Summary Report

South-Asia Learning Exchange Workshop on

Patient's Rights and Private Medical Sector Accountability

23rd and 24th January 2018, Mumbai

"Those who has less in life should have more in law."

Organized by SATHI for
Thematic Hub on Patients Rights and Private Medical Sector Accountability,
associated with COPASAH

Background

"The global trend towards privatization in health systems, and increased dependence on private health care, poses significant risks to the equitable availability and accessibility of health facilities, goods and services, especially for the poor and other marginalized groups" - UN Special Rapporteur on Right to Health (2012)

Today private health institutions and providers play a major role in the provision of health services in developing countries, including South Asia and Africa. However, the reliance on the private healthcare may be problematic from the patient's rights perspective. Different studies in India and Africa have demonstrated that the private health sector's promise of efficiency and quality do not hold true in reality, and in fact, pose significant challenges regarding affordability, access and quality of health care.

The relative size and functions of the private health sector differ significantly from country to country. Recent investments in health in many LMICs have led to an explosion of unregulated private health services with high levels of out-of-pocket expenditure (USAID 2012, 5). In addition to existing individual small-scale entrepreneurship, large private multinational corporations have now entered into the healthcare market. However, the issues that dominant private sector health provision raises for patient's rights and accountability of the private sector is still a relatively new field of enquiry for the health and human rights community.

On this background, SATHI- as COPASAH's thematic hub on "Patient's rights and private medical sector accountability," organized a learning and exchange workshop on accountability of private medical sector and patient' rights involving civil society activists from India, Bangladesh, Nepal and Sri Lanka, in collaboration with CHSJ.

Objectives of this learning workshop were-

1. to understand the contextual challenges of private sector regulation and patient's rights in the mentioned LMICs.
2. to enhance the knowledge base of citizens, academicians, civil society organizations and doctors regarding specific accountability deficits that exist in the private health sector.
3. to identify strategies and policies that can mitigate the impact of the private health sector on patient's rights, and overall right to health care.
4. to put patient's rights into the center of the privatization debate.

Key Takeaways From the Sessions

Inaugural Session-

Dr. Abhay Shukla- Welcome and Context Setting

"Stethoscope is not on the chest, it is on wallet"-

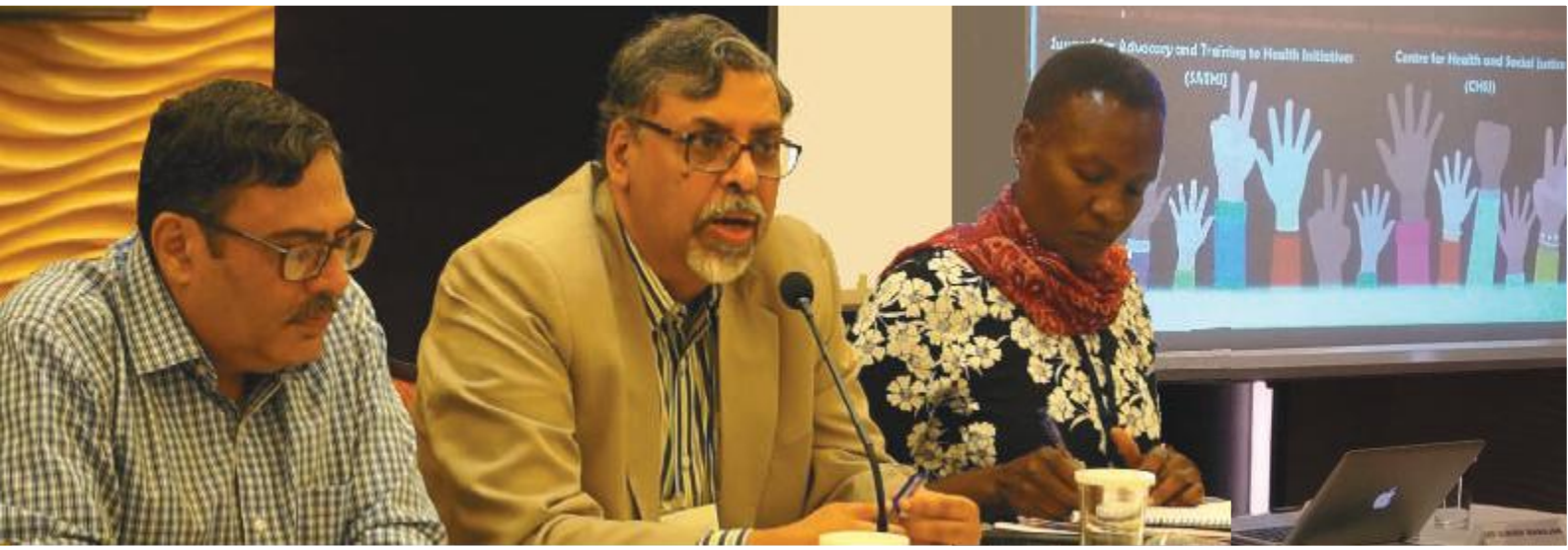
Global and venture capital in healthcare has made it a super-profit industry in India. e.g., 45% of investment in Apollo comes from foreign capital. In this industry, who are the owners? Who are the workers? And, who is a raw material? Obviously, investors are owners, barring top-notch doctors all the junior doctors and paramedics are workers, and the patient is raw material from whom maximum profit is extracted. The annual growth rate of the private healthcare in India is 23%, no other industry is growing at this rate.

"Those who are supposed to heal are now grabbing and exploiting, and this should be a great concern to all of us."- Dr. Abhay Shukla set the tone of the meeting with these lines and shared instances where the corporate hospitals exploited helpless patients. He observed that health care has now transitioned from a mission to a profession, from a profession to business and from business to a racket. Healthcare has now turned into a profit-maximizing industry, and corporatization has further enhanced capital accumulation. Although this is a grim scenario, there is a silver lining-people are retaliating, and cracks are now appearing in a narrative of the private health industry. e.g., in a strong indictment of the Medical Council of India (MCI)- an apex regulatory body of medical education and practice, the Parliamentary Standing Committee made scathing observations about it's functioning.

Abhay further added: what is it that unites us? - it is our collective concern for patients rights and confronting the impact of ever-increasing corporatization and commercialization of health care.

