit the specific context of the respondent, in accordance with his/her profession, background and ideological position. When individuals and organizations were approached for the study, the interviewer also requested to obtain the relevant literature available with them that would complement their narratives.

Broadly speaking, the study set out to look at:

1. The Indian Council for Medical Research (ICMR), one of the oldest medical research bodies set up by the Government of India for the formulation, coordination and promotion of biomedical research,
2. Non-governmental organisations that have been addressing issues of ethical concern through their activities,
3. Institutes backed by religious bodies where ethical pursuits are a strong component of their identity,

4. Individuals who are either part of these structures or have been independently pursuing activities which come under rubric of bioethics.

Since the study resorts to oral history as its methodology, this report comes across as primarily a descriptive narration constructed by and also restricted to the perceptions put forward by the respondents in the study sample. While the report makes no claim to have captured the exhaustive view of all people and organizations working in bioethics, it asks only to be seen as a representative documentation of the route bioethics has taken in the country, and to provide a comprehensive overview of the field, especially when such a history had been both lacking and much called for.

4.2 Ethical considerations

The study proposal was submitted to the Institutional Ethics Committee at Anusandhan Trust for consideration and clearance. Consent forms were handed to the respondents before the interviews; the forms stated in details the objectives of the study and sought written permission from each person to audio tape the interviews. Separate permission was also sought to name individuals and institutions since this is a historical preview and needs to be located in facts. However, if at all someone wished to stay anonymous, the study complied with it.

5. Mapping the field

5.1 The official route

It is befitting to start with the ICMR story as it is the official body that instituted the *Policy Statement on Ethical Considerations involved in Research on Human Subjects* as early as in 1980, just a year after the *Belmont Report* had been issued by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979. The purpose of the Belmont Report was to protect participants and subjects in the clinical trials and research studies involving ethics and healthcare research.

To provide a brief history of ICMR: it was instituted in 1911 as the Indian Research Fund Association and became the Indian Council of Medical Research in 1949. It was set up with the objective to foster research in India, develop infrastructure and create community support. Naturally the task of formulating guidelines for ethical research also came to rest with the ICMR.

Dr. Vasantha Muthuswamy, former Senior Deputy Director General and Head of the division of Basic Medical Sciences, Traditional Medicine & Bioethics, and of Reproductive Health and Nutrition, at the ICMR recounts how the work on the guidelines had been initiated by the then institute Director General, Dr. C. Gopalan in 1978. When Dr Gopalan retired in 1979, the guidelines were almost ready. The report was released the following year when Dr Ramalingaswami took over as the Director General, ICMR. On the global front, it was also the time when "[T]the revelations of the Tuskegee Syphilis Study and several other instances of questionably ethical research [had] propelled the old medical ethics into the world of bioethics" (Jonsen, 2000; 18). Muthuswamy opined that the international discussions that were globally garnering attention at that time must also have substantially contributed to setting the stage for the ICMR scientists to start thinking of a policy for India as well.

As is evident from the ICMR policy statement, the impetus also came from already existing international guidelines such as the 1947 Nuremberg Code, the World Medical Association Declaration of Helsinki (1964) modified by the 29th World Medical Assembly in Tokyo in 1975. Added to this was the consciousness that India had opened its doors wider than ever to medical research on human subjects. One of the highlights of the ICMR Policy was the need for institutional ethics committees to overlook clinical research[3]. However, the 'pink booklet of ICMR' – as people came to call the policy book – was hardly heeded to by those in the medical research field. "With the Belmont Report, it became mandatory in the U.S. that every institution doing research should have an institutional review board (IRB) and they must follow the principles laid out by the Belmont report … Having a law made a difference, it even became compulsory for them to teach bioethics in life sciences and the medical curriculum. Everybody had to undergo a course in bioethics. In India such things did not happen … As a result, there are institutions which do not follow the guidelines even now," explains Muthuswamy, adding how the process got flagged off in the right way but continues to remain unimplemented largely because it is not mandatory to abide by the policy guidelines.

In 1996, sixteen years after the first guidelines were released, the then Director General, Dr. G. V. Sathyavathi initiated a revision to the 1980 policy statement. Dr. Sathyavathi set up a committee headed by retired Chief Justice M. N. Venkatachalaiah, chairperson of the National Human Rights Commission, to look into the draft revision process. This was also the year when ICMR decided to organise a training course for some of its personnel in the field. Identifying 1996-97 as the years when she had her first brush with bioethics, Muthuswamy recounts: "That was the time when ICMR was awarded

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[3] Muthuswamy draws attention to the distinction between practice ethics and research ethics. In the U.S. a lot of bioethics activities stem from the use of dialysis, life support systems, transplants and others. In a context of high demand and scarce resources, a God committee comprising of two physicians, a minister, lawyer, homemaker, businessman and a labour leader is set up in the Seattle artificial Kidney Center, which captures public imagination, setting the stage for hospital ethics committees. Such events, related to practice ethics, never happened in India. With the 1947 Nuremberg Code, the 1964 Helsinki Declaration and the 1979 Belmont Report getting formulated, research ethics becomes more popular, observed Muthuswamy.

the World Health Organization (WHO) fellowships. We got some 13 to 14 fellowships every alternate year, whereby ICMR personnel could go for trainings to different institutions across the world … When this came up in 1996-97, Dr. Sathyavathi […] requested the WHO that some ICMR personnel be trained in bioethics. The WHO suggested the Kennedy Institute of Ethics in Georgetown University, Washington D.C. that offered an intensive bioethics course […] Two of us were nominated from India to do a 16-week intensive course … Since the WHO fellowship was only for 12-weeks, we were there from August till November 1997." Muthuswamy was the Deputy Director at the ICMR at that point. The other person selected to attend this course was Dr. Rema Mathew, Assistant Director at the Tuberculosis Research Centre, an ICMR institute in Chennai.

When Muthuswamy travelled to the U.S. on the fellowship to attend the programme, the revision of the policy guidelines was still underway. The task of circulating the draft among select people came to rest with Dr. Nandini. K. Kumar, who was working in the same department as Muthuswamy. A clinical pathologist by training, Kumar, who had started out as a researcher in 1985 in the ICMR's state-of-the-art project on traditional medicine, had joined the ICMR headquarters as a senior research officer in the area of traditional remedies. She too recounts the years 1996-97 as offering her, her first exposure to ethics, when she joined Muthuswamy's department. Since she was handling the traditional medicine research, that unit was "[A]lso transferred to the bioethics division because I was the continuity there," says Kumar, who is now retired as the Deputy Director General of ICMR, but continues to be actively involved in bioethics education at the National Institute of Epidemiology, ICMR institute in Chennai. After obtaining her Masters degree in bioethics from the University of Toronto, Kumar went on to become the Programme Officer for Traditional Medicine Research and Bioethics at the ICMR.

To return to the 1996 initiative to revise the ICMR policy guidelines: in an attempt to include public participation in the revised draft, the ICMR held public debates in four regions of the country –

Delhi, Kolkata, Mumbai and Hyderabad. "Though we called it a public debate … the participation was quite restricted. Because in India, I don't think the public participates in all these debates because they think it is for the technical people … So majority of the participants were doctors, NGOs [who were] already working in that field, like the Centre for Studies in Ethics and Rights, Mumbai; Community Health Cell, Bangalore; SAMA, New Delhi; individuals like Brinda Karat and people from the nursing field and media," narrates Muthuswamy. She added that the ICMR had also invited people who were involved in ethics. Taking off from the feedback received in these public debates, alterations were made to the draft and Dr. Ramalingaswami was called upon to be the chairman of a sub-committee to look into the final version while the Justice Venkatachalaiah Committee worked on the final edit. Thus was born the revised *Ethical Guidelines for Biomedical Research on Human Participants* in 2000. Traversing through the journey of the guidelines, Kumar emphasised how the 1980 guidelines was a visionary statement in itself except for its stand on "traditional medicine"[4]. "The Statement spoke about clinical trials, informed consent, ethics committees, who should constitute it and so on. This was in 1980. However, it got formalised only in 2000 … Most of the scientists during that time didn't even know this existed," added Kumar.

But even as the guidelines were released in 2000, the then Director General, Dr. N. K. Ganguly felt it was "[A]lready time for another revision … He was after me to revise the guidelines and that is how we finally revised it in 2006," narrates Kumar.

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[4] The 1980 ICMR guidelines insisted that "[F]or clinical evaluation of plants being utilized for therapeutic purposes, assessment of treatments being used in the traditional systems of medicine, the protocols for such clinical research should again be approved by the Ethical Committee of the institute. There is no need for clearance to be obtained from the Drug Controller of India for such trials of products are already in widespread use in the traditional systems of medicine today in the country" (ICMR: Policy Statement on Ethical Considerations Involved in Research on Human Subjects. New Delhi: 1980).

Bioethics dissemination

Muthuswamy's 12-week bioethics training at the Kennedy Institute of Ethics spun a process of dissemination. The ICMR nominated individuals from different institutes and organisations to undergo bioethics training in various institutes abroad with the Fogarty fellowships[5]. The training started in 2000 and as Muthuswamy says, "We chose individuals from institutes where ethical pursuits were on and which also had a strong ethics committee." A list of the first few individuals to travel for this training includes:

- Dr. Nandini Kumar – Indian Council of Medical Research, New Delhi
- Dr. G. D. Ravindran – St. John's National Academy for Health Sciences, Bangalore
- Dr. V. M. Nair – Kerala State Institute of Health and Family Welfare, Trivandrum
- Dr. Sunita Bandewar – Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai
- Dr. J. S. Srivastava – Central Drug Research of India, Lucknow
- Dr. Anant Bhan – Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai

Another training course, mainly for the ICMR personnel, under the Forum for Ethics Review Committees in Asia Pacific (FERCAP)[6], a WHO 2000 initiative, was offered at the Western Institutional Review Board in Olympia, U.S. About eight ICMR institutes like the National Institute of Nutrition (New Delhi) and the Tuberculosis Research Centre (Chennai) which had functioning ethics committees were chosen for

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[5] The Fogarty Centre was set up to further the mission of National Institutes of Health, U.S. For more details, see http://www.fic.nih.gov/About/Pages/default.aspx.

[6] FERCAP "was conceived in Bangkok, Thailand on 12 January 2000 after much thought and deliberation among a group of bioethicists and medical experts with the objective of fostering an improved understanding and better implementation of ethical review of behavioral and biomedical research in the region. FERCAP is the result of the realisation that ethics requires collective wisdom and there is need for a systems approach to address important health research issues in Asia and the Western Pacific". For more details, see: http://www.fercap-sidcer.org/whatsfercap.php

training in IRB functioning process. The period also marks the formulation of standard operating procedures (SOP) to train and aid in the effective functioning of Institutional Ethics Committees in the country.

Another illustrative example of how the government body took upon itself the task of capacity building in bioethics among various individuals/groups is when an ICMR proposal submitted to the National Institutes of Health (NIH) by Dr. Kumar received a grant for the period 2004 to 2008. This training involved short term courses for undergraduates, graduates, researchers and faculty members in the medical sciences and non-medical specialities. During this four-year period, the ICMR trained about 1500 people in bioethics. An interesting phenomenon observed here is the way in which different interest groups are roped in to assist the ICMR in this endeavour.

For instance in 2006, the ICMR organised a bioethics workshop for social scientists. Elaborating on the workshop, Kumar says, "There were a number of applications and I [asked] Amar Jesani's group because they […] could manage it better as a team as they had already run such workshops. They could do it in a cohesive manner … and the workshop was well appreciated." As we proceed further in this report we shall observe how interest groups constantly associate with one another while consciously or unconsciously contributing to the corpus of knowledge of bioethics in the country.

After the four-year stint at capacity building in different parts of the country, Drs. Muthuswamy and Kumar submitted another proposal in 2008 to the Fogarty Centre to develop a distance education programme in bioethics. The grant came through and was finally implemented in 2010, in collaboration with IGNOU, New Delhi. The training involved experts from various institutes, including Prof. N. Sreekumar, IIT (Madras) and Prof. Pravesh Jung Golay as members of the faculty. Currently, 50 trainees from all over India are part of the programme. Dr. G. D. Ravindran, Professor of medicine and medical ethics at SJNAHS, Bangalore, observed – at the second National

Bioethics Conference in 2007 – that since 2004, the ICMR's efforts at sensitising students and faculty throughout the country has generated tremendous interest in medical ethics in the country. Kumar presents the various bioethical activities, including training programmes, taken up by the ICMR in different regions of the country in her paper *Bioethics activities in India* (2006).

