

**THEMATIC HUB ON ‘PATIENTS RIGHTS AND PRIVATE MEDICAL  
SECTOR  
ACCOUNTABILITY-ASSOCIATED WITH COMMUNITY OF  
PRACTITIONERS ON ACCOUNTABILITY AND SOCIAL ACTION IN  
HEALTH (COPASAH)**

**WORKSHOP REPORT**

**SOUTH-ASIA LEARNING EXCHANGE WORKSHOP ON PATIENT’S  
RIGHTS AND PRIVATE MEDICAL SECTOR ACCOUNTABILITY**

**ORGANIZED BY  
SUPPORT FOR ADVOCACY AND TRAINING TO HEALTH  
INITIATIVES (SATHI) AND  
CENTRE FOR HEALTH AND SOCIAL JUSTICE (CHSJ)  
VENUE-YMCA, MUMBAI, INDIA  
JANUARY 23-24, 2018**



## **PARTNERS**

**Support for Training and Advocacy to Health Initiatives (SATHI):** is an Indian civil society organization based in Maharashtra state working in the health sector since 1998, which has been a pioneer in the area of promoting community and social action for health rights in India. Through its consistent promotion of participatory action and advocacy together with policy research, SATHI has been able to give prominence to the issue of patients' rights and regulation of private medical sector within Maharashtra state, and also at national level in India. SATHI has been contributing to strategies of the health movement for social accountability and responsiveness of private medical providers, since over a decade. This strategy has been based on a combination of three complementary approaches: enabling civil society organizations and activists to demand protection of patients rights in the private medical sector; creating a voice in favour of rational health sector regulation within the medical profession; and engaging with the State government to promote and shape regulation of the private medical sector, with emphasis on social accountability and participation.

**Centre For Health and Social Justice (CHSJ):** Centre for Health and Social Justice (CHSJ) is a national civil society resource organization working on policy issues related to social justice perspective oriented governance and accountability primarily in the domains of health justice and gender justice. CHSJ focuses on networking, capacity building, research and evidence based advocacy as primary strategies in its work which is grounded in 10 states on different themes. CHSJ seeks to strengthen governance and accountability in public health and gender justice through technical support, research, and policy advocacy. It is registered as a Charitable Trust with headquarters in New Delhi and field interventions in more than 10 states of India. Community action for Health rights, reproductive and sexual health rights, masculinities and gender form the predominant themes of CHSJ's intervention at present.

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**Yours Sincerely,**

**Core Group of Thematic Hub on Patients Rights and Private Medical Sector Accountability**

Abhay Shukla(India), Abhijit More(India), Ameer Khan(India), Deepika Joshi(India), Farida Akhter (Bangladesh), Indira Chakravarthi (India), Jagadeesh Bista (Nepal), Jashodhara Dasgupta (India), Madhur Basnet (Nepal), Manuj C Weerasinghe (Sri Lanka), Md. Sayedur Rahman (Bangladesh), Moses Mulumba (Uganda), Sirimal Peiris (Sri Lanka)

## INTRODUCTION

In many low and middle income countries (LMICs) especially in South Asia and Africa, the private healthcare sector is playing pivotal role in providing healthcare. This has created many opportunities for better healthcare as well as posed significant challenges regarding quality, affordability of care, ethical practices and patient's rights. With this, there is growing discourse of need for regulation of private medical sector and to protect patient's interest in healthcare set ups, especially protection of patient's rights. However there is a need for a platform bringing together activists and practitioners, which would help develop the discourse on accountability of the private medical sector. In this regards, thematic hub on "Patient's rights and private medical sector accountability" associated with COPASAH initiated in 2017-18, as a platform for promoting networking as well as facilitating exchange of experiences and perspectives among civil society organizations and networks working on issues related to private health sector regulation and patient's rights, with a focus on South Asia.

COPASAH (Community of Practitioners on Accountability and Social Action in Health) is a global network of community of practitioners who share a community –centric vision and human rights based approach to health, health care and human dignity. (For more details see [www.copasah.net](http://www.copasah.net) ).

The thematic hub works through organizing global thematic webinars, networking and alliance building in South Asia, regional consultations, and capacity building of activists. As part of it, Learning Exchange Workshop on accountability of private medical sector and patient's rights involving civil society activists from India, Bangladesh, Nepal and Sri Lanka, was jointly organised by SATHI (Support for Advocacy and Training in Health initiatives) and CHSJ (Center for Health and Social Justice) on 23<sup>rd</sup>, 24<sup>th</sup> January 2018 at Mumbai.