"Triangular Struggle" -

MCI dissolution is now a possibility, and there is discussion regarding setting up the National Medical Commission. We as concerned group citizens need to contribute and intervene in this discussion. Ultimately, it is not only about doctors, their professional associations, and the government. It is also about people who receive health care and are affected by the unaccountable private health sector. This is essentially a triangular struggle wherein besides doctors and the government, citizens are equal stakeholders.



Dr. Abhijit Das- COPASAH

COPASAH was formed to give legitimacy to bottom-up knowledge created by a group of people who were working with the communities. MDGs and SDGs commitment to improving population health also came with an evidence-based practice approach, without giving much credence to contextual variables in developing countries. On this background, COPASAH consciously attempts to build bottom-up knowledge which is built by working with communities on the frontiers of the health care system.

There is increasing trend of private interests shaping public policies-resulting onto public-private partnerships and growth of private healthcare solutions. COPASAH's hub on the Private Health Sector hosted by SATHI, is part of this effort. It needs to be critically reviewed.

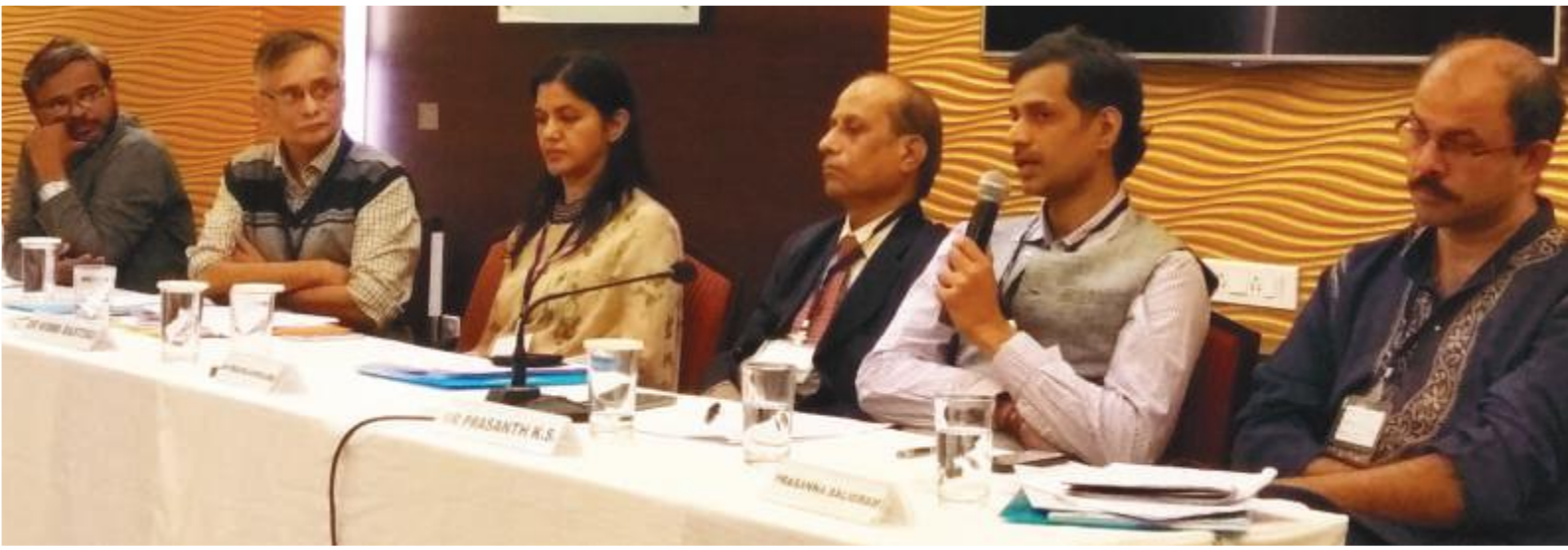
Mr. S.C. Sinha- Hon'ble Member- National Human Rights Commission (NHRC) India

The National Human Rights Commission (NHRC) has formulated a draft charter of Patient's Rights, with the help of activists, academia, and experts. Once it is adopted, it will apply to both public and the private hospitals.

This charter would include provisions like- Right to Information, medical records and reports, Right to emergency medical care, Right to informed consent, Right to privacy, Right to the second opinion, Right to transparency in rates and care according to standards. It has also recommended the State Governments either to adopt central Clinical Establishment Act (CEA-2010) or to enact a similar specific law to safeguard patient's rights.

Ms. Winfred Lichuma- Kenya (Member of the Independent Accountability Panel appointed by the UN Secretary General)

Women, children, and adolescents are at the heart of the comprehensive change the SDGs envisage. For this reason, the UN Secretary-General characterized the Global Strategy as a front-runner platform for the implementation of the SDGs. The Global Strategy's key accountability principles prioritize the role of national leadership and ownership of results, strong country capacity to monitor and evaluate, and a reduction in the reporting burden by aligning multi-stakeholder efforts with the systems countries use to monitor and evaluate their national health strategies. As such, accountability includes not only the tracking of resources but also prioritizing results and rights as set out in the Global Strategy. One of the stakeholders in this process is the private sector.



Session 1- Perspectives and Experiences of Policy Makers and Shapers in India

Dr. Pravin Shingare- Director of Medical Education and Research (Government of Maharashtra)

There is a legislation proposed by the Maharashtra State Government to curb the prevalent practice of cuts and commission by the doctors. The Maharashtra State Government is also considering to modify Maharashtra Medical Council through legal amendments.

Dr. Shingare enlisted measures the Maharashtra State Government is taking to safeguard patient's rights. Notably, there is also a plan to bring in Anti-Cut Practice Act, to ensure that patients are not exploited. Accidental emergency care, free beds in the charitable hospitals, concessional rates of care to poor patients in trust hospitals are some of the key focus areas of government oversight on the private sector.

Prashanth K.S.- Senior Consultant, National Health Systems Resource Center (Govt. of India)

This Clinical Establishment Act will provide a reliable database for clinical establishments, categorize and classify types of clinical establishments and will help the government in obtaining data for various public health interventions, determine standards and bringing in uniform standards.

The Central Government has notified the Clinical Establishment Act under the article 252, and the states are expected to legislate it. Currently, 16 states and all the Union Territories are planning to implement it. The scope of Clinical Establishments Act includes Registration, Regulation, Facilities and Services, All recognized systems of Medicine, Public and Private except defence clinical establishment.