How have the individuals trained by the ICMR, utilised bioethics in their own fields, especially in implementing ethical principles such as autonomy and informed consent in their research and practice? What impact have the training programmes had on bioethical activities in India? What changes have they ushered in, which probably did not exist earlier? How have these training programmes changed or contributed to the job profiles of the participants? These questions surely prompt further research in the field. While the present study interviewed a few of the beneficiaries of the training programmes like Dr. Sridevi Seetharaman, pathologist, Swami Vivekananda Youth Movement, Mysore, and Dr. S. Swarnalakshmi, IRB Manager, YRG Care, Chennai, the list is hardly representative to reflect on these questions. The following short section is only to determine how the ICMR propels bioethics as a term of reference essentially in research ethics.

5.2 Bioethics as personal or group interest

Mapping the history of an institution such as the ICMR is a relatively easy task as it functions as a cohesive body with a given legitimacy of being a government enterprise. Its location affords it the advantage of being a nodal, visible agency for change. The same would not be true for non-governmental organisations or societies or associations or even institutes such as the Christian Medical College, Vellore, or SJNAHS, Bangalore.

This study attempted to retrace a history of bioethics by looking at some individual trajectories, taking into consideration each respondent's location and his/her biography. Talking about the institutions the respondents are attached to would also be inevitable to the exercise of tracing the history of bioethics. This was achieved made possible by collating from the interviews, crisscrossing through years and organisations wherever necessary.

A. Ethics on a religious note

Religion in general and Christianity in particular, has consistently engaged with issues within the larger purview of bioethics such as euthanasia, in-vitro fertilisation and now clinical trials (Gregory, 2009) and taken positions in accordance with the tenets of the said religion. This is in keeping with the role of the Church in the medical field, which has gone to the extent of even determining the ethical norms for the practice of medicine. For instance, the International Federation of Catholic Medical Associations (FIAMC), founded in 1966, draws its origins back to the late 19th century when Pope Leo XIII called for the formation of organised groups of Catholic professionals. The first guild of Catholic doctors came up in response to the call when a French doctor launched a guild from a provincial town that acquired a national dimension in 1907 and soon other countries followed.[7]

Promoting respect for life

One of the first centres for biomedical ethics to be set up in India was Federation Internationale des Associations Medical Catholique (FIAMC) Bio-Medical Ethics Centre (FBMEC) in Mumbai in 1981. The resolve to establish it was taken up at the 14th World Congress of the International Federation of Catholic Medical Association held in Mumbai in 1978. The task was entrusted to Dr. Chicot J. Vas, a leading neurologist and founder member of FBMEC, who had just been elected as the secretary general of the organisation. At that time it was the sixth centre for medical ethics in the world and the first in Asia, Australasia

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[7] For more on the history of FIAMC: http://www.fiamc.org/institutional_information/history/short-overview-of-the-history-of-fiamc/

and Africa.[8] A consultation workshop was organised in Mumbai which was held over a period of fifteen months to discuss and formulate ethical standards against the backdrop of "[D]ecline in ethical standards of functioning in some sections of the medical profession and the pharmaceutical industry … [It] was attended by twenty-four men and women of goodwill and experience, drawn from the drug industry, the medical fraternity, the legal profession, the civil service, the consumer activists and the public at large" (Vas & de Souza, 1989). Ethical issues were no longer restricted to only doctors' conduct with patients, their families and colleagues, but extended to larger concerns of rights and responsibilities. The FBMEC was founded to deliberate these ethical issues and provide the teachings of the Church in these areas.

Dr. Nicholas Antao, a consultant orthopaedic, arthoscopic, sports medicine and joint replacement surgeon from Mumbai, and a managing trustee of FBMEC has been involved with the Centre since the 1980s. He recalls how FBMEC set out to ensure that medical ethics was ingrained in their students. "We prepared a draft of ethics, or oath I should say, which the medical students should take and abide by, and we circulated it among the interns belonging to the Guild of the Catholic Medical Doctors." It was in fact at the Guild that Antao had his first encounter with ethics. He was the secretary of the Guild and its spiritual director, and Father Caesar D'Mello gave him a book titled *Current Problems in Medical Ethics: a Comprehensive Guide to Ethical Problems in Medical Practice* authored by Father George Lobo. When Dr Vas was transferred to Goa Medical College and the then Executive Director Dr. Eustace de Souza found it difficult to commute to the Centre, the mantle was passed on to Antao. The Centre's essential role has been to impart bioethics education and bioethics writing besides holding regular workshops and seminars in collaboration with other groups. The ethics of abortion, of dealing with HIV positive patients, ethical dilemmas in orthopaedic practice, bioethics instruction in various Christian institutes, including in schools of Mumbai are instances of some of the bioethical activities of FBMEC.

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[8] More about the aims and genesis of FIAMC at: http://fiamc.blogspot.in/2009/02/aims-genesis-of-fiamc.html

Once again to be noted in the FBMEC's journey in bio-medical ethics is the attempt to connect and collaborate with other interest groups. While the priority is to have an interchange of ideas with centres of catholic inspiration involved in bioethics work such as the Catholic Bishops' Conference of India (CBCI), New Delhi, the Centre has made efforts not to remain insulated from other groups. For instance, Dr. Eustace de Souza, who co-edited a book on ethical concerns in AIDS with Dr. Vas in 1991, not only contributed a write-up on AIDS to the *Indian Journal of Medical Ethics* in 1994, a year after its inception, but also sent a congratulatory note to the editor of the journal and conveyed his sincere hope that the journal will "flourish as it should". In the same issue, the IJME published ethical guidelines for Catholic doctors, contributed by FBMEC. Dr. de Souza eventually became a regular contributor to the IJME. Later in 1995, the FBMEC organised a seminar on ethical and legal issues in healthcare at the K.E.M. Hospital and Seth G.S. Medical College, Mumbai, along with the Association of Medical Consultants. A detailed report of the conference was published in IJME in 1996 (Pandya, 1996).

Another instance is when the FBMEC associated with the Forum for Medical Ethics Society (FMES), which publishes the IJME, in 2008 to assist the Bombay Orthopaedic Society to hold a seminar on the ethical and legal dilemmas in orthopaedic practice (Fernandes, 2008). The seminar witnessed the coming together of medical experts like senior neurosurgeon Dr. Sunil Pandya, senior orthopaedic Dr. K. V. Chaubal, former dean of Sion Hospital Dr. Armida Fernandez and Dr. Antao, social scientists Dr. Amar Jesani and Neha Madhiwalla, theologist Fr. Stephen Fernandes and Supreme Court advocate Joaquim Reis, among others.

Fr. Stephen Fernandes, a trained theologist from the Pontifical University of Rome and currently the director of FBMEC, joined the Centre in 1983. He recalls how Dr. Vas started the operations in a small room "to promote respect for life." When the Centre began a certificate course in healthcare ethics in 2003, it was with the intention of disseminating the same value. Approximately 45 participants enroll each year and the instructors come from various fields including law, social sciences and medicine – and not necessarily from a Catholic background. For instance, Prof. Vibhuti Patel, trustee, Anusandhan Trust and Head of Department, Economics, SNDT University, Mumbai, has been a faculty member on the FBMEC course ever since it got instituted. The FBMEC's collaborations with other interest groups, however, is never at the cost of compromising on its Christian ideology and conviction in ethical issues stemming from experimental, diagnostic or therapeutic actions prevalent in the biomedical field, be it abortion, euthanasia or technologically assisted reproduction. Says Antao, "It is not only religious people who attend this course. There are many from different professions and not only old people but younger ones too. It's a good feeling for course organizers … that the message is spreading, people are interested, they want to come and learn."

A case of two medical institutes

Apart from the FBMEC this study looked at two medical institutes which have a deep-rooted engagement with ethics. The rationale behind choosing these institutes was: (i) They are Christian institutes, one set up by Catholic Bishops' Conference of India, and another by an American missionary woman; and (ii) They are the country's oldest medical colleges, and (iii) Ethics has played a very important role in both these institutes ever since their inception. However, it needs to be mentioned that the marker 'religious' institutions, merely represents the foundational identity of an interest group or individuals serving it and is not always illustrative of the positions the individuals assume while engaging with bioethics.

To digress a little at this juncture, Muthuswamy who is well acquainted with the bioethics scenario in the country insists that "religion in India does not play much role in bioethics Religion has not interfered in India except Christianity to an extent because of its opposition to abortion and such things. As far as Hinduism and Islam are concerned, they have never interfered in the debates … as it happens in other countries.” What we also need to consider here is that even on occasions when interlocutors in India feel compelled to talk about ancient Hindu texts like *Charaka Samhita* or *Sushrutha Samhita*, it never encases the arguments as drawing from ‘religion’, even if the issues are discussed as ‘Hindu bioethics’. It is somehow collectively understood as Indian contribution to bioethics. However, the study has not explored whether and how bioethics is engaged with, in other religions apart from Christianity.

St. John’s National Academy of Health Sciences (SJNAHS), Bangalore

At the annual convention of the Catholic Hospital Association of India in the southern town of Mangalore in 1971, Fr. George Lobo, Professor of Christian Ethics, delivered a lecture on moral theology in relation to birth control. At the convention, the Association members unanimously accepted Fr. Lobo to be their consultant moral theologian. In a foreword to what is perhaps one of the earliest texts on medical ethics, the Executive Director of the Association hailed its author, Fr. Lobo, for “[I]ncorporating the latest healing related moral insights” (Lobo, 1974; 6). In the book, with firm religious conviction, the author discusses issues pertaining to the patient as person, ethical codes, euthanasia, organ transplant, morality of abortion and other modern medical concerns while also attaching as appendix the Declaration of Helsinki, the International Code of Medical Ethics and other important documents of the time. In the preface, Fr. Lobo writes that though the book is written in the Catholic tradition, he has tried to extend the ethical dialogue with other Christians and the modern secular world.

Dr. G. D. Ravindran, while talking about his introduction to ethics as a medical student around 1979, recalls how Fr. Lobo’s book proved extremely useful amidst the otherwise scant ethics literature. Back then, St. John’s Medical College was one of the few medical institutes in the country which had a separate department of medical ethics. Instituted along with the college in 1963, the course aimed to train and orient medical graduates towards healthcare in rural areas and provide them a firm foundation in ethical principles. Up until 1984 the course was taught by chaplains.

To go back a little in time, SJNAHS – then only St. John's Medical College – was established by the Catholic Bishops' Conference of India in 1963. It was set up with a mission to train doctors who would be ready to serve 'the medically unreached' of the nation. Ethics became a part of the medical curriculum. When Dr. Ravindran joined St. John's in 1988 as staff, the ethics department had Fr. Thomas Kalam, who was "the first person who had specialised in medical ethics and bioethics." Attached to the Carmelites of Mary Immaculate (CMI), Fr. Kalam's outlook on biomedical ethics was not governed by his religious convictions. In a very interesting article *Teaching Medical Ethics – a reflection* (1999), Fr. Kalam narrates how he accepted the offer to teach biomedical ethics in SJNAHS in 1985 on the condition that, "I should be allowed to teach medical ethics, and not religious ethics" (1999; 47).

Then there was Fr. C. M. Francis, another luminary figure in medical ethics whose book *Medical Ethics* (1993) became a prescribed textbook for undergraduate medical students. He was the founder-director of Sree Chitra Tirunal Medical Centre Society for Advanced Studies in Specialities, Trivandrum, and the founding editor of *Health Action*, a HAFA (Health Accessories for All) National Monthly published by CHAI (Catholic Health Association of India). He also held other important positions.[9] Recalls Ravindran, "Fr. Francis was one person who used to talk about ethics in every way." But the person who succeeded into convincing Ravindran into learning and teaching bioethics was Fr. Alfred Mascarenhas, the then Dean of SJNAHS.

One of the first Fogarty fellows in bioethics in India, Ravindran is of the opinion that bioethics, involving a whole gamut of

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[9] Fr. Francis was felicitated for his long standing commitment to medical ethics at the second NBC, Bangalore, 2007.

standpoints including medical ethics, acquired prominence in India chiefly because of international collaborative research, advances in medical technologies, commercialisation of the medical profession and the Consumer Protection Act of India (1986), which eventually brought doctors within the purview of law. Diploma courses such as those offered by The Institute of Law and Ethics in Medicine (TILEM), National Law School of India University (NLSIU) became popular among practicing doctors as there was now a greater need to learn about legal aspects governing their practice. Dr. Joga Rao, advocate solicitor and healthcare consultant, elaborates that while ethics is a kind of appeal to the conscience of an individual to act in a particular manner, in India, ethics, especially that related to medical research, experimentation or care is not merely an appeal to the people's conscience. It is "[E]ndorsed by parliamentary legislations. To that effect, in India, ethics is nothing but law, as of now. As per the code of medical ethics 2002, it is not a profession-driven guideline but an Act by the Indian parliament." Ravindran also draws attention to controversies in health like the injectable contraceptive issue in the 1980s[10], the illegal clinical trials conducted at the Regional Cancer Centre in Trivandrum in November 1999 for the sponsor institution Johns Hopkins University, and the organ transplant controversies that come up from time to time which have provided the impetus for bioethics in India. "If you look at the way bioethics debate has gone, it is always in relation to some problem that we faced," he adds.

