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The National Bioethics Conference

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COMMENTS

The National Bioethics Conference: looking back and looking ahead

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Starting on November 17, 2010, the *Indian Journal of Medical Ethics* Third National Bioethics Conference (NBC) will hold a four-day programme of discussions, debates and learning on governance in health care.

Thirty-eight organisations, from across the country, have collaborated to make this happen. These are teaching institutions, hospitals, non-governmental organisations, ethics committees, and advocacy groups. Medical practitioners, social scientists, students, researchers and policy makers, from medicine, research and public health, from all parts of India and from Australia, Bangladesh, Canada, Pakistan, Sri Lanka, Turkey, the United Kingdom and the United States are expected to participate in the programme. The venue of the meeting, the All India Institute of Medical Sciences in New Delhi, is also an indication of the importance this subject has assumed at the national level.

This is a good time to reflect, on the two conferences gone by and on the meeting to come. What was the original aim of the NBC? Has it led to greater interest and involvement in health care ethics by groups and individuals around the country? What lessons have been learned after each conference? Finally, what do we aim to achieve at this November meeting and in other NBCs in the future?

Inception of the idea

When the first National Bioethics Conference was conceived almost six years ago, a small group of us were taking stock of developments in health care ethics in India, and thinking about what the next step should be.

Women's, health and other activist groups in India had laid the basis for an "ethics movement" in this country. They had long opposed unethical contraceptive research and policies. They had also critiqued the health care system for denying care to the majority, and the health care industry for promoting unethical practice.

The journal's roots, established in 1993, were in an activist organisation largely of medical professionals agitating against unethical practices, and the journal reflected their concerns. Over the years it had begun to include a different type of review and analysis, an attempt to look at health care beyond the practice of medicine to bring in the voices of students, researchers, health policy makers and those from disciplines other than medicine.

We believed that the journal's steady growth over a decade indicated that the groundwork had been laid for the growth of an intellectual community, of researchers, activists and others concerned about ethical aspects of health care in India and other developing countries. The aim of the small band of people who put together the first conference was to bring together a diverse group of organisations and individuals in an effort to give a platform for bioethics discourse in this region.

The conference was held at a time of debates on major issues in health care ethics. Government health programmes such as the provision of antiretroviral drugs and disease eradication efforts challenged a failing public health infrastructure. Clinical trials for an HIV vaccine were to be launched. Privatisation and corporatisation of health services, encouraged by government policy on medical tourism, was growing at the cost of health care for the poor. With regulatory changes in January 2005, India was likely to become a preferred site for outsourced clinical research by multinational drug companies, exploiting a vulnerable population and inadequate monitoring mechanisms. International trade agreements exacerbated global power inequities in a country already battling injustices of caste, class and gender, all of which have direct and indirect impacts on people's health, the health care system and the ethics of health care provision at the individual as well as the institutional and community levels.

Government, private and non-governmental institutions, including medical colleges, hospitals, and research institutions, collaborated to organise the NBC; organisations with very different perspectives participated; and medical practitioners, legal professionals and social scientists were among those represented. All this suggested that ethics was becoming the

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concern of a larger community, and would have to include inputs from different groups and fields Indeed, the conference sought to give space for discussion and debate on "the emergence of bioethics as linked to biomedical and social science disciplines in India - in relation to the globalising world and in terms of the pressures exerted by that process on the developing countries." (1: S6)

NBC 1 and Mumbai

The first conference - Ethical challenges in health care: global context, Indian reality -was organised around four sub-themes: ethical challenges in HIV/AIDS; ethics of life and death in the era of high-tech health care; ethical responsibilities in violence, conflict and religious strife; and ethics and equity in clinical trials.

Twenty institutions collaborated to organise the first NBC in November 2005.The 350-odd participants, affiliated to 140 organisations, came from all over India as well from Pakistan, Sri Lanka, Iran, Philippines, the US, Canada and Australia. Participants included health care providers at all levels of the system, medical educators, biomedical and social science researchers, and programme planners and implementers. The extensive media coverage in the NBC indicated its press worthiness - a comment both on the novelty of the meeting to the general public, as well as the growing relevance of and commitment to bioethics in India.

The inaugural session provided the context for debates on bioethics in India: "those in need of care and those providing care and conducting research in India". (2: 27) The global context was "outsourcing of research, changing regulatory mechanisms and constrained resources in India, and the need for ethical guidance on the way forward". (2: 27) Keynote speeches, papers, workshops and posters at NBC 1 gave a broad picture of ethical dilemmas in biomedical, social science and public health research and health care delivery in India. Pre-conference satellite sessions included a debate for medical students, and a WHO workshop on ethics review processes.