Dr. Nimmi Rastogi, Health Advisor- Chief Minister's Office, Delhi Government

"Political will"

What was the problem?-

Many Private charitable trust Hospitals were non-compliant regarding a provision of health care to the economically weaker section of the population. There was rampant overcharging, record maintenance was poor. There were serial offenders, and multiple complaints were filed on the grievance helpline. Incidence happened in Fortis & Max Hospital was the last straw, and people were outraged.

How did Delhi government respond?-

Nine-member committee was formed under the Director General of Health Services (including representatives from Indian Medical Association, Delhi Medical Council, and a representative from the Pharma) to look into private sector compliance and study rates and issue recommendations to cap profit

margin by private hospitals. Their recommendations include not more than 15% margin on diagnostic tests, not more than 30% margin on procurement cost of implants, not more than 50% margin over procurement cost of medicines and consumables, and charges prominently displayed in the hospital.

Ability to take punitive action-

The license of the Max Hospital was canceled in December 2017, for wrongly declaring live baby dead. This disciplinary action sent a stern message to other private corporate hospitals and nursing homes.

Later on (May 2018), Delhi Health Minister announced draft price capping policy for private hospitals, wherein the private hospitals would be allowed only unto a 50% profit margin over the procurement price of medicines and other consumables.

The government who has better capacity and will to provide public health services are capable of effectively regulating the private health sector too; this could be a key take away from Dr. Rastogi's presentation. Delhi Government's vision of " Swasthya Swaraj," and their related tangible actions in the form of Aam Aadami Mohalla Clinic, Jan Swasthya Samitis, and Swasthya Mitras is giving the whole set of new insights on patient-centric approach.

"Our intention is if we expand patient-centric approach; cater to their primary health needs, make them aware of the basics on health & hygiene and allow the community to participate in health delivery actively we will empower them to need us less and less. Till that happens, we are willing to hold their hand and make sure they get their due."

Dr. Prasanna Saligram- Azim Premji University

The regulatory puzzle in India-

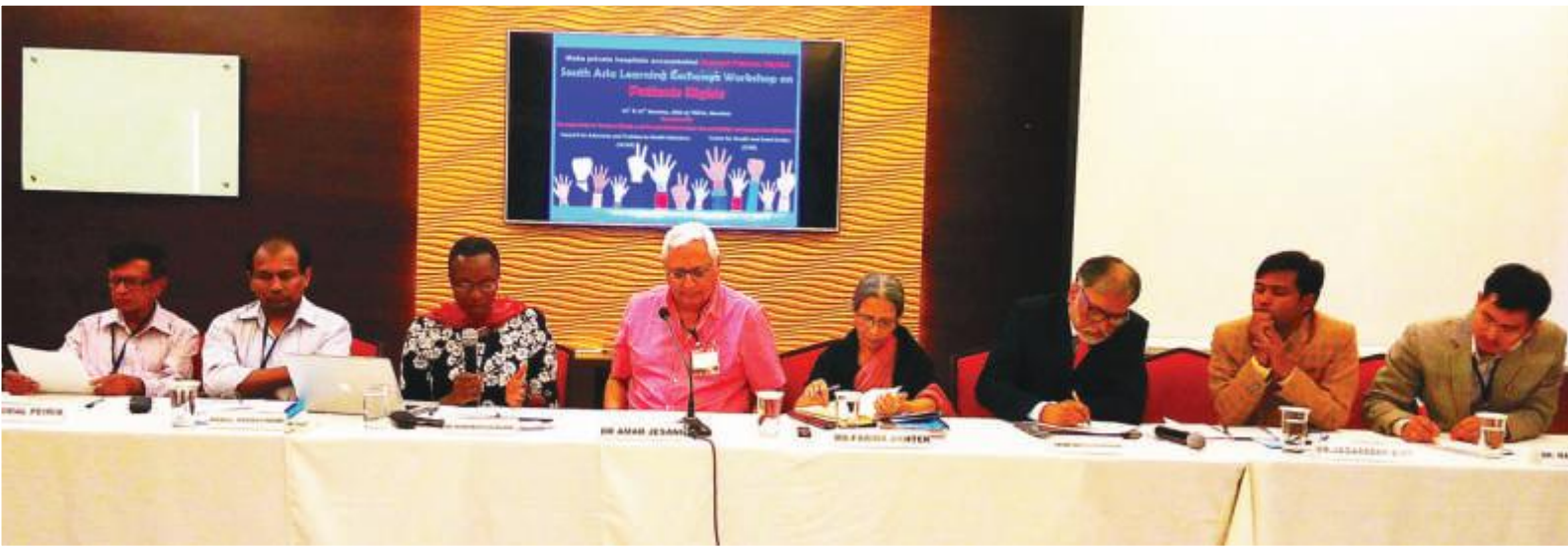
Is regulation, as a legal lexicon, a panacea in making the private sector accountable? Perhaps not. An ideal would be to enhance the scope for community participation in regulatory frameworks.

Although "Charters" are voluntary, it is a useful tool to frame rights and community priorities. Right to Healthcare framework should be the basis of regulatory architecture, which would make the grievance redressal mechanisms more stringent and relevant to the community.

Dr. Arun Gadre- ADEH

There is a valid concern among the doctors that operationalization of regulatory framework should not become a mechanism of corruption for the state officials. The Alliance of Doctors for Ethical Health Care (ADEH) has evolved not just as a mechanism to encourage doctors to protect patient's rights but also to safeguard progressive elements within the medical fraternity. Appealing to sensible and rational voice among the doctors, and creating a constituency of internal advocates is a new strategy, and initial signs are encouraging.

ADEH along with other five organizations is demanding reforms in the MCI. We are not under the illusion that the proposed National Medical Council (NMC) bill will be progressive. We have already developed a critic of the NMC and are planning further advocacy on this issue.



Session 2 - International Panel Discussion on Country Level Issues and Approaches for Regulation of the Private Medical Sector

Countries represented in this panel discussion were Kenya, Sri Lanka, Bangladesh and Nepal

Chair- Dr. Amar Jesani, Indian Journal of Medical Ethics

The private sector in the countries mentioned above had unique characteristics shaped historically by how state-supported and regulated it.