At SJNAHS, especially since they started the intern's forum in 1992, these current ethical issues have formed topics for debates in the medical ethics course, especially meant for the medical interns. This is in addition to the debates on ethical dilemmas faced in everyday hospital practice and other theoretical instructions. Their ethics instruction became a model to emulate in 1999, when the Rajiv Gandhi University of Health Sciences, Karnataka, collaborated with CHC

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[10] In 1986, some women's groups across the country filed a petition to the Supreme Court seeking a stay on the clinical trials of the injectable contraceptive Net-En after news broke that a primary health centre in Andhra Pradesh was using the contraceptive in a family planning camp without following the informed consent protocols. For more on this see 'Net En: another chapter in the saga of injectable contraceptives.' Available at: https://sites.google.com/site/saheliorgsite/health/hazardous-hormonal-contraceptives/net-en

Bangalore, SJNAHS Bangalore and a host of other experts to "explore all aspects of teaching medical ethics in the medical curriculum … in the context of the ordinance governing MBBS degree programme of the University which introduced the teaching of medical ethics in the curriculum" (Narayan, Lewin, Srinivasa, & Francis, 1999; 3).

Apart from ethics teaching, the SJNAHS also forms a collaborative centre for various other interest groups. For instance, in 2007 the ICMR held a 10-week ICMR-NIH bioethics training programme in coordination with SJNAHS. A year earlier, in 2006, it organised a day's programme on *Ethics, Human Rights in Medical Education* in collaboration with UNESCO-Bangkok and Eubios Ethics Institute, Bangkok. The programme was attended by Dr. Darryl Macer (UNESCO), Mr. Jayapaul Azariah (All India Bioethics Association), then also the president of Eubios Institute's Asian Bioethics Association, Dr. Ravi Narayan (CHC Bangalore), Dr. Joga Rao (NLSIU) and Sr. Daphne Viveka, former professor of biochemistry at Sophia College in Mumbai, among others.

As indicated in the context of the ICMR story, the study illustrates once more how interest groups constantly associate with one another while informing the discourse on bioethics in India.

Christian Medical College (CMC), Vellore

Founded in 1900 by an American missionary woman Dr. Ida S. Scudder, the CMC is "unashamedly a Christian hospital, drawing its inspiration from the example of Jesus Christ."[11] In its mission statement it emphasises its commitment to high ethical standards.

No surprise that one of the institute's earliest ethics committee dates back to 1971, when the country's first successful live donor renal

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[11] See: http://www.cmch-vellore.edu/pdf/patients/CMCinserviceofthenationsince1900.pdf

transplant was taken up. As Dr. Prathap Tharyan, Professor of psychiatry and Director, South Asian Cochrane Network & Centre, recounts, “When I joined CMC as a student in 1974, we did not have a course on ethics. But the institution had already started an ethics discussion. We were the first institution in the country to do renal transplants. This was in 1971. When you do renal transplants, you have to get consent from donors. So the institution at that time set up an ethics committee purely for this […] to ensure that the donors related were not being coerced.” However, a more formal IRB or ethics committee, authorised by the CMC Director, came into existence in 1994. Tharyan, who has been associated with the research ethics committee since 1995-96, recalls how the emergence of HIV cases in CMC in the mid-1990s, set the stage for ethical deliberations in a way. “We were one of the first institutions to deal with HIV cases. We had a lot of discussion on how to prepare the institution to deal with HIV,” he adds. It involved not just the doctor and patient but a whole gamut of people including nurses and other staff involved in patient care. It was then they realised what they need is “clinical ethics kind of a thing … We should allow any employee in this institution, who is troubled by an ethical issue … to be able to approach us and say ‘we want help to solve this problem’.” And that is how, says Tharyan, the clinical ethics committee at CMC was born.

Tharyan, who is closely associated with many ethical deliberations of CMC, both research and clinical, and is an editorial board member of the IJME, believes that while science is all about wanting to keep doing more and more, ethics is about, ‘should we do it?’ and ‘how should we do it?’, about decisions that can be arrived at only though collaborative and collective effort and never in isolation. It being a Catholic institution, ethical decisions at CMC seem to have been guided not merely by religious conviction but by taking into account various issues such as justice and socio-cultural locations of patients. For instance, in a lecture on ethics in critical care, Tharyan presents the case of a patient[12] with Lou Gehrig’s disease, a motor

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[12] Full presentation available at: http://www.jpowerpoint.com/Ethics-in-Critical-Care--PPT.html

neuron degenerative disease. The patient went into respiratory depression at CMC and had no chance of bouncing back. After three months in the ICU, the bankrupt family decided to take the paralysed man off his respirator. How does a doctor caught between a patient who can still speak with his eyes and also write, and a family that asks for an end to their hopeless situation, take the call? Especially if the doctor is aware that keeping such a person alive is equal to denying other people a bed and respirator, resources that are so scarce? Such situations are matters of justice versus individual autonomy versus collective good, as Tharyan puts it. After discussions with the ethics committee, they finally decided for euthanasia. "We are not here to fight with death. The moment you understand this, the answer becomes very clear. We are here to help people to cope with suffering. […] Infact I even said, let the law come,[13] I will challenge them. Can you make a law which you cannot implement, when you have made no provision for it? You cannot dictate that I keep somebody else alive. That is not my constitutional duty or yours unless you are willing to pay for that," states Tharyan who is very clear on the issue.

A characteristic of the CMC has been its long-standing engagement with public health. For instance, the Low Cost Effective Care Unit set up in 1982 was "an attempt to practice medicine that was rational, of good quality and of the lowest cost" (Bhattacharji, 2010; 104). Patient's autonomy, patient as a partner in the healing process, patient empowerment – these concepts were the driving forces without the garb of bioethics. The absence of bioethics as a term even while talking about issues coming under its purview appears to be true in majority of the instances involving other groups in India as we will keep discovering through the study.

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[13] What Tharyan implied here was that he was willing to face legal action for openly advocating for euthanasia.

B. Ethics in a temporal frame

In *A Short History of Medical Ethics*, Jonsen argues how the discipline of bioethics "is not unified by a single dominant theory or methodology" (2000; 117). Questions of ethical dimensions of science and medicine have invariably involved people from every field, thus making it interdisciplinary. This invocation of a collective wisdom to reflect on ethical issues has surely prompted such an intermingling of individuals from different interest groups.

Perhaps in no other sector is such intermingling witnessed as in Societies and non-governmental organisations. So, while we talk about the Forum for Medical Ethics Society (FMES) Mumbai, for instance, we will encounter individuals who are part of its bioethical activities while operating from different locations such as SJNAHS Bangalore, CMC Vellore, Indian Institute of Technology, legal consultancies, Tata Institute of Social Sciences, private medical practice, medical colleges and hospitals across the country, other NGOs and so on. Earlier we saw how bioethics assumes an identity through official sponsoring as in the case of the ICMR or religious backing as in the FBMEC. Yet another way it permeates the arena is through advocacy, activism and research groups. Talking merely about the activities of these groups or its individual participants will be incomplete if we do not delve into the factors that presaged and prodded them.

As we have seen in the case of ICMR, bioethics in India received a fillip through regulations and guidelines, but that is only one side of the story. If we study the way it has evolved outside the government machinery, in the non-governmental sector, the concerns that prompted an engagement with bioethics have to do with the changes that the country faced in the sociopolitical and economic structuring of the health sector. In India, it was not the war crimes, not even the advances in medical technology but factors such as allocation of resources in a context of growing urban bias including misdistribution of medical personnel in the rural and urban areas; failure to develop a permanent health service for the rural and poor populations; medical practice being reduced to curative services rather than working towards preventive and social measures; unproductive campaigns against communicable diseases; nutritional problems; the excesses of the Emergency (1975-77) when the government, among other things, got offensively serious about family planning; the growing monopoly of the drug industry[14]; the rise of private practice in the 1970s and the accompanying commercialisation of medical practice – which had tremendous influence on civil society individuals who came together as groups to form an alternative voice and find solutions to the prevailing problems, that led to the emergence of the questions that would come to define bioethics in the India context.

New awakenings

In the early 1970s, a group called the Tarun Shanti Sena, a Gandhian group whose members, some of them medical doctors, dedicated their time to relief work in disaster and conflict zones. The Medico Friend Circle (MFC) grew out of the interest of these doctors; the MFC started out as a letter they wrote to each other and circulated among friends. Amar Jesani, who was in the thick of the Navnirman movement[15] as a medical student in Baroda recalls how two of the doctors, Drs. Anil

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[14] In his essay *The Drug Industry – An Analysis*, A. R. Phadke describes, through facts and figures, how the penetration of multinational companies, monopolisation and target on maximum profits have been the crucial defining features of the drug industry. "The drug industry like any other industry, produces only to the extent that drug can be sold at a *reasonable profit* in the market, irrespective of the needs of the people" (1977; 81).

[15] Amar Jesani who began as an activist participating in various rights movements in the 1970s and early 1980s, came from a Gujarat based Muslim family which had witnessed riots in the state in 1969. Jesani's initiation into activism happened as a medical student when he became part of student activism in Gujarat in 1973-74. The period also saw a steep rise in food prices. Students living in an engineering college hostel protested against the price rise and the agitation soon turned violent with the Congress government in Gujarat resorting to ruthless measures to check the striking students. The movement spread fast across the state under the banner of Navnirman Samiti, and ultimately witnessed the stepping down of the then chief minister Chimanbhai Patel. Jesani recalls how things changed between 1974 and 1978: the change was also visible in the healthcare sector where healthcare as a state responsibility soon dissipated in the face of the increasingly strong foothold the private healthcare sector gained in the country. Though many students soon fell out of the movement which was fast assuming a political nature, Jesani feels that one of the many successes of the Navnirman movement was that it triggered a need in several, to work for the poor of the country.

Patel and Ashvin Patel, both from Baroda, frequented his medical college to recruit like-minded people into their group. And what started as a letter in the early 1970s, recalls Jesani, finally crystallised as the MFC in 1974.

The MFC is a nation-wide platform of "secular, pluralist, and pro-people health practitioners, scientists and social activists interested in the health problems of the people of India".[16] Noting that after Independence, though there had been a rapid growth in healthcare services initiated by the government, the rise of the private healthcare sector as a major provider of medical care, the subsequent commercialisation of medical care, the skewed development of health services in rural areas, the neglect of preventive and social measures to solve health problems – these and other factors influenced the group to come together and "foster among health workers a current that upholds human values and aims at restructuring the healthcare system".[17] Since healthcare was part of the larger system, the MFC believed that fundamental changes in the health system could only occur as part of "a total social transformation in the country".[18] A range of topics including contraception, abortion and eugenics, were discussed as part of bioethical concerns in the First World, find a place in the MFC's bulletins since 1976 (all available online). Many of the issues the MFC has raised concerning health services in India have had an impact on the shaping of bioethics in the non-governmental sector as evidenced through the present study.

While the MFC's influence can be largely noted in the area of public health ethics, another influence for bioethics in India has come from the human rights and women's movements working in areas related to health and healthcare. In order to retrace these influences we shall rely on a great extent on the interviews collated as part of the study.

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[16] Medico Friend Circle. Perspective. Available at: http://www.mfcindia.org/main/perspective.html

[17] Ibid.

[18] Ibid.

Gateway to ethics

"Human rights provide me a lot of anchoring in ethics. Today, for me, the value system to analyse morality is human rights. Not theology or philosophy," opines Jesani. After shifting base to Mumbai in 1979 he subsequently joined the Foundation for Research in Community Health (FRCH)[19] as researcher; he was also simultaneously involved in the trade union movement, besides becoming a part of the Mumbai chapter of the MFC. As an activist he grew aware of the skewed nature of the health services in the urban slums, the unregulated rise of the private healthcare sector, the growing distance of the government from providing healthcare services to its people, doctors' apathy towards the marginalized population including prison inmates (which he witnessed during the Mumbai textile workers' agitation), and violation of women's rights.