Learnings from NBC 1

Post-conference discussion identified issues to be addressed in future meetings. The exchange of experiences and ideas in a developing discipline requires more space within the programme for more discussions. Again, the newness of the subject in India meant that the absence of discussion on certain subjects, such as the ethics of research on development, or with vulnerable populations, ethics of public health policy, and the philosophical bases of ethics was acutely felt. Finally, some participants commented that the meeting could have been an opportunity to discuss and develop concrete guidelines in various fields in clinical practice and public health.

Many of the issues discussed in NBC 1 were not new; the newness lay in the "act of coming together to engage in a passionate and committed dialogue and the plurality of voices present made the NBC a landmark event, giving much cause for hope by illustrating the enormous potential for sincere thought, passionate concern and careful action on bioethics in India." (2: 30)

NBC 2 and Bangalore

When the conference moved to Bangalore in November 2007, it reached out to a new group of organisations, and a greater presence of the academic community, with the collaboration of a large number of educational institutions, mostly from the south of India. Over 500 delegates, speakers and other participants attended, from a wide range of disciplines -- healthcare professionals, academicians, researchers, media professionals. Interestingly, there were many retired professionals and laypersons.

The theme of the conference was "moral and ethical imperatives of healthcare technologies" As developments in medical technology are governed by private industry rather than government policy, they are decided according to their profitability rather than the need for them, giving rise to a number of ethical questions "such as those related to the appropriateness and equitable distribution of technologies; the need for setting priorities in research; the role of government and/or independent agencies in regulating research and the use of health care technologies; and the control of intellectual property." (3: S5)

A number of technology-related ethical issues were discussed: dilemmas posed by life-prolonging technologies when used on the terminally ill, on neonatal intensive care, as well as the organ trade, assisted reproduction, and vaccine research, and the question of international trade agreements and access to essential drugs. However, some of the discussions in the conference went beyond this theme, including research ethics, bioethics education and ethics of public health. The keynote speakers came from primary care, intensive care and traditional medicine, to health economics, public health, health administration and health policy.

The growing importance of research ethics review led to discussions and workshops on this subject. Film screenings brought ethics to life and workshops for journalism and medical students highlighted the role of ethical communication of medical issues. A pre-conference meet brought together

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students from medical and related disciplines to discuss the dilemmas they could expect once they entered the profession.

Learnings from NBC 2

Participants remarked that the conferences were helping raise the level of dialogue on important issues in biomedical ethics, with the involvement of many college and university students. The "distinct Indian and subcontinental flavour... was a significant strength of the conference and should be maintained for future events." (4: 37) The coverage of a range of topics relevant to different groups interested in bioethics in India, the use of multiple formats - plenaries, papers, posters, workshops, films, discussion groups - and the involvement of 38 organisations were key elements of the success of NBC 2.

However, many of the concerns of NBC 1 were reiterated after NBC 2. There was too little time for discussion. Participants had very different levels of knowledge on these subjects, making the exchange of ideas difficult. Certain fields required specialised knowledge in order for the participants to have fruitful discussions, but there were few experts in these fields present at the conference. Regulation - or the lack of it - was a major concern expressed repeatedly throughout the conference. The need to use the conference to develop guidelines, expressed at the first NBC, remained unfulfilled in NBC 2. It was also pointed out that practitioners from other systems of medicine should be included. Finally, it was important enable discussions between participants at different levels of understanding and regional concerns.

It is clear that the interest in ethics is growing steadily, within different specialities in health care, and this is evident in the striking improvement in the abstracts submitted to NBC3. However, while there is a greater concern and level of thinking on ethics of health care in this region, we are only now beginning to see the emergence of an indigenously developed body of thought.

There is also the question of sustaining such efforts, because of the work involved in people and organisations coming together and organising a programme of this scale.

NBC 3, Delhi: looking forward

The theme for the third national conference is governance. The plenary speakers include academics, activists, practitioners and policy makers. The three plenary sessions will look at structural inequities in health and health care; the frameworks of policy and law related to health care including access to drugs; and mechanisms for ethics review, monitoring and regulation, including regulation of medical education and practice, . These and related issues will be discussed in almost 70 papers, 14 workshops and some 25 poster presentations.

This is a good and opportune time to discuss governance in health. Several new initiatives are emerging in health care and medicine in India such as the National Rural Health Mission, restructuring of the Medical Council of India and the draft National Health Research Policy and the Knowledge Management Policy for Health - service, education and research. by the Department of Health Research, Government of India. Some of these have been circulated for public opinion. All these are areas that need debate and discussion with an ethical lens. Policies in areas such as privatisation of medical insurance and the use of emerging technologies also need to be evolved. Perhaps at the end of this conference a clearer concept will emerge of how to move forward in these and other areas of health ethics in India. We look forward to meeting many friends and readers of the journal at Delhi. The journal has sought to be not only academic, but also activist and we hope that this conference will continue to reinforce both roles.

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