Questions for panelists-

1. *From citizen's point of view, what are the common violations of patient's rights in the private sector and nature of medical malpractice in your country/region?*
2. *What kind of regulatory framework for private hospitals is operational in your country? To what extent it is effective and responsive to people's concerns?*
3. *What are the key lessons and experiences regarding regulation of the private health sector?*

Ms. Winfred Lichuma- Independent Accountability Panel, Kenya

Kenya is among the few African countries which do recognize health as a constitutional right. Within the devolution agenda, health provision is primarily the responsibility of the county governments. Many policies related to the standardization and regulation have primarily remained at the national level with minimum ownership at the county level. The private sector is mostly unregulated or minimally regulated.

"We have all the laws and acts necessary to regulate the private health sector, but the real challenge is at the implementation level."

- *Kenya's Patient's Rights Charter 2013, although a progressive document, largely remains unknown not just among the communities but even among the medical fraternity. The private health sector has now almost monopolized certain domains of the health services with severe consequences for patients.*
- *Most of the private hospitals do not accept patients unless deposit is paid upfront.*
- *The Medical Board-responsible for setting ethical standards and regulation includes only doctors and their professional associations, and no representation to CSOs and other concerned groups of citizens. So, nepotism is widespread.*
- *Medical tourism is widespread, with India as a preferred destination.*
- *The Health Insurance Industry has now flourished, but it only insures public servants- relatively a minuscule percentage of Kenyan Population. There is a need to study how many insurance companies are operating in Kenya and to what effect?*

Mr. Telge Sirimal Wijitha Peiris - Public Health Consultant, and Dr. Manuj Weerasinghe- University of Colombo, Sri Lanka

"We are derailing from the solid public health foundations that we had for past 160 years (..Sri Lankan Health System is one of the oldest in the Asian region and was established in 1854), and this is a serious matter for the public health activists".

"Asymmetry of information among doctors and patients is leading to various types of violations".

Although health is not a fundamental right in the Sri Lanka constitution, a 2010 Supreme Court judgment enshrined the right to health under the right to life.

The thin line between public and private-

The private health sector in Sri Lanka is growing at the expense of the public health services, 80% of the private health provision is by the government health functionaries after the official working hours. There is a lack of adequate regulation and policies to curb this trend.

Sri Lanka has a high literacy rate, but that does not translate into literacy of health entitlements. So, unnecessary investigations, expensive prescriptions, and unregulated fees are relatively common.

Early trends of commercialization-

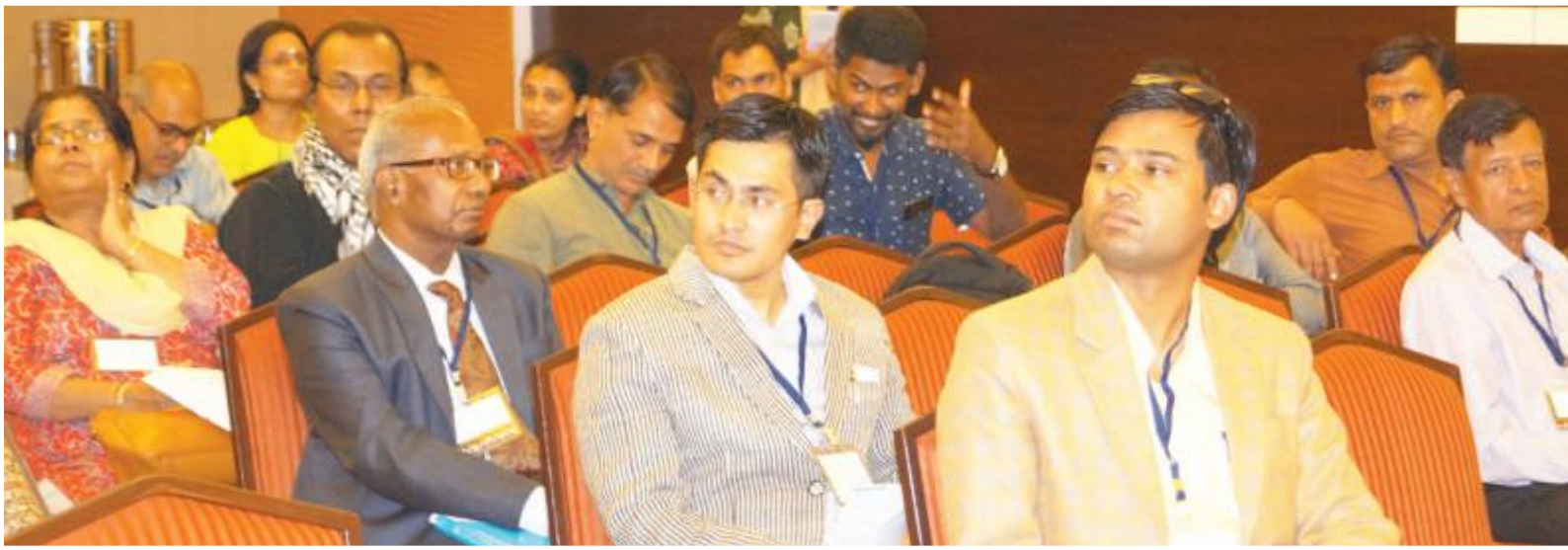
- People feel branded medicine is better than the generic medicine. Media played a role in establishing brand is better than the generic narrative.
- Cost recovery of expensive imaging techniques, like CT Scan or MRI, is through unnecessary screenings.
- There is no legislation to control the drug trade; they are sold in the open market under several trade names.
- The Private Medical Institution Regulatory Act 2006 is still not enforced properly.

A multi-pronged advocacy approach -

People's Health Movement (PHM) Sri Lanka is advocating for making the Right to Health as a constitutional right. In collaboration with the trade unions, progressive medical professionals, and the politicians, PHM is advocating for a National Drug Policy, fair trade agreements wherein right to health of the people is protected.

Rise and fall of Apollo Hospital in Sri Lanka-

International Finance Corporation decided to fund Indian healthcare group, Apollo Hospital, to establish an ultra-modern hospital in Sri Lanka. This project was also the first instance of Foreign Direct Investment (FDI) in Sri Lankan health sector. However, in 2009, the Supreme Court gave a verdict that the Sri Lanka Insurance Corporation (SLIC) which had taken control of the privately built Apollo Hospital, should be brought back under the state control. In a damning observation, the court found that the motivation of for the privatization of SLIC was to primarily conform to donor recommendations of the IMF and the Asian Development Bank, rather than the stated reasons of liberalization of the insurance industry in India. Effectively, Apollo Hospital came under the state



control in 2009, and the Lanka Hospitals Corporation terminated licensing and support services agreement with the Apollo Hospitals in November 2009.