The years between 1975 and 1980 saw the coming together of women's voices against gender discrimination and violence (Burte, 2008). The growing unrest had only worsened during the Emergency days when the government went into overdrive effecting forced sterilisations. The Emergency excesses led the people to question not only the government's role but also the ethics of doctors who were conducting these operations and (forced) sterilisations. One of the issues that precipitated protests from the women's movement was the scam of Dalkon Shield, an intrauterine contraceptive device. Vibhuti Patel narrates how the trials for Dalkon Shield[20] took place during the Emergency. There were several cases of uterine perforation and septicemia following the use of the IUD but "none of the doctors experimenting during Emergency were ready to give any evidence" of the same. Though the facts came out in the open in 1978 after the excesses of Emergency had passed, no records of the trials have been

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[19] For more on FRCH, see Antia N. H. *A life of change* (2009).

[20] Tick (1983) writes how by 1975, an estimated 15 million IUDs were in use around the world. The IUDs had been accepted in the face of publicised dangers of the birth control pill. But around the mid-1970s, the IUDs began to draw criticisms and complaints, and the one which was estimated to have caused the highest medical complications and become the most widely litigated against products in the pharmaceutical history was in fact Dalkon Shield.

found", says Patel. The IUD incited several public hearings globally; in Mumbai too the women's movement made efforts through campaigns to reach out to the medical colleges, but all evidence was destroyed. "Nothing came from India, so there were no claimants from India, the way they had in other countries" adds Patel as she recalls similar consistent campaigns, in some cases even public hearings, against vaccines such as estrogen-progesterone forte, against animal trials, and contraceptives such as Depo Provera, Net-En, Norplant and Quinacrine sterilisations which stretched through the 1990s and which contributed towards raising questions about informed consent and ill-treatment of human subjects and animals. The guideline for biomedical research, prepared by the ICMR, was in fact a result of the pressure from several people's organisations, insists Patel.

One of the earliest women's groups was Forum Against Rape started in Mumbai in 1979, which was later called the Forum Against Oppression of Women. Patel, having lived through the social struggles in her student days in Gujarat, became part of the Forum. She recalls, "In Mumbai, the immediate issues that were facing us were the plight of women working in factories. There were no standardised labour laws. They were made to work long hours, face sexual harassment, then there was the question of poor wages, lack of toilet facilities and safe transport." The Forum launched a campaign demanding a 24-hour separate compartment for women in the locals rather than the then existing practice of converting the women's compartment into a general one after 8 pm. The group launched a newsletter, *Feminist Network* (called *Stree Sangharsh* in Hindi) to reach out to the masses. The Forum launched campaigns against domestic violence, rape, sex determination tests and other such gender discriminations in Mumbai. An elaboration of these issues is critical to this study because issues such as contraception, abortion and sex determination that today form part of bioethics started out by being key agendas for the women's movement.

One of the first issues that occupied the women's movement of India is the foetal sex determination tests that became popular in the 1970s and 1980s with the growing availability of medical technologies.

Patel narrates an alarming story of how in the early 1970s Amul Dairy had introduced Chorionic Villi biopsy for cows and buffaloes as Gujarat had little need for many bullocks owing to the availability of tractors soon after the Green Revolution. The foetal sex determination test was used to allow only female foetuses to be delivered so that there were more cows for generating more milk. The same test came to be used on women so that the female foetus could be aborted.

The increased availability of ultrasound machines in the mid-1980s escalated sex-selective abortions leading to a consistent low in the male:female sex ratio. The first visible movement against sex selection started in Mumbai in 1983-84, as Jesani. Advertisements had come up all over in trains, buses and other public places stating how it is better to spend INR 500 at the moment than INR 5 lakh as dowry later and this triggered protest from the Forum Against Oppression of Women. Patel narrates, “When we did the study of sex selection abortions, we started seeing this issue from the angle of medical ethics and also [began to debate over] whether science and technology are a boon or a bane.” Their efforts at curbing the proliferation of sex determination tests paid off when Maharashtra became the first state in the country to come out with Maharashtra Regulation of Prenatal Diagnostic Techniques Act in 1988.

It is another matter that this law and other subsequent laws have done little to improve the situation and sex selection continues unabated. Manisha Bhalla in her essay *The Land of the Vanishing Girls* (2004) cites Sabu M. George, a health activist working in the area of sex selective abortion and who is one of the petitioners to the Supreme Court against the government’s non-implementation of Pre-Natal Diagnostic Techniques. She argues that the law would work only if ethical medical practice was in place first. Though never encased under the identity of bioethics, these issues have been at the forefront of many NGOs like CEHAT, Mumbai, and Mahila Sarvangeen Utkarsh Mandal (MASUM), Pune.

Activism, advocacy, research show the way

The Anusandhan Trust was set up in 1991 by nine friends who came from varied backgrounds but shared a common vision. Against the backdrop of prevalent controversies and malpractices, the Trust emerged with a goal to "establish and run democratically managed institutional structures undertaking research, welfare, services, education, training and advocacy in various fields and locations for the well being of the disadvantaged and the poor; and to collaborate with organisations and individuals working with and for such people".[21] The activist and research experiences of the funding members had already highlighted the gaps in the growth of the health sector and their inability to address these gaps in their respective locations prompted them to come together and set up a base of their own.

The first centre to come up under the Trust was the Centre for Enquiry into Health and Allied Themes (CEHAT) in 1994, soon after the Babri Masjid demolition in 1992 and the consequent violent events that rocked Mumbai. CEHAT, phonetically also meaning 'health' in Hindi, was poised to take up research, advocacy, training and service in health and allied themes. Jesani recounts, "It was more of an institutional structure and the idea of CEHAT was to do research in order to help out social movements." He describes how his research experience at the FRCH along with Manisha Gupte and Ravi Duggal's experiences[22] helped in forming the base for the setting up an ethics committee at CEHAT. One of the first funded projects taken up by CEHAT was on abortion. This Ford Foundation funded project went on to build substantial literature on abortion in India. Dr. Sunita Bandewar, an anthropologist trained in bioethics from the University of Toronto,

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[21] See http://www.anusandhantrust.org/

[22] Manisha Gupte, who has worked on several projects of CEHAT, is the founder of MASUM) Pune. Since 1987, MASUM has been working on health related issues, domestic violence, womens' resource development of rural and tribal people. Ravi Duggal, a sociologist and active member of the MFC, has worked extensively on the private health sector and financing of health systems in India and was the co-coordinator of CEHAT from 1999 to 2005. Jesani, who started his career with Gupte and Duggal at the FRCH in 1983, recalls how the three were inseparable for nearly seven years, doing most of their research together. Their work together at the FRCH propelled them into looking deeply into ethics of research in the later years at CEHAT.

recalls how the abortion project ushered her into ethics when she joined CEHAT in 1994. Bandewar, now based in Pune as an independent bioethics consultant, was nominated to pursue by the ICMR to pursue a Masters level course in bioethics from Toronto, in 2003. After returning with formal training in bioethics, Bandewar briefly became part of the Centre for Studies in Ethics and Rights (CSER), a new venture of the Trust, which is discussed later in this study.

In keeping with its roles as a research centre providing active support to activism and offering constructive interventions, CEHAT, in a joint initiative with the Public Health Department of the Brihanmumbai Municipal Corporation (BMC) set up Dilaasa in 2001. Dilaasa was conceived as a hospital-based crisis centre, the very first of its kind, to respond to domestic violence (Deosthali, Maghnani & Malik, 2005). Though CEHAT did not establish itself as a bioethics centre, the nature of its work in health and healthcare since 1994 laid the foundation for the rise of a separate bioethics centre in 2005. While working towards its goal of collaborating with other organisations and individuals, the Anusandhan Trust has, in turn, paved the way for several individuals to diversify into ethics. For instance, Dr. Mala Ramanathan, Additional Professor, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute of Medical Sciences and Technology, Trivandrum, recounts how in 1999, "CEHAT made us do ethics because our proposal for the Abortion Assessment Project of India needed ethical clearance. In my earlier research, we had considered ethical issues, but we saw it merely as a technical issue – not one that required more engagement than ensuring methodological soundness.

Dr. Suneeta Krishnan, Adjunct Associate, Epidemiology and Statistics unit, St. John's Research Institute, SJNAHS Bangalore, describes her acquaintance with Jesani in 2001 as her "first introduction to somebody in India who actively was thinking on working on bioethics". Both Ramanathan and Krishnan are now on the editorial board of the IJME. Barun Mukhopadhayay, anthropologist at the Indian Statistical Institute, Kolkata, encountered bioethics in Manila in 2004 where he was attending a course for which Jesani was one of the instructors. The experience, he narrates, changed his perception about research. The training prompted him to go back to his research field in Darjeeling and seek the participants' feedback and perception about his research.

If we consider the various levels of narrations in this section, we can begin to see how issues in bioethics have drawn interest groups together or made interest groups possible and sustained them long enough to operate through collective wisdom.

Setting a base for medical ethics

The Forum for Medical Ethics Society (FMES) emerged from an effort by a group in Mumbai to expose malpractices in the Maharashtra Medical Council in 1992. The history goes like this: in 1989 a few individuals from the MFC like Jesani and Anil Pilgaokar and other practicing doctors from Mumbai like Dr. Yash Lokhandwala, Dr. Sanjay Nagral, Dr. Santosh Karmalkar, Dr. Arun Bal and Dr. Sunil Pandya decided to fight the Medical Council elections with an intention to expose the malpractices in the body. Recalls Pilgaokar, a former biochemist and activist, "I think it was Bal who said that, 'We just complain that there is no ethics and we don't do anything. If we are so particular, then there is the Maharashtra Medical Council election, we have to contest that'". They were aware that winning such an election was not an easy task but they made a commitment in their manifesto that even if they lost they would continue fighting for medical ethics. That is how FMES was born. In 1993, the Forum began a newsletter which found popular circulation among medical students and among doctors as well. The group formed a study circle and unfailingly met every Wednesday at neurosurgeon Dr Sunil Pandya's department. The very first issue of the journal published in August-October 1993, then as a newsletter, started with the Medical Council election story and covered a whole range of issues from clinicians being complicit with the state in throwing patients' autonomy to the wind, to inviting readers' comments on an issue that appeared in a newspaper regarding a complicated case of a pregnant woman with tetanus. At the end of its first year, the Forum decided to convert the newsletter into a journal, calling it *Issues in Medical Ethics* and later it renamed *Indian Journal of Medical Ethics*. It is self-funded, indexed and peer-reviewed journal, with contributors from across the globe and dealing with a host of ethical concerns in health and healthcare, especially in India.

Dr. Sanjay Pai, consultant pathologist at Columbia Asia, Bangalore, has an interesting story about his initiation into the Forum. "In 1995, I came across this issue [of] *Issues in Medical Ethics* and it looked good. I knew one of the names on the board, Sunil Pandya, professor of neurosurgery, who was just next door [to me]. I was at Tata Memorial Centre, Mumbai then. And I knew that he was a good man, and I said here is one small group which is trying to do some good. I promptly wrote a cheque for INR 1000 and sent it off to them saying that I will become a life subscriber […] Then over the next one year every time I came across an article on ethics, I would photocopy it and send it off to Sunil Pandya. I had not met him and he had not seen me although we were just on the opposite sides of the road. I was there for about one-and-a-half years. Then in 1996, July-August when I was sitting in Tata Hospital, the phone rang. It was him on the phone and he said 'We meet every Wednesday in my office. We would like you to come and join us'." Though he initially felt unsure, Pai went to the Forum and since then has remained an active member. Over the years the Forum grew – under several editors including Arun Bal, a founder member of FMES – to include not only medical practitioners but also individuals from other fields. "We naturally want more alliances as there are many enlightened people and their association will be crucial in the long term. This is an experiment. How far it will last, what kind of tension will be there, I do not know. But we are opening it up and bioethics as a term is coming in handy to strike this balance and build them all together," Jesani, editor of the IJME since 2012, says on a hopeful note.

So far, the journal had prided itself as being the only journal of its kind in Asia. “The only indexed journal in medical ethics from Asia is the IJME, so at least on that front we are doing well,” says Sanjay Pai who overlooks the review pages of the journal. The only other journal which also carries articles on ethics regularly, besides other issues is, according to Pai is, the National Medical Journal of India (NMJI). “Whenever someone has to submit a paper on ethics in India, they choose one of the two journals depending on who they want to address. The NMJI is only for medicos whereas the IJME is for a larger audience including philosophers … frankly, half the editorial board of one sits on the editorial board of the other.” Pai adds.

In 2004 the Forum conceived of a conference format in bioethics to include players not merely from bioethics but the entire health field on a national scale. The first National Bioethics Conference (NBC) was organised in 2005 in Mumbai, which proved to be one such platform for people from all walks to come together. The conference, organised around four issues (ethical challenges in HIV/AIDS; ethics of life and death in the era of high-tech healthcare; ethical responsibilities in violence, conflict and religious strife; and ethics and equity in clinical trials) saw a participation of 350 healthcare providers, medical educators, biomedical and social science researchers and others from 20 institutions (Ramanathan, Krishnan, & Bhan, 2006). “Apart from Amar [Jesani], Nobhojit Roy was another key player in the first NBC. He came from Sion Hospital and worked for BARC Hospital. He was a mainstream doctor. His connection with medical doctors in Mumbai was critical,” recounts Neha Madhiwalla, who has been closely associated with NBC since its inception and is currently the coordinator of the CSER, Mumbai. Comparing the NBC to conferences organised by the ICMR, Muthuswamy says, “[NBC] comprises the entire healthcare area. Issues of equity, accessibility, all those come out. But when you look at the ICMR ethical guidelines and most of the conferences held there, they are restricted to research ethics.” Analysing the circumstances under which the NBCs were conceived, Madhiwalla in her editorial in the IJME notes how bioethics has largely come to mean “embracing the paraphernalia of the international research ethics regulation" (2011) including guidelines, ethics committees and training programmes. The need to go beyond this boundary and think about the varied possibilities bioethics holds for a country like India through wider debates and discussions paved the way for NBC. For a majority of the participants located in various regions of India, who were part of this study, IJME and its NBC was the singular reference for a visible platform of bioethics in India. The conference format is such that it attracts a range of individuals – researchers, clinicians, ethics committee members, government representatives, bioethicists, social scientists and theologians with specific interest in bioethics.

The second NBC was held in Bangalore in 2007 and attracted participation from 36 organisations, while the third was held in New Delhi in 2010 and saw the participation of 38 organisations. What drew the organisations, which had not necessarily identified their activities or work as bioethics, together to the conference could warrant a study in itself. One member from each organisation sat on the Organising Committee and the speakers were selected through a consensus. "They all came from different backgrounds and agreed to a common set of participants. It is something remarkable and I cannot explain how it has happened," bemuses Jesani. He recalls a small controversy that arose during the second NBC when a few participants put up anti-abortion posters which were in conflict with the ideology of the FMES. It were Dr. Sunil Pandya and Dr. Armida Fernandez, former Dean of Sion Hospital Mumbai and trustee of FBMEC, who were on the National Advisory Committee of NBC and helped to dilute the situation. But that is not to say there is no room in NBC for a difference of opinion. For instance, Mala Ramanathan describes the NBC as "a great accreditor" of an individual. She says, "Because there is so much diversity in the group, that everyone is accepted. And there is no rejection. You can't say that of all disciplinary groups. For instance, I work in an institution where I'm not a mainstream discipline person. I'm a social science person in a medical institute […] You can't be part of the mainstream in such a setting, so you have to be always in the periphery, watching others become a part of it. To legitimize your self esteem, your existence, you need to go to a space like the NBC where you are allowed to be, whoever you are!” A major success of the NBCs so far has been its success in creating a corpus of knowledge on bioethics in India at a time when bioethics is still trying to find firm roots as a discipline in itself.

A close study of the members on the editorial board of the IJME will help illustrate how bioethics has been successful in bringing together varied interest groups on a single platform. Since its uninterrupted quarterly publication 1993 onwards, the IJME has published on a significant corpus of bioethical subjects like ethical dilemmas in the area of HIV/AIDS treatments, narco-analysis, abortion, foetal sex selection, public health policies, medical malpractices, organ transplant, clinical trials and others, inviting both arguments and counter arguments from its contributors. On the editorial board are doctors, lawyers, NGO activists and social scientists, not only from different parts of India but different countries too. It would indeed be a useful source for further study to analyse where discussions of bioethics in India stand in comparison to discussions in the West, where bioethics is a much more established field.

Institutionalising ethics

The Centre for Studies in Ethics and Rights (CSER) is a unit of the Anusandhan Trust. The CEHAT was already working on a host of issues in healthcare and services like reproductive rights, human rights, patient rights and gender violence. So, what then prompted the rise of CSER as a separate organization with a distinct role to play?

Jesani narrates how an ethics programme initiated in CEHAT was not expanding as originally conceptualized, especially because CEHAT’s hands were “completely full”. It was at a time when he had returned to Mumbai in 2003 after his stint as Programme Coordinator at the Sree Chitra Tirunal Institute of Medical Science and Technology, Achutha Menon Centre for Health Sciences, Trivandrum. Jesani realised it was necessary to consolidate work on ethics at one place. The CSER arose as the logical conclusion to these two situations. Jesani volunteered to establish the Centre. As an activist with a firm base in human rights movements and a belief that the basis for bioethics in India is human rights movements, he only found it natural for ethics and rights to coexist. Amidst "debates" on whether the CSER was indeed necessary, timely impetus was provided by leading U.S. bioethicist Ruth Macklin, who visited India in 2004. Neha Madhiwalla recounts how the first three years of the CSER were like a "threatened abortion" – because for the first three years the Centre had no projects on bioethics.

In this period the Centre afforded space for the IJME, which though in circulation since 1993, had no permanent office structure. "Without the institutional support of the CSER, we could not have had the NBCs," Jesani narrates. So in the initial years of the CSER, work was confined to working for the IJME and monitoring and evaluation projects. And there was the need to deal with criticism regarding the efficacy of a new centre when CEHAT was already functioning. And to add to it was the "jab" that CSER was merely a secretariat of the IJME, especially after having assisted in organising the first NBC. Says Madhiwalla, "These were things we had to face … There was no Indian model at that time. There were no bioethics centres in India that were, as such, secular. So we had to look at Joint Centre for Bioethics (JCB) or Hastings Centre in the U.S." The Hastings Centre was the closest example for the CSER as it was an independent centre, not linked to any university. Madhiwalla is quick to point out that resource-wise they could never dream to be Hastings Centre though.

The CSER began with a broad vision – to look at ethics in general, including medical, law and social welfare. Two of the first people to join CSER were Sunita Bandewar and Anant Bhan, one an anthropologist, another a doctor, both trained in bioethics at the University of Toronto. Bandewar and Bhan are now both based in Pune, where they work as bioethics researchers for national and international organizations; both of them are inclined towards research ethics. Jesani was working in the area of clinical trials. Dr. Nobhojit Roy and Madhiwalla were interested in clinical practice, a less worked on area, and hence one that attracted less funding than research ethics did. The journey to make CSER sustainable was anything but easy, as Madhiwalla recounts. “How do we do something meaningful in the Indian context which fits within the domain of bioethics but is not necessarily confined to just ethics, but also includes rights? At the same time we had to distinguish ourselves from our counterparts CEHAT and SATHI. And, of course, [from the] IJME,” she says. It took several rejections before a proposal co-authored by Sandhya Srinivasan, journalist and presently consulting editor of the IJME and Madhiwalla was selected by the Wellcome Trust. The project was a two-year one to conduct a qualitative study of perception of ethics and ethical challenges among obstetric care providers in Mumbai hospitals.

By 2007-2008, the CSER had become a ‘stop-over’ for a bunch of individuals trained in bioethics by the ICMR. Despite initial adversities, the CSER managed to find its ground and complete several projects like ‘Ethical issues in research on pharmaceuticals in India’, ‘Making TB programme gender sensitive: a case study of Mumbai’ and take on many more like, an ethical analysis of the practice of obstetric care in Mumbai, and another project on critical perspectives on biomedical and health experimentation in South Asia, by 2010. Envisaged as a research and training institute, the CSER has on its board faculty members from varied backgrounds including medicine, media and the social sciences. The Centre also has its own institutional ethics committee to scrutinize its proposals. After five years of steadfast effort at identity formation, Madhiwalla feels “Vision-building in CSER is still not a complete exercise.”

Networking for people’s health

At the outset, Support for Advocacy and Training to Health Initiatives, SATHI, located in Pune, is an action centre of the Anusandhan Trust which branched out from CEHAT in 2005 after being part of it for seven years. A collaborative primary healthcare project with three People's Organizations – Shramik Mukti Dal Kolhapur, Maharashtra; Kashtakari Sanghatana, Thane, Maharashtra; and Adivasi Mukti Sanghatan in Madhya Pradesh – set the ball rolling for SATHI. The SATHI has been part of Jan Swasthya Abhiyan (JSA), a network of 21 organisations with varied ideological backgrounds, which came together to organise the National Health Assembly in solidarity with the People's Health Assembly (PHA). The PHA was again a coming together of people's movements and other non-governmental civil society groups in 2000 to remind the world about the forgotten commitment of the Alma Ata Declaration, where Governments of countries gave a written promise promising "Health for All by 2000".

Dr. Anant Phadke, medical doctor turned activist working as a senior advisor at SATHI, is an active participant of the JSA. His is again a story of long association with groups like the MFC, All India Drug Action Network (AIDAN), and All India People's Science Network (AIPSN). "I've been part of five to six organisations related to science and health movements in India and in most of them we've taken up issues which have some direct bearing on ethics," he says. For instance, he is the founder-member of AIDAN, a national network of several non-governmental organisations which emerged in 1981. One of the first campaigns launched by AIDAN was against hazardous drugs and drugs which were banned and withdrawn by companies from the country of origin. They first started with a campaign against oestrogen-progesterone forte, a formulation used in the early 1980s to detect pregnancy, which had the potential to cause congenital malformations. Their campaign forced the Drug Controller of India to conduct public hearings at the behest of a court order and finally the formulation was withdrawn. Phadke narrates another campaign with which he was involved in the early 1990s. They chanced upon evidence that the Sassoon Hospital, a state-run medical hospital in Pune, was planning to remove the uteruses of some mentally challenged girls and women aged 15-40 years through laparoscopic vaginal hysterectomies, apparently in the best interest of the women. Several women's organisations including Janawadi Mahila Sanghatana and individuals came together to form a group called Prayas. "We lodged a PIL in the court and complained to the Medical Council of India ethics committee that the move was unethical … There was a lot of debate in Pune," Phadke recounts. Amidst severe criticism, Phadke, Gupte and others wrote to the Human Rights Commission, which moved the ethics committee of the Medical Council of India, which in turn declared the move unethical. Surely such consolidations and concerted efforts as represented by interest groups in this section demands an in-depth study. How has bioethics in India drawn inspiration from these activist and advocacy health initiatives, which while being fragmented, also remain interconnected?

Prioritising patient rights

Dr. Arun Bal, one of the founder-members of the FMES and Editor of the IJME for some years, is also a founder-member of the Association for Consumer Action on Safety & Health (ACASH). A voluntary organisation addressing health-related consumer issues besides advocating the rights of the consumers, ACASH was founded in 1986 – the same year that the Consumer Protection Act came into existence in India. But its emergence had little to do with the Act and more to do with their own involvement in the consumer protection movement since early 1980s. Bal, a trained doctor with a doctorate in political science, relates how a group of friends, some part of the Consumer Guidance Society of India (CGSI) in the late 1980s, felt a need for a unified organisation dealing with all aspects of health. The result was ACASH. As a practicing doctor involved in healthcare and the consumer movement since 1981, Bal felt the need to look beyond his discipline for tackling issues that he encountered in these movements. No surprise then that ACASH was a coming together of friends like Dr. R.K. Anand (founder-president of ACASH), Dr. Manohar Kher, Dr. Amdekar and Yogesh Kamdar from varied disciplines, including law.

The ACASH set out with several objectives including the aim to educate and organise consumers; to provide a forum for redressal of consumer grievances; and to network and collaborate with other organisations like AIDAN, Voluntary Health Association of India (VHAI) and WABA (World Alliance for Breastfeeding Action). It also decided to engage in consumer activism, research and mobilisation in health-related issues. It is also an active collaborator with and technical advisor to various government bodies**.** Its milestones, among others, are in the areas concerning cases of infant and young child nutrition.[23]

However, ACASH essentially approaches ethical concerns from a human rights perspective. Bal, who has written on patient rights and responsibilities (available on the ACASH website) is against "putting labels to groups". "Bioethics in India will have to evolve through healthcare issues … I see many challenges for healthcare and as healthcare evolves in changing globalisation and economic liberalisation, many new issues are likely to emerge and they need to be tackled. It is necessary that we have more broad-based organisations which involve many more doctors, and ethics needs to get out of classrooms and seminars and courses," he says. Bal is however, scathing in his criticism of bioethics debates. He continues, "Private practitioners are almost completely out of it. This is because ethics people only talk of theory and not the practical problems faced by practitioners." He is impatient about attempts at labeling groups, saying that anyone concerned with patient welfare and working towards that should be considered as doing bioethics work – "There should be no caste system in people working for healthcare." Like Ravindran of SJNAHS, Bangalore, Bal too sees the Consumer Protection Act as a turning point for bioethics in India.

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[23] The official website of ACASH (http://www.acash.org/index.htm) lists its successes with cases of violation since 1993.