Dr. Madhur Basnet - B.P. Koirala Institute of Health Sciences and Dr. Jagdishchandra Bist- Health Activist, Nepal

Out of 22 medical colleges in Nepal, only 4 are government medical colleges, and the remaining 18 are private medical colleges, mostly owned by politicians. These colleges charge substantial capitation fees, and anyone who can pay can get admission.

Privatization as a trend consolidated in 90's along with the arrival of democracy and liberalization in Nepal. Although the regulation of the private health sector is part of policies, it remains weak at the implementation level.

Health is enshrined as a constitutional right two-years ago; however, its operational framework is not yet developed. In the absence of tangible grievance redressal framework, patient's rights violations are common. The Nepal Medical Council, Nursing Council, and the Health Professionals Council are responsible for regulating the professionals and enforcing the code of ethics. However, these bodies are not very effective.

The physicians who are working in the government sector are also allowed to do the private practice. Similarly, the National Health Insurance also includes private hospitals as service providers. Both these trends are causing further privatization and commercialization of the health care.

Dr. Md Sayedur Rahman- Health Activist, and Ms. Farida Akhter, Executive Director, UBINIG, (Policy Research for Development Alternative), Bangladesh

Post independence, impressive health gains that Bangladesh achieved were primarily through conscious investment in the primary and preventive health care.However, that scenario is changing; the urban middle and aspirational class goes mostly to the private sector. India 's corporate healthcare trend has also influenced the health-seeking behavior of the people and concurrent policy actions by the state.

Over the last decade, Government hospitals did not increase as much as the private sector hospitals have grown. Absence of credible regulator is also on enabler factor.

There is a trend of a nexus between the public health hospitals and the private hospitals. Even at the government-owned sub-district hospitals, there are agents hired by the private clinics to lure patients. There are many instances of malpractice-like questionable use of ICU services, unwanted scanning and operations, and withholding dead bodies until payments are made.

Bangladesh has also emerged as a sought-after destination for clinical research. However, regulatory frameworks governing the research and trials are extremely weak.

Session 3- Lessons from the Campaigns and Initiatives by civil society for the Regulation of the Private Medical Sector in India

Dr. Anant Phadke - Campaign for Maharashtra Clinical Establishment Regulation Bill- Jan Arogya Abhiyan

Many factors have led to the unregulated growth of the private sector in India, notable are- lack of legal framework, absent political will, powerful doctors lobby and growing influence of the corporate players in the healthcare.

Given this adversarial background, JAA played an active role in advocating for the amendment of the Bombay Nursing Registration Act (BNHRA)-1949. This Act was primarily applicable in a big city and was reduced only to registration of the nursing homes. Although the Act was amended in 2006, the amendments were perfunctory. JAA actively pushed for the further amendments- particularly regarding the inclusion of Patient's Rights in the revised Act.

When the Central Clinical Establishment Act was enacted in the year 2010, JAA prepared the critique of CEA-2010.

There were some positive features of the Central CEA, JAA retained those, but advocated for the improved version of Maharashtra State specific CEA. ("No for Central CEA, Yes for Maharashtra State CEA")

JAA organised mass signature campaign for patient's rights. Also used pamphlet e-petition for patients rights.

JAA actively liasoned with elected representatives. Government of Maharashtra set up a drafting committee to come up with Maharashtra Clinical Establishment Bill. JAA representative was also part of the committee. Bill is submitted to State Government.

Although MCEA Bill-2014 is still not tabled in the Assembly for approval, patient's rights & Grievance Redressal mechanism as an issue have drawn the wide attention of people, policy-makers, and the private sector representatives. This has helped in mainstreaming the discourse on Patient's Rights.

Ms. Akhila Vasan- Karnataka Jan Arogya Chaluvali (KJC)

"The Story of the Karnataka Private Medical Establishment Act (KPMEA) amendment is a story of citizen's battle against the exploitative profiteering by the private health sector. This is not so much about what was achieved but about the immense possibilities when the health rights discourse is democratized, of what ordinary citizens can do to assert their rights."

The Karnataka Private Medical Establishment Act (KPMEA) was inadequate and struggle with the State was to advocate and enforce pro-people amendments to this Act. KJC's essential demand was to establish a state-level body to oversee the implementation of the Act and to oversee the protection of patient rights. Additionally, the District and State level Health Rights Tribunal should be established to address violations in the private sector, and there has to be a rational basis for arriving at standardized costs of care in private establishments based on size, location, and other considerations.

In 2016, Justice Sen committee was appointed to

propose amendments. However, out of 30 representatives on this committee, which was heavily skewed in favor of the private sector, only one representative was from the citizen's group.

Social pressure on the government to make the committee more inclusive- built the public pressure on the committee. Dalit Sanghtans in 16 districts met the officials to submit a memorandum that Jt. Sen committee should hear CSO's too. KJC representatives also met Members of Legislative Assembly (MLAs), across the parties, to raise questions in the Assembly.

Indian Medical Association's (IMA) backlash and false propaganda- the e.g.Capping cost of care in private hospitals is "anti- Constitutional" as it interferes with doctors' fundamental rights. Several laws already govern the functioning of the private medical establishments- Karnataka Medical Council, Consumer Protection Act and various Commissions. So, KPME not required.

In June 2017 Amended Bill presented in the Assembly, and there was a six-hour debate on the Bill. MLAs across the party lines welcomed the bill as being 'pro-citizens,' and the bill was referred to the Joint Select Committee (JSC). The JSC held a consultation in 2017. Amendment Bill was passed after many modifications in December 2017.

Ms. Malini Aisola- All India Drug Action Network

"Drug pricing policy in India covers only 10% of total medicines in the market."