A case for public health ethics

In 1983, two doctors, teaching community medicine in SJNAHS, then St John's Medical College, Bangalore, quit after being disillusioned by the "phenomenally biomedical" nature of their work which considered "non-medical, non-disease-oriented, non-treatment" approaches to health as outside the curriculum. It was a time and place where, for instance, worrying about malnutrition without delving into the agricultural policy issues was the norm. They quit secure jobs realising that if they wanted to be truly interdisciplinary, they needed to look at health not merely in terms of 'diseases', but through social, economic, cultural and political lenses, and that, for this end, a biomedical structure was neither appropriate nor adequate.

The two doctors – Drs. Ravi and Thelma Narayan – decided to travel to the interiors of India to see for themselves the potential community health held. By then they had been considerably influenced to look at health through an interdisciplinary lens, courtesy their association with groups like Indian Social Institute (ISI), Bangalore, Voluntary Health Association of India (VHAI) and the MFC. Says Ravi Narayan, "There was a disconnect between the ethics that I had been taught as a student, which was more about issues such as abortion and euthanasia, whereas [...] in MFC and ISI, we talked about social justice issues, about access, equity and things like that." After six months of travel and six more months of reading and reflection, they set up the Community Health Cell (CHC) in Bangalore in 1984. With them was a close friend Gopinath who had also quit as secretary to the head of the Department of Community Medicine in St. John's. A few years later, two more doctors from St. John's – Drs. Mani Kalliath and Shirdi Prasad – also joined the boat.

The Bhopal disaster in 1984 brought the CHC closer to various other interest groups like AIDAN and Asian Community Health Action Network (ACHAN), besides the MFC, CHAI, VHAI and the Christian Medical Association of India (CMAI). The CHC's journey in community health was marked by an effort to network with other like-minded groups to create a critical mass for health and development. It also included on its board some senior individuals who were "rational and ethical". Dr. C. M. Francis, then retired from SJNAHS, joined the CHC and went on to write his book on medical ethics. Then there was Dr. D.K. Srinivasa, retired Dean of Jawaharlal Institute of Post Graduate Medical Education and Research (JIPMER), Pondicherry, who, during his tenure had "set up the first medical teacher training centre."

According to an in-house publication of the CHC, the review of its first five years threw up a recommendation to register the study-reflection-action team from 1984-89 as an autonomous society carrying ahead CHC's work thus far. In 1990, they registered as the Society for Community Health Awareness Research and Action (SOCHARA). While the CHC was the functional unit, SOCHARA was envisioned to build on the work of CHC. From 1994 onwards the CHC expanded its community health training activities, besides working towards strengthening the health movement at all levels. For instance, between 2003 and 2006 Ravi Narayan acted as the coordinator of the global People's Health Movement secretariat. Though the CHC has never identified itself with bioethics, it believes "ethics permeates every aspect of any health-related issue." Ravi Narayan sees the field as coming from the West and the ICMR as an instrumental body in popularising bioethics. "We are doing many things that come under that. But we didn't use the term 'bio' […] We left the biomedical model long back and brought ethics into the social community era … We should go further and call it public health ethics."

Thelma Narayan believes it is context-specific and there is a great need to dwell more on glaring issues in health in India like under-nutrition, hunger and starvation, which come under the purview of public health ethics. Also on the organising committee of the second NBC, Thelma feels that rather than a more westernised discussion of bioethics, as some papers had focused on in that conference, the need of the hour is to develop bioethics from and for an Indian context.

Ethics beyond healthcare

In the mid 1980s, the University of Madras relaxed its rule for its PhD students, allowing them to attach themselves to an additional discipline provided they registered with one more supervisor from the selected department. Prof. J. Azariah, then teaching zoology at the University, encouraged two of his students to diversify into a different discipline. They chose psychology. Azariah's journey in interdisciplinary work that began then, culminated in his discovery of bioethics. A chance meeting with bioethicist Darryl R. J. Macer (Regional Advisor on Social and Human Sciences in Asia and the Pacific, UNESCO, Thailand and founder of Eubios Ethics Institute Thailand) in 1992 in Chennai, ushered Azariah into the field of bioethics. Macer's take on bioethics as a "love of life" (1998) encompassing an ethical concern for everything in the world including environment, animals and humans appealed to Azariah. When Azariah shared his students' 'trans-disciplinary'[24] work with Macer, he suggested they work in partnership. They set off with a project on bioethics education and awareness in schools in Tamil Nadu, India, seeking to collect data on the knowledge of Indian teachers in bioethical issues in order to "understand the real ability of teachers to introduce bioethics there" (Vittabai, Azariah, & Macer, 2003).

In 1996 the All India Bioethics Association (AIBA) was formally registered and in 1997 it held its first international workshop-cum-seminar on bioethics in Chennai. Being from a university, Azariah could apply for his share of government grants for the seminar. The seminar had 300 participants including philosophers, poets, historians, educationists, lawyers, marine biologists and theologians and the proceedings were later published as a book (Azariah, Azariah, & Macer, 1997). In 1998, Azariah, Macer and three others travelled across the country networking with institutions/individuals and spreading the word on bioethics. Their stops included the VMKV Medical College, Salem; the National Law School of India University, Bangalore; the National

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[24] Azariah feels 'interdisciplinary' is about separate disciplines collaborating together whereas 'trans-disciplinary' is disciplines crossing boundaries to become one unit, and bioethics should be trans-disciplinary in essence.

Chemical Laboratory, Pune; Ahmednagar College, Ahmednagar; and the All India Institute of Medical Sciences, Delhi. The meetings also won them members for AIBA. In 1998, the AIBA started a newsletter called AIBA *Newslink*, meant only for private circulation, and carrying nuggets and short pieces, mostly rhetorical, on issues such as abortion, fertilisation, ethics of human genome sequencing, euthanasia and organ transplant. Staking claim for initiating the birth of bioethics in India, the first volume of *Newslink* states: "The birth of bioethics in India is as follows: It was a casual meeting between Prof. Darryl Macer and Dr. Jayapaul Azariah … and the relationship grew … The first International Workshop-cum-Seminar on Bioethics in India was held at the University of Madras during January 1997." In his interview to our study, Azariah emphasised that "ours is the first attempt to bring bioethics to India." While "it was Medical Ethics in Bombay", theirs was bioethics encompassing all ethical concerns. Over the years AIBA went on to hold bioethics conferences in Madras Christian College and Loyola College, Chennai. In 2003, AIBA organised a world conference on Nature, Science, Technology and Religions: Our Common Bioethical Issues. An editorial in the AIBA newsletter of December 2003 reports: "There were agnostics, atheists, 'pagans', Christians … theologians, scientists and social scientists, social activists, Hindus, Hindu S*anyasies* (sic) (saffron clad *yogi*), *Aiyappan* Devotees (a Hindu sect with black dress) and Muslims" at the conference. A workshop on high school bioethics was also held by Macer for school teachers.

In 1998, while Azariah was still the head of the Department of Zoology, the Academic Council of the University of Madras approved the restructured B.Sc Zoology curriculum which had included bioethics as one of its component. Azariah narrates how nobody took the course because there were no jobs for bioethics. Since it was a new area of study, there was also some resistance to it within academic circles. But Azariah continued to take students to work in bioethics. The activities of AIBA with 146 members to boast of, slowed down after 2000, when Azariah retired from service. "We had funds for three more years. The mistake we did was we were too ambitious in publishing six newsletters each year. If we had kept to two, we would have still been publishing it," he rues. But one passion he still harbours is to continue with bioethics education, if possible involve in restructuring the curriculum. "If I were in the university, I would have brought all the people together to do this work," he says, reliving the days when he actually started his tryst with bioethics with such power. All through the interview, his emphasis on the importance of a space like a university set-up which can provide a notable structure, visibility and identity to an event, in this case the dissemination of bioethics, could not be ignored.

Debating the right to die

The Society for the Right to Die with Dignity (SRDD), now known as Mahaprasthana (Grand Exit), was founded by noted parliamentarian Minoo Masani in 1981 to campaign for the right of the terminally ill individuals to end their life if they so desired (Raju, 2007). S. V. Raju, editor of *Freedom First*, *The Liberal Magazine* published from Mumbai, joined the Swatantra Party in 1959. He was then a 29-year-old political science graduate looking for a job. He joined Masani and from then he was "associated with anything Masani was associated with". Ever since SRDD was founded, Raju has been a member of the Society, keeping it together in times of high and low. Raju relates how attempts at making euthanasia legal started in early 1980s when Vasantdada Patil was the chief minister of Maharashtra. Dr. Sadanand Varde, member of the state legislative council and later President of the Society, moved a "private member's Bill for legalising a Living Will, an advance directive issued by an individual stating one's wish for the withdrawal of artificial life supports or treatment. He narrates an interesting story. 'That was the only Bill in Maharashtra, I believe at that time, which was circulated for public opinion, because some doctors and the Catholic Church were opposed to it, even now they are opposed to it … and they did counter-campaigning. According to the papers that we have, a large majority supported the Bill. The then chief minister Vasantdada Patil was favourably inclined. But after the Bill was circulated for public opinion and public opinion was more [in favour of euthanasia] than what the doctors and the Catholic Church would have liked, he suddenly said that his partymen (Congress) will not support the Bill because his party men were divided on this. And so what Varde did was, when the Bill came up for admission, he absented himself … so the Bill fell without being voted. Varde did so because if you put a Bill and if it gets defeated, taking it up again becomes a major problem. 'It is already a defeated bill. It has been rejected by the assembly, why should we take it up again?' will be the refrain. So he did not want to leave his people who come after him, similarly inclined, with no options'." That was a big point of the society's work.

After Masani, the Society and its objectives found a strong proponent in Dr. B. N. Colabawalla, a famous urologist in Mumbai then, who played a key role in pressurising the Indian government to enact the Human Organ Transplant Act of 1994. In his booklet, *Reflection on freedom to choose, dying with dignity, voluntary euthanasia,* he wrote how his personal experience with his mother, who died after much suffering from chronic kidney disease, triggered his interest in the issue. It made him wonder more deeply about moral and ethical means for a way out of this dilemma both for the patient and himself. The Society gradually attracted the attention of several others, mostly of doctors. Dr. Nagraj Huilgol, who joined Nanavati Hospital in 1980 and went on to build a state-of-the-art radiation oncology centre there, has been with the Society for over two decades now. Having closely worked with cancer patients, he realised what terminal pain is and that sometimes only death can be a palliative. "When I say this, I'm cognizant of the fact that one should make all efforts to alleviate pain … but at the end of the day when someone finds very existence an ordeal, then the person has the right to live only as long as he or she wants to. And also to seek termination. As much as the doctor has the right to refuse. And that not too many understand," elaborates Huilgol who is editing a book on medical ethics along with Dr. Rohit Manchanda and Varsha Dutta.

In 1995, when Dr. Colabawalla was debating on euthanasia in a talk show on television, Dr. Surendra Dhelia, a family physician who has his clinic in south Mumbai, was impressed by his views and spoke to Colabawalla seeking membership to the Society. Dr. Colabawalla was the chairperson of the Society then. At that time, there were roughly about 300 members and Dhelia soon went on to be part of the Executive Council. Subsequently Dhelia appeared in a number of national television debates on euthanasia and right to abort, the latest being the Aruna Shanbaug case. "Recently in March 2011 when Hon'ble Supreme Court delivered the judgment in Aruna Shanbaug's case (Ms Pinky Virani v/s Govt. of India) our members were invited to give their views on this controversial subject. This included almost all reputed TV channels like NDTV (Hindi and English, including 'We the People'), CNN IBN (Hindi, Marathi and English), Star, Headlines, and Aaj Tak in addition to various print media, national as well as international," relates Dhelia. He practiced what he preached and in 1996, he and his family decided to let his aged father, who was terminally ill, die a peaceful death.

It was Dhelia who introduced R. N. Bhaskar, consulting editor *Daily News Analysis*, to the Society in 2008. Bhaskar, who has written in the print media on the Aruna Shanbaug case, says, "The clamor for allowing death is growing for two reasons: one where a Aruna Shanbaug blocks a bed and 30,000 patients die because a bed is blocked in a country where medical resources are not easily available, you have a demand side anguish and protest against a bed being blocked. On the other hand there is a group of people that believes that when life has lost dignity it should not come in the way of death. And I support both the camps." In 2008, the Society organised a symposium in Mumbai on the right to die with dignity. This was yet another step towards creating a noise in the public and the media regarding the necessity to legalise voluntary euthanasia and Living Will. The Society had a cause to celebrate that year. The Law Commission of India had recommended that euthanasia be legalised, adding strict conditions against its misuse. Says Raju, "The Society definitely put on the map for public discussion this question of freedom to live and freedom to die. But for the Society, most of India would not have known about this [euthanasia debate] at that time." It got itself impleaded in a petition filed by 'Common Cause' in the Supreme Court seeking legal sanctity for voluntary euthanasia and the Living Will. Though functional since 1981, the Society had not registered itself. Recently when they decided to formally register, the name ‘Society for the Right to Die with Dignity’ was rejected on the grounds that the title involved ‘right to die’ which was unlawful and illegal.

Characteristically, never once has the term bioethics been used in any of the Society’s discourses. Dhelia rounds it up saying, “I have never employed the term bioethics and have no idea about the various connotations of this term”.

6. Conclusion

This study set out to draw an outline of the history of bioethics in India from 1980 till 2010. Though briefly, the study has attempted to show how health issues taken up by interest groups such as the MFC or the women's movement, in a way, set the stage for bioethics to make its entry through one of the side wings. The key player on this stage has been human rights. The consolidated and concerted efforts in ushering change, a characteristic of the interest groups, opened up entry points for bioethics in India. The official route was not laid out in visible terms until the 1990s, and even then its scope was largely restricted to research ethics.

The other entry points it gained, drawing on inspiration from different interest groups, helped it to consolidate a place for itself, even if it meant through different labels. Among the groups we looked at for the study, institutes like St. John's and the CMC still largely deploy the word 'medical ethics'. The IJME has grown with time to include bioethics in its idiom and occupy an unrivalled space as the "only such journal" in the country. The IJME's unique initiative – the NBC – was an important launching pad for bioethics, making it at once visible nation-wide. The CSER started out to look at ethics in different spheres but bioethics became its main preoccupation. For the ICMR it is "one of the several activities". The FBMEC opts to call it bio-medical ethics. The AIBA's description of bioethics is all encompassing while groups like SATHI, ACASH, CEHAT and SRDD, whose some activities are within the purview of bioethics have, at no point, felt compelled to use the term for promoting or describing their activities. If anything, the idiom is human rights. For the CHC, the predominating need has been to go beyond the bio-medical model and engage with issues of public health, issues such as *access* more than *rights*, which in a way complicates the understanding of bioethics.

The study has also illustrated how questions pertaining to the ethical dimension of science and medicine invariably involved people from every genre and field, thus making it interdisciplinary. The invocation of a collective wisdom to reflect on ethical issues prompted an intermingling of individuals from different interest groups. Centres like the SJNAHS, Bangalore; National Institute of Mental Health and Neurological Sciences, Bangalore, or the Achutha Menon Institute in Trivandrum afforded space for collaborative efforts.

6.1 A need for identity

While war crimes, illegal trials, new inventions in biological and medical technologies, debates on the allocation of limited resources, issues concerning eugenics and gene therapy – to name a few – formed the crux of bioethical concerns of First World countries, the same does not hold completely true for the rise of bioethics in India. It cannot be disputed that bioethics has come to India as an import from the West, but bioethics in India cannot be restricted or comprehended within the parameters of research ethics guidelines, ethics committees or even bioethics training courses. Unfortunately little has been done to collate a history from various movements like those in human rights, women's rights, consumer rights or public health initiatives that have strongly impacted and informed the bioethics discourse in India. The experiences that have shaped healthcare in India are different from those in the West, and bioethics has to be understood through these experiences, these contexts.

Even as it includes issues such as euthanasia, in-vitro fertilization, gene therapy, ethics in clinical trials and others, bioethics in India has to equally concern itself with questions of poverty, hunger, disease, government's skewed developmental programmes, people's needs and inequities. Medicine cannot be practiced in a consultation room alone or ethics cannot merely appear on a piece of paper. It cannot be merely regulated by ethics committees or a set of guidelines for clinicians to adhere by. It has to be related to the social, cultural and economic aspects of health and disease. For bioethics to evolve thus, it first requires to acquire an identity of its own by consolidating the histories that have shaped the vast field of health in India. Offering course options or creating job opportunities in bioethics can be more meaningful if bioethics in India is situated in the histories that have shaped health initiatives and concerns.

6.2 Limitations of the study

This is an exploratory study and carries with it certain limitations:

I. It has not delved into individual journeys in bioethics in India. Like the case of Sr. Daphne Viveka, whose journey in bioethics began in the 1980s. An Erasmus Mundus bioethics scholar, she is now vice-president (India) of Asian Bioethics Association and associated with the Society of the Sacred Heart in Patna working in the field of remedial education. How are these journeys contributing towards shaping bioethics in India? How are their associations or networking with other groups/individuals being played out? What are the available platforms?

II. Second, the study has not covered some other groups in the country whose activities have contributed towards raising bioethical concerns. Or, whose contributions have paved the way for bioethics to co-opt and assume an identity in India. For instance, Saheli, a women's resource centre in Delhi set up in 1981. The group has taken up several health issues over the years, especially against hazardous contraceptives like Net-En, Norplant and Depo Provera. Many of these campaigns have been in collaboration with other women's and child rights' groups. Then there is SAMA, a resource group for women and health in Delhi, one of whose objectives is to conduct action research and document issues critical to women's health with an ethical perspective. Some of its publications are a case in point.[25] Another group is Society for Scientific Values[26] set up by scientists from Delhi in 1981 (registered in 1986) with an intention to improve the climate of scientific research by emphasising need for promoting ethical values. Prof. K. L. Chopra, president of the Society, explains how they investigate into serious misconduct which includes plagiarism in research and fraud, and

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[25] For more see: http://www.samawomenshealth.org/pubs_otherjournals.html

[26] For more see: http://www.scientificvalues.org/index.html

the institutes covered are mostly big names like the IITs, IISc and top medical institutes. Though they do not get into legal battles, they create pressure on the institutes to penalise the wrong-doers.

III. The study has also not looked at the vast area of HIV/AIDS that has impacted bioethics in India.

6.3 Notes for the future

By collating a history of bioethics through personal experiences, even while looking at influences that could have triggered these histories, the present study has hoped to illustrate how bioethics can be understood within an Indian framework. The field is slowly gaining ground through academic courses, workshops and conferences, and collective efforts of physicians towards establishing medical humanities units, like the Medical Humanities Cell at Seth G.S. Medical College and KEM Hospital in Mumbai and the Centre for Ethics in Yenepoya Medical University, Mangalore. But more consolidated efforts are necessary to showcase bioethics grounded in the country, drawing from its various histories.

The study throws up the following possibilities for consideration:

i. All along it is seen how varied groups come together to play out bioethical concerns. While we have not foregrounded the idea of interest group as a conceptual device, such an exercise could be productive. There is considerable secondary literature on interest groups, which the study has not delved into. An in-depth study of such collaborative efforts conceptualised as interest groups and the manner in which these efforts prompt change would be interesting to pursue;

ii. In instances where law determines what is ethical, how bioethics gets situated and what are the roles it assumes and boundaries it acquires that provides it a stage of its own?

iii. The study has raised a few questions pertaining to the impact of training programmes on bioethical activities in India which would be useful to engage with;

iv. How does bioethics as an import from the West address issues plaguing public health in India – issues of scarcity and unequal distribution of resources? How does it play out in an atmosphere of hunger, poverty, conflict and diseases that emanate from these circumstances?

v. How does bioethics account for a place for itself in India? What are the spaces it inhabits? How does it set itself vis-à-vis human rights? Is bioethics merely echoing the concerns of the West, applying the concerns and principles directly in their imported state or is it widening its focus to reach a wider public, thereby ensuring a wider relevance for itself in India?

vi. What are some of the perspectives on bioethics of individuals engaged in activities that concern the ethics of healthcare?

The questions surely prompt further studies in the field of bioethics in India.

Annexure: List of participants.

The information is culled from the interviews and the curriculum vitae the participants shared for this interview. While the information provided below does not exhaustively represent the participants, it lends focus to the bioethical activities these individuals are engaged in either as part of their professional work or individual interest.

	Participant	About the participant	Location
1	Dr. Amar Jesani	A medical doctor turned social scientist from Gujarat, Jesani is an independent researcher and a visiting faculty to many institutions both in India and abroad. He is a trustee of Anusandhan Trust which manages three institutions –CEHAT, CSER and SATHI. He has taught at the AMCHSS, Thiruvananthapuram and has published extensively on issues related to bioethics. He is a founding member of the FMES, Mumbai and currently the editor of the IJME.	Mumbai
2	Dr. Anant Bhan	A physician with a Master degree in bioethics from the University of Toronto, Bhan is a consultant researcher working on bioethics and public health. As a bioethicist he is associated with Ethical, Social and Cultural Program for Challenges in Global Health Initiative. He has been associated with several civil	Pune

		society organisations including CHC and CSER. Bhan is a member of FMES and the NBCs.	
3	Dr. Anant Phadke	A medical doctor turned activist, Phadke is associated with a number of organisations such as AIDAN, Lok Vigyan Sangathan and the MFC, and with movements like Shramik Mukti Dal and People's Health Movement or JSA. A prolific writer, Phadke is currently a senior adviser at SATHI, a unit of the Anusandhan Trust.	Pune
4	Mr. Anil Pilgaokar	A former biochemist, Pilgaokar worked as a researcher in KEM Hospital and BARC hospital, Mumbai before moving into the pharmaceutical industry, where he was involved in marketing and training. He gave up his job and decided to engage in voluntary activities and since the 1980s has been associated with a number of NGOs like LOCOST, FRCH, MASUM, Anusandhan Trust, CEHAT and ACASH. He is a founding member of FMES and a long standing member of MFC. He was felicitated in the second NBC for his contributions to public health activism and the field of bioethics in India.	Mumbai

5	Dr. Arun Bal	A post-graduate in surgery, Bal also has a PhD in political science. He is the founding member of FMES and former editor of IJME. He is the president of ACASH and founder president of Diabetic Foot Society of India. A visiting professor with Amrita Vishwavidyapeeth, Kochi, Bal is also the chairman of Ethics Committee of the MCI, since July 2010.	Mumbai
6	Dr. Armida R. Fernandez	Former dean of LTMMC & LTMG Hospital, Sion, Fernandez is the founder secretary of SNEHA. She is a trustee of FIAMC Bio-Medical Centre and has held several important positions at the national and international level. A well-known neo-natologist, she is also the recipient of several awards.	Mumbai
7	Dr. Barun Mukhopadhyay	An associate professor at the Biological Anthropology Unit, ISI, Kolkata, Mukhopadhyay has been involved in extensive research with communities in Sikkim, Darjeeling and other parts of West Bengal. He got introduced to bioethics in a course in Manila in 2004, where he attended the bioethics sessions conducted by Dr. Amar Jesani. He subsequently has been part of the FMES.	Kolkata

8	Dr. D. K. Srinivasa	Former Dean of JIPMER, Pondicherry, Srinivasa joined the RGUHS as consultant curriculum developer. He was a consultant for Disaster Preparedness Training and a resource person for the National Medical Teacher's Training Centre at JIPMER. He has been associated with SJNAHS and CHC. He is the chairman of Devraj Urs University Ethics Committee.	Bengaluru
9	Sr. Daphne Viveka	A former professor and head of the department of chemistry/biochemistry at Sophia College, Mumbai, her brush with bioethics was as early as 1982 when she went to the Kennedy Institute of Bioethics on the extension of a scholarship. An Erasmus Mundus bioethics scholar, she is now vice-president (India) of ABA and associated with the Society of the Sacred Heart in Patna working in the field of remedial education.	Patna
10	Dr. G. D. Ravindran	A professor of medicine and medical ethics at SJNAHS and a Fogarty Fellow in bioethics, Ravindran is the Country Director of CMMB and technical advisor to Catholic Bishops' Conference of India. He is a resource person for bioethics workshops and courses conducted by the ICMR. He	Bengaluru

		also contributes to IJME.	
11	Dr. Jagadeesh N	A professor of forensic medicine at Vydehi Institute of Medical Sciences and Research Centre, Jagadeesh is also the editor of *Journal of South India Medico Legal Association*. He has a bachelor's degree in law and postgraduate diploma in medical law and ethics. Jagadeesh is an honorary consultant of CEHAT and a member of FMES, where he also actively contributes to its journal IJME.	Bengaluru
12	Prof. Jayapaul Azariah	A former director of School of Life Sciences and former professor and head of Zoology, University of Madras, Azariah is the founder president of All India Bioethics Association and former president of ABA. He is a member of the Board of Directors, International Association of Bioethics.	Chennai
13	Dr. Joga Rao	He quit his job as additional professor of law at the NLSIU, Bangalore, to become a practicing lawyer in healthcare law and ethics. He coordinates the activities of Legal Excel, besides serving as visiting faculty at NLSIU. He is also the chairperson of IECs of many hospitals and a member of various NGOs/Trusts working in the area of healthcare.	Bengaluru