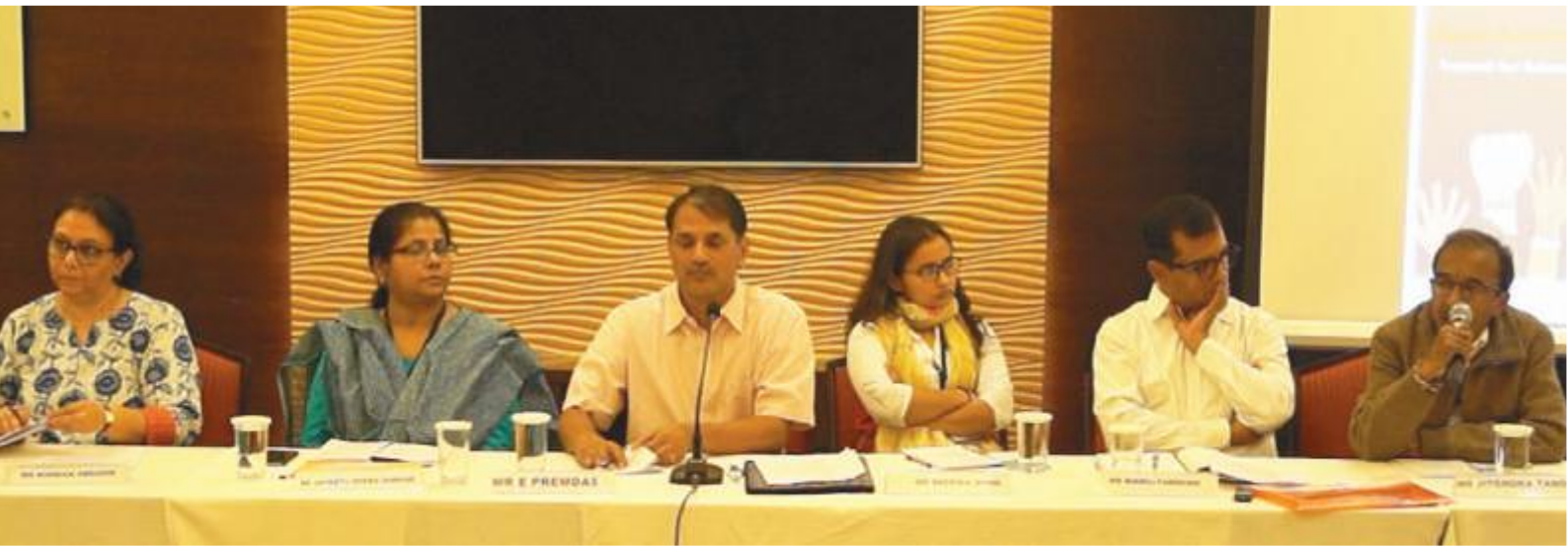
Regulation of essential medicines and medical equipment prices is AIDAN's area of work. Its public interest litigation is on drug pricing control, wherein AIDAN is arguing for a comprehensive drug pricing policy which should cover all essential medicines, and the pricing mechanism should be switched to the cost-based mechanism.

For effective advocacy and social action on the medicine issue CSO's need to equip themselves with all the technical knowledge and market strategies. One of the successes of AIDAN 's and other CSO' campaign is prices of the cardiac stent and knee implant is now capped. However, this is relatively a small success since there are many different types of equipment where the trade margin is still significantly high.

Amulya Nidhi- Health Activist from Swasthya Adhikar Manch

"Clinical trials in India make poor participants vulnerable, because in many instances there is nexus between regulator, sponsor, and investigator. Non-transparency is further exacerbated because of weak legal framework."

The clinical regulatory bodies lack expertise and adequate human power. Corruption is rampant, and informed consent of poor illiterate people is not taken. The authorities have not addressed the absence of any credible ethics committees to look into clinical trial operationalization independently. Swasthya Adhikar Manch's Public Interest Litigation (PIL) in the Supreme Court was focussed on safeguarding patient' right undergoing clinical trials in Madhya Pradesh. They have documented multiple cases of violations tasing critical questions about the ethics, safety, and legality of clinical trials. This advocacy led to the suspension of eight doctors, and the Chief Minister of Madhya Pradesh initiated a departmental enquiry of 11 doctors in 2012. However, no action was taken against the erring doctors- though enquiry confirmed serious lapses in clinical trials. Citing no action, Swasthya Adhikar Manch filed PIL against the Union of India in 2012.



Session 4- Panel Discussions on lessons from campaigns and initiatives to protect Patient's Rights, in India

Parallel Session 1-

Chair- E. Premdas- COPASAH, Secretariat

Mr. Manoj Pardeshi- General Secretary of Network of Maharashtra for People Living with HIV.

HIV patients still face discrimination and stigma in the private hospitals. Especially, patient's who require surgery are frequently denied services. It is estimated that 2.3 million people in India are HIV +ve, around 50% are women. Many of these women are denied HPV pap smear test because they are positive. Effectively, the percentage of HIV +ve women dying of cervical cancer is very high.

Mr. Jitendra Tandel- Rugna Mitra and Citizen's Doctors Forum, Mumbai.

Many dialysis facilities do not have licences or qualified staff to handle the dialysis the patient. Reusing dialyzers is frequent, and hardly anyone knows that it needs to be changed after every patient. Mr. Tandel himself is on dialysis and actively campaigns for patients who require dialysis services.

Ms. Jayeeta Verma Sarkar- People for Better Treatment (PBT), Kolkata.

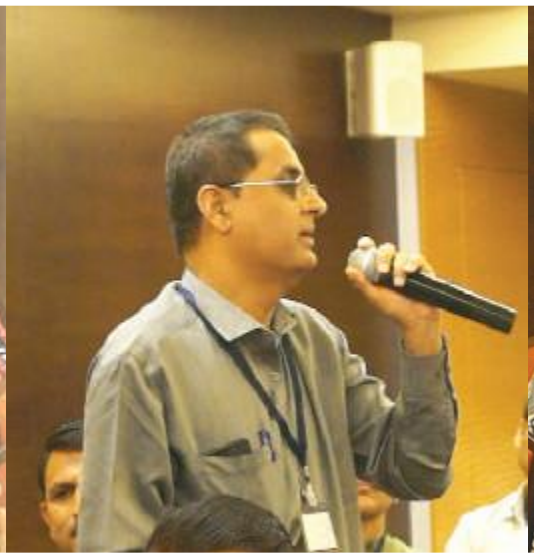
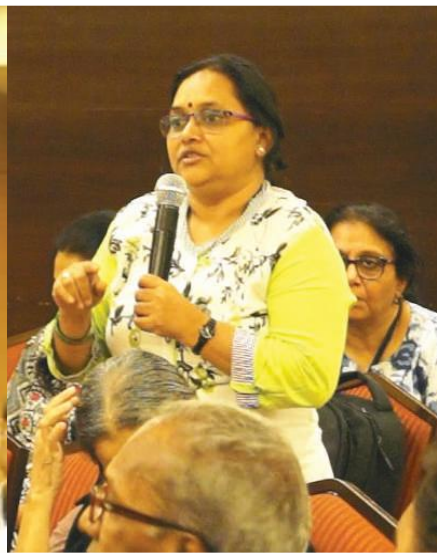
The PBT is the voluntary organization campaigning for the rights of the patients by highlighting medical negligence by doctors, both in public and the private health sector. Dr. Kunal Shah started this campaign in Kolkata after his lost his wife because of medical negligence of doctors in Kolkata-based Advanced Medicare Research Institute (AMRI). Ms. Jayeeta is an ardent volunteer in this campaign and helps victims of medical negligence to file complaint against erring medical establishments and doctors.