14	Prof. K. L. Chopra	A former director of IIT Kharagpur, he now serves as advisor /consultant to several academic and industrial organisations in the country. He is the president of Society for Scientific Values. He is the recipient of Padma Shri, conferred on him by the Government of India in recognition of his contributions to science and engineering in India.	New Delhi
15	Dr. M. G. Narasimhan	He quit his job as a lecturer in English to complete a PhD in the IISc, Bangalore. His significant research contribution is in the area of scientific controversy and history and philosophy of biology. He is the deputy programme coordinator at the School of Humanities, National Institute of Advanced Studies. Widely read in bioethics, his interest in the field stemmed from his acquaintance with the Human Genome Project debates.	Bengaluru
16	Dr. Mala Ramanathan	With a PhD in Population Studies and MA in Medical Anthropology, Ramanathan is serving as additional professor at AMCHSS, Sree Chitra Tirunal Institute for Medical Sciences and Technology. She is also the member of the editorial advisory board of IJME, member of FMES and	Thiruvanantha puram

		member of the ethics committee, Institute for Research in Medical Statistics, ICMR.	
17	Mihir Desai	A founder member of the Lawyers Collective, Desai was later involved in the setting up of the Human Rights Law Network and Indian People's Tribunal. He was instrumental in setting up India Centre for Human Rights and Law (ICHRL), of which he was a director for 10 years. He was the first co-editor of *Combat Law*, a bi-monthly magazine. Having taken up several healthcare issues from the human rights perspective, Desai has co-edited *Health Care Case Law in India*, an important reader striving to establish health as a human right, published by CEHAT and ICHRL.	Mumbai
18	Dr. Nagraj Huilgol	Head of the radiation oncology division at Nanavati Hospital, Huilgol is associated with several national and international associations. He is the founder member of the Society for Cancer Research and Communication and former treasurer of the Society of Health Professionals (India) for Health and Human Rights. He is a long standing member of the SRDWD or	Mumbai

		Mahaprasthana. He is the editor-in-chief of *Journal of Cancer Research and Therapeutics* and is currently co-editing a book on medical ethics.	
19	Dr. Nandini K. Kumar	She retired as the deputy director general senior grade from the ICMR and ever since has been involved, as a NIH grantee, in bioethics education through distance learning at the National Institute of Epidemiology, Chennai. A Fogarty Fellow graduate in bioethics, she has been instrumental in initiating the first online PG diploma course in bioethics in India under ICMR-IGNOU joint initiative. She is a member of several international and national committees and a member of the international panel of President Obama's Commission for Bioethical Issues.	Chennai
20	Neha Madhiwalla	Madhiwalla, who was closely associated with CEHAT, became the coordinator of CSER in 2007, where she is also involved in health research. She is a visiting faculty at the TISS, member of FMES and associated with Sahyog, a community-based initiative for primary health and education for women and girls. A regular contributor to IJME, she has been	Mumbai

		proactively involved in the functioning of NBCs.	
21	Dr. Nicholas Antao	A senior consultant orthopaedic, arthroscopic, sports medicine and joint replacement surgeon, Antao is the managing trustee of FIAMC Biomedical Ethics Centre. He is associated with several Societies and organisations and engaged in community outreach activities. He is also the editor of *Orthofront*, a newsletter of Bombay Orthopaedic Society. Besides rendering professional and voluntary medical practice, Antao also teaches bioethics.	Mumbai
22	Dr. Padmaja Samant	She is an associate professor, obstetrics and gynaecology department, KEM Hospital and Seth G S Medical College. Samant encountered bioethics at a training programme in AMCHSS, Tiruvananthapuram in 2003, where she attended the bioethics sessions conducted by Dr. Amar Jesani, who was a visiting faculty at the Centre. She was later associated with CEHAT and became a member of FMES. She is now the member secretary of the Medical Humanities Cell at her hospital.	Mumbai
23	Dr. Prathap Tharyan	Tharyan is professor and head of the department of	Vellore

		psychiatry, CMC, Vellore. He is the coordinator of the South Asian Cochrane Network and member of the Scientific Advisory Group, WHO-ICTRP and of the steering group of the Clinical Trials Register-India. He is also the editor of the Cochrane Schizophrenia Group and on the editorial board of IJME.	
24	Dr. Pravesh Jung Golay	Assistant Professor of Philosophy at the Indian Institute of Technology Bombay, Golay is associated with the ICMR in their bioethics activities such as online bioethics course jointly managed by ICMR-IGNOU. He is on the managing committee of FMES and on the Institutional Ethics Committee of the Anusandhan Trust.	Mumbai
25	R. N. Bhaskar	A senior journalist and educationist, Bhaskar has taught in India and abroad. He has worked with several print media like the *Indian Express, Financial Express, Mint*, and *Forbes India*, besides being associated with television networks for four years. Currently a consulting editor with *DNA*, he is also an advisor with Observer Research Foundation and advisor, distance learning, Don Bosco Institute of	Mumbai

		Technology. He is the secretary of the Society for the Right to Die with Dignity (SRDWD) now known as Mahaprasthana.	
26	Dr. Ravi Narayan	He gave up his job SJNAHS to set up the CHC. A public health consultant and health policy researcher, Narayan is closely associated with the people's health movement in India or Jan Swasthya Abhiyan and the Global People's Health Movement. A consultant of NRHM, Government of India, Narayan has been associated with several organisations such as the MFC, Catholic Health Association of India (CHAI), and ICMR.	Bengaluru
27	Mr. S.V. Raju	Known as the person who has kept the Society for the Right to Die with Dignity alive since its founder Minoo Masani passed away, Raju, with a political science background, is the editor of *Freedom First, the Liberal Magazine*, published by the Indian Committee for Cultural Freedom.	Mumbai
28	Dr. Sanjay A. Pai	A pathologist with Columbia Asia, Pai is a member of various ethics committees including ICMR Regional Occupational Health centre, Bangalore and Columbia Asia Hospitals, India. He is Hon. Professor of Pathology at the	Bengaluru

		International Medical school, M S Ramaiah Medical College, Bangalore. He is on the editorial board of the IJME, *Mammology, Kathmandu University Medical Journal* and *BMC Journal of Cardiothoracic Surgery*. A member of FMES, Pai is an active participant of the NBCs.	
29	Dr. N. Sreekumar	An associate professor of philosophy in the Indian Institute of Technology Madras, Sreekumar's interest areas include Professional and Practical Ethics. He is associated with the ICMR as a resource person. He is on the faculty of the ICMR-IGNOU online bioethics course.	Chennai
30	Dr. S. Swarnalakshmi	A post graduate in personnel management and industrial relations, and in business management, Swarnalakshmi has undergone the ICMR-NIH Intensive Training Program on Bioethics. She is the Institutional Review Board Manager at YRG Care, and a member several groups like FERCI, Public Responsibility in Medicine and research and FMES. She is also involved in organising the annual bioethics symposium at YRG Care.	Chennai
31	Dr. Sridevi Seetharaman	She is a pathologist at the healthcare centre run by the	Mysore

		Swami Vivekananda Youth Movement, Mysore, a development organisation working in the rural areas since 1984. An Erasmus Mundus post graduate in bioethics, she is a faculty of CSER and a member of FMES, where she is also part of the editorial advisory board of IJME.	
32	Fr. Stephen Fernandes	A professor of Moral Theology at St Pius X College, Fr Fernandes is also the director of FIAMC Biomedical ethics Centre housed in St Pius X College. He is the Co-Convenor of bioethics course offered by the Centre since 2003. He is part of the International Association of Catholic Bioethicists and collaborates with CBCI Delhi on various activities.	Mumbai
33	Dr. Suneeta Krishnan	A PhD in epidemiology, Krishnan is an adjunct associate professor at the epidemiology and Statistics Unit SJNAHS and assistant adjunct professor at the University of California. She has been involved as a consultant and faculty in various organisations such as the ICMR, AMCHSS and IIM Bangalore. She is part of the editorial advisory board of IJME and is actively involved in the NBCs.	Bengaluru

34	Dr. Sunita Bandewar	A PhD in anthropology, Bandewar has a MHSc in Bioethics from the University of Toronto Joint Centre for Bioethics. She was associated with CEHAT and CSER and was a senior research fellow on the Ethical, Social and Cultural Program for Grand Challenges in Global Health Initiative. An independent researcher, she is member of the International Research Ethics Board Medecins Sans Frontiers (MSF) and of FMES.	Pune
35	Dr. Surendra Dhelia	A practicing family physician for over 30 years, Dhelia is a managing committee member of the Indian Medical Association, Mumbai. He is an office-bearer and managing committee member of the Bombay C Ward Medical Association. He is the Joint Secretary of the SRDWD and has participated in a number of media debates on euthanasia including NDTV, IBN Lokmat and Star TV.	Mumbai
36	Dr. Thelma Narayan	An epidemiologist and health policy analyst and activist, Thelma Narayan, quit her teaching job at SJNAHS to set up CHC. She is part of several health initiatives such as NRHM and the National Health System Resource Centre. She is an active	Bengaluru

		member of JSA and the Global People's Health Movement. She coordinates the Centre for Public Health and Equity, an additional functional unit of Society for Community Health, Awareness, Research and Action that started in a CHC initiative. She was part of the group that prepared the ethical guidelines in social science research in India, brought out by CEHAT.	
37	Dr. Vasantha Muthuswamy	Former senior Deputy Director General of ICMR, New Delhi, Muthuswamy has been associated with the development of 24 guidelines both national and international. A WHO Fellow on biomedical ethics from Kennedy Institute of Ethics, USA, Muthuswamy has been responsible for bioethics dissemination in India through workshops and courses. She is a member of several national and international bioethics bodies including both government and non-government organisations. She is the president of FERCI, chairperson of FMES and on the editorial advisory board of IJME. She was felicitated in the 3rd NBC.	Coimbatore
38	Dr. Vibhuti Patel	She is professor and head of the Department of	Mumbai

		Economics, SNDT Women's University. A recipient of several awards including Outstanding Citizenship Award, Patel is associated with several governmental and civil society groups in India and has worked extensively in the area of women's rights. She is a founder member and trustee of the Anusandhan Trust and Trustee of VACHA, Women's Research and Action Group (WRAG) and Satya Vijay Seva Samaj in Mumbai. Patel is on the faculty list of the bioethics course initiated by FIAMC Biomedical Ethics Centre.	

List of acronyms used:

AMCHSS: Achutha Menon Centre for Health Science Sciences, Trivandrum

AIBA: All India Bioethics Association

AIDAN: All India Drug Action Network

AIPSN: All India People's Science Network

ABA: Asian Bioethics Association

BARC: Bhabha Atomic Research Centre (Hospital), Mumbai

CBCI: Catholic Bishops' Conference of India

CHAI: Catholic Health Association of India

CEHAT: Centre for Enquiry into Health and Allied Themes

CMC: Christian Medical College, Vellore

CHC: Community Health Cell, Bangalore

ACASH: Association for Consumer Action on Safety & Health

CGSI: Consumer Guidance Society of India

CSER: Centre for Studies in Ethics and Rights

FIAMC: Federation Internationale des Associations Medical Catholique

FBMEC: Bio-Medical Ethics Centre of the FIAMC

FERCAP: Forum for Ethics Review Committees in Asia Pacific

FMES: Forum for Medical Ethics Society

FRCH: Foundation for Research in Community Health

HAFA: Health Accessories for All

ICMR: Indian Council of Medical Research

IEC: Institutional Ethics Committee

IGNOU: Indira Gandhi National Open University

IJME: Indian Journal of Medical Ethics

ICHRL: India Centre for Human Rights and Law

ISI: Indian Statistical Institute

JIPMER: Jawaharlal Institute of Post Graduate Medical Education and Research, Pondicherry

JSA: Jan Swasthya Abhiyan

MASUM: Mahila Sarvangeen Utkarsh Mandal, Pune.

MCI: Medical Council of India

MSF: Medecins Sans Frontiers

MFC: Medico Friend Circle

NLSIU: National Law School of India University, Bangalore

NBC: National Bioethics Conference

NIH: National Institutes of Health

NRHM: National Rural Health Mission

PHA: People’s Health Assembly

RGUHS: Rajiv Gandhi University of Health Sciences, Karnataka

SATHI: Support for Advocacy and Training to Health Initiatives

SOCHARA: Society for Community Health Awareness Research and Action

SNEHA: Society for Nutrition, Education & Health Action

SRDD: Society for the Right to Die with Dignity

SJNAHS: St. John's National Academy of Health Sciences, Bangalore

IISc: Indian Institute of Science, Bangalore

TILEM: The Institute of Law and Ethics in Medicine

TISS: Tata Institute of Social Sciences, Mumbai

VHAI: Voluntary Health Association of India

WABA: World Alliance for Breastfeeding Action

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