Ms. Nisreen Ebrahim- Rangoonwala Foundation (India) Trust, Mumbai.

Although Mumbai has many organizations giving financial support to needy patients, there are very few who make them aware of exploitation in the private sector and their rights. Ms. Nisreen's organization runs a awareness campaign on patient's rights. SATARK Campaign to Alert Patients and Their Rights. From July 2016 to December 2016, they have contacted more than two lac people on the issue of patient's rights.

Ms. Deepika Joshi- Public Health Resource Network (PHRN), Chhattisgarh.

Chhattisgarh has it's own state specific Act to regulate private hospitals. In a positive deviation from the national CEA, it has a Patient's Rights Charter and Grievance Redressal System, and the rate control measures. Jan Swasthya Abhiyan and the PHRN played an active role in exerting pressure over government to implement this act.

Parallel Session 2-

Chair- Dr. Shakeel, Jan Swasthya Abhiyan, Bihar

Mr. R P Y Rao - Society for Awareness of Civil Rights, Mumbai.

The medical device industry is a den of corruption and profiteering in India. Mr. Rao pointed to a nexus between suppliers and medical establishments and how this leads to an inflated cost of the medical devices. He is regularly campaigning and seeking judicial intervention in regulating the prices of wide spectrum of devices including coronary and peripheral stents, intraocular lenses, cochlear implants, pacemakers, catheters, syringes, and needles.

Mr. Govind Bhosale-Kagad-Kach-Patra-Kashtakari Panchayat (KKPKP), Pune.

KKPKP is a trade union of waste pickers and works for their rights, including health rights. The union, through their campaign, is focussing on availing free healthcare for poor patients in Charitable Trust Hospitals, under the available schemes. Mr. Bhosale cited cases where a union has to fight to ensure that Charitable Hospitals comply with the existing rules of free treatment to poor patients.

Ms. Shreya Nimonkar- SETU Pratishthan, Mumbai.

Ms. Nimonkar narrated her story of medical negligence, and how her hysterectomy went wrong. She has registered the complaint against the erring doctor and in a consumer court and the Maharashtra Medical Council. Now she runs Setu Pratishthan to help victims of medical negligence.

Mr. Shashikant Mane- SANGRAM, Sangli, Mumbai.

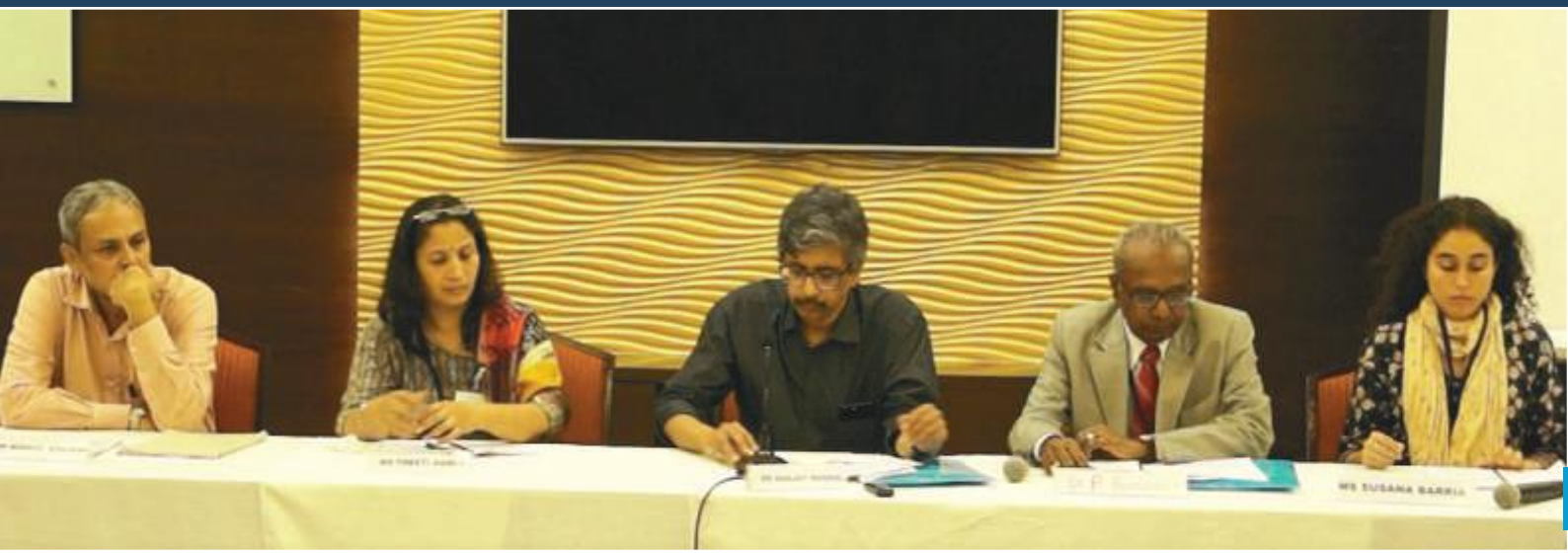
Discrimination against the HIV patients in the district and the sub-district hospital is rampant. Mr. Mane shared various experiences of how sex workers are routinely subjected to negligence and discrimination in the government hospitals.

Adv. Jyoti Bhakre- Consumer Activist, Pune.

As a consumer activist, Ms. Bhakare shared experiences about medical negligence, fabrication of documents, denial of documents to the patients. She also cited how the court judgements are misinterpreted by the hospital lobby to protect its vested interests.

Ms. Pravesh- Mareez Haq Abhiyan, Uttar Pradesh.

He shared an experience of overcharging by the private hospital for a normal delivery. Mr. Pravesh, sought a help from local elected representative to ensure refund and also disseminated information about what can be done when private hospitals charges someone exorbitantly.



Session 5- Alliance Building with Rational, Ethical Doctors and Health Workers

Chair- Dr. Sanjay Nagral- Forum for Medical Ethics Societies

Preeti Damale- Pune Citizens Doctors Forum (PCDF) and Dr. Mirajkar- Mumbai Citizens Doctor Forum (MCDF)

Bridging the trust deficit between doctors and patients is at the core of these forums. The PCDF has created a website, wherein patients have rated their doctors on transparency, behavior, and counseling. This forum is also playing a role in creating awareness and public opinion on patients and doctors relationship. Through the website www.mypcdf.org, this forum is not just facilitating dialogue between patients and doctors, but also does knowledge building of ordinary people by periodically uploading comprehensible information about medicine and healthcare. In MCDF there are few doctors, social workers, and lawyers who are committed to work and fight for better healthcare services.

Ms. Susana Barria- Researcher, Public Service International, New Delhi.

Private hospitals are also not accountable to their workforce. There are ample of cases where private hospitals have an exploitative culture, where paramedics face maximum brunt; particularly nurses and other support staff.

> ***We thus find ourselves at a crossroads: health care can be considered a commodity to be sold, or it can be considered a basic social right.***
>
> ***It cannot comfortably be considered both of these at the same time.***
>
> ***This, I believe is the great drama of medicine at the start of this century. And this is the choice before all people of faith and good will in these dangerous times.***
>
> ***- Paul Farmer***

Stories of grit and resilience

"Can you tell me the MRP of the cardiac stent?"

This was the question **Adv. Birendra Sangwan** asked the doctor, who treated the father of Birendra's friend and charged whopping INR. 1,26,000. The doctor declined to answer, and what followed is a remarkable story of fight back by a well-meaning lawyer.

The hospital did not provide a bill for the stent, and he couldn't get price details anywhere. Sangwan filed an RTI to check how many hospitals in Delhi performed angioplasty using the stent, and found that the pricing of the device varied from one hospital to another. Further, he filed another RTI, through which he got to know that the stent was covered under the Drug and Cosmetic Act, but it was not included in the National List of Essential Medicines (NLEM), which consists of those medicines which must be affordable for the citizens of India.

Sangwan was baffled to discover that the same stent was priced Rs. 23,000 under the Central Government Health Scheme (CGHS), whereas the private hospitals were charging hefty sums. This enormous gap in pricing motivated him to file public interest litigation (PIL) in 2015 to get the device within the ambit of NLEM. But no heed was paid to this litigation for months. After court judgement, it was brought under NLEM. But Government didn't cap it's prices.

But Sangwan kept pursuing the matter by filing contempt of court case. Eventually, the National Pharmaceutical Pricing Authority (NPPA) capped bare-metal stents at Rs.7,260 and drug-eluting stents at Rs. 29,600.

His grim observation was "…major roadblock was dealing with widespread lobbying and influence of private hospitals and doctors, and various pharmaceutical companies and departments who were parties to the foul play."

What is personal is also public

"….as Adya lay, strapped and unconscious, the only sign of change we saw was the daily SMS from Fortis accounts department indicating a change in the bill"

Mr. Jayant Singh's story is emblematic of unaccountable and non-transparent corporate health sector. His seven-year-old daughter-Adya was admitted in the reputed Fortis Memorial Hospital, in Gurgaon. Various print and electronic media vividly report a sordid tale of how this well-known hospital treated Adya and Jayant Sinha. Adya was admitted on 31st August 2017 with Dengue Shock Syndrome, and passed away on 15th September 2017. Fortis gave Mr. Singh a bill of 15 lac rupees, the family was charged for 660 syringes and 2700 gloves, and there was 1700% margin on consumables and medicines. Besides inflated bills, Mr. Singh is fighting Fortis for unreasonably prolonged treatment, and a more serious charge is hospital has forged his and his wife' signatures on the consent form. Most serious charge Mr. Sinha has levied against the Fortis is their attempt to bribe and buy his silence. The fact-finding panel set up by the Haryana Government has observed that Fortis overcharged Rs. 12,800 for eight units of platelets in spite of knowing that they have to charge at Rs. 400 per unit only. Hospital also erred in transferring the patient from life support to life support, which in this case would entail arrangement of an appropriately equipped ambulance. On 7th December, Haryana's health minister publicly said that - " in simple words, Adya' death was not a death, it was a murder."

Mr. Sinha is resolute to fight this battle to the point when people who erred in treating his daughter are punished. He is also vouching for systemic changes so that instances like his daughter' death does not happen in future.

Way Forward-

> **"Finally, we are not alone in our struggle to regulate the private sector and make it accountable. We are making some significant strides, and the state and media are recognizing the importance of this agenda."**

Next Steps-

1. Forming a National level forum for communication and coordination in various states for ensuring legal protection to patient's rights and regulation of private hospitals from a citizen-centric viewpoint.
2. Intervening in the current process of NMC bill and giving submission to Joint Parliamentary Committee with a focus on ensuring an empowered and multi-stakeholder ethics committee with strong representation to CSO and emphasis on protection of patient's rights in private hospitals.
3. Actively providing inputs in reorganization and reform of Maharashtra Medical Council and other state medical councils in India.
4. Following up effective capping prices of cardiac stents, intensifying efforts to ensure regulation of prices of all implants and devices across the country.
5. Keeping in view, successful campaign in Karnataka and experiences of other states, launching a vigorous campaign in Maharashtra and other states for Clinical Establishment Act.
6. There are many case stories where the patient becomes victims of medical negligence, overcharging, malpractice, over-prescription and diagnostic tests etc., to bring all these case stories on a common platform and to have common private hospital watch website and also to link other related websites- such as PBT.
7. Documenting case stories and come out with a book of patient stories.

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