Building upon the experiences and learning from various initiatives in LMICs, this workshop was organized to enhance the knowledge base of citizens, academicians, civil society organizations and doctors regarding broad range of issues related to conceptualization, awareness generation and implementation of patient's rights in LMICs. Over 60 health activists, doctors, public health experts, lawyers came together in this unique Learning Exchange Workshop on Patient's Rights. All came together to share and learn from each other's experiences on private

sector accountability that exists in different parts of the country as well as at South East Asia level.

This workshop was first of its kind in bringing together activists from diverse campaigns and networks united by their concern regarding gross commercialization of healthcare and its negative impacts on ordinary people.

Participants ranged from campaign for capping of prices of cardiac stents protesting against gross overcharging and negligence in corporate hospitals, successful campaign for regulation of private hospitals in Karnataka, Jan Swasthya Abhiyan units from Maharashtra, Tamil Nadu, Orissa, Madhya Pradesh, Rajasthan and other states, Satark Mareej Abhiyan from Mumbai and Mumbai Citizens Doctors Forum, Pune Citizens Doctors Forum, People for Better Treatment, All India Drug Action Network etc. International participants in this workshop included senior health activists, lawyers from Bangladesh, Nepal, Sri Lanka and Kenya.

**Day-One (23<sup>rd</sup> Jan 2018)**

## **INAUGURAL SESSION**

Welcome Address -**Dr Abhay Shukla**, SATHI, Jan Swasthya Abhiyan and COPASAH

Inaugural address- **Mr S.C. Sinha**, Hon'ble Member- National Human Rights Commission, India; **Dr Abhijit Das**, Global Convener of COPASAH;

Dr. Abhay Shukla welcomed all the honorable participants as part of thematic hub on “Patient’s rights and private medical sector accountability” associated with COPASAH. He set the tone to the learning exchange workshop by contextualizing and providing few examples in the violations of patient rights due to the weak regulatory framework that exists for the private medical sector. The dominant private medical sector, its commercialization and corporatization is becoming a serious matter of concern to access and avail health care and hence it is a time of concern for patients and ordinary people. He mentioned the difference between commercialization and corporatization of health care. In the process of commercialization profit motive is the sole intention and it includes individual private practitioners, those who are running their own small nursing homes, small private hospitals etc. Whereas in the process of corporatization there is company who runs chains of hospitals with maximizing huge profit industry with an intention to have large capital accumulation such as Apolo, Max, Vedanta, Narayana Hrudalaya, Sahyadri Hospital etc. Dr. Shukla theorize this health care industry in which there are three actors first is investors who are the owners, second are the doctors and other supporting staff who are the workers, and the third is the patients who is the raw material for them. This profit making and capital accumulation intention is going to dominate the entire healthcare sector which is concern for all of us. There are many victims of this and hence it is time of great concern and there is crossroads, whether the health care will become a completely grossly commercialized entity or whether it will become a human right is a big question. It is gathering of health activist to explore the solutions to battle with this commercialization and corporatization of health care which has serious implications on people’s health. He also drew comparative parallels to other countries from South Asia. It is time of gathering of activist to share and as well as to bring major strategies to tackle this situation with a solution. He ended his



address by quoting the great Dr. Babasaheb Ambedkar's slogan, "*Educate, Organize and Struggle.*"

**Dr. Abhijit Das** introduced COPASAH, its beginnings and the trajectory of the growth of its idea. He briefly explained about the COPASAH which stands for Community of Practitioners on Accountability and Social Action in Health. Its beginning gets back to seven years back where a community of people who are engaged in working with the communities for improving the health of the population and on accountability in health came together to build bottom up knowledge. The importance of this is to interact regularly and sharing and exchanging the experiences with the members of the community. The trajectory of COPASAH came into context where there was attempts to improve the health of the population through MDG or SDG. However most of the solutions were mostly driven from evidenced based practice on large scale experiments which were being done in particular way. It was important to understand that one particular solution won't work and there are different situations which are very much complicated. In this whole arena the agency of communities was completely missing even though it was understood since Alma Ata declaration (1978) that communities are important stakeholders of this process. Few members thought to come together and to create a platform which focuses on building up bottom up knowledge which is built from what practitioner's experiences working with communities of the frontiers of the health care system. The focus is on learning across context and is also on building knowledge. It is also to have alternative evidence based paradigm in order to understand what works in which contexts and what kind of lessons can be drawn from. Hence the COPASAH includes large number of people across global geographies. The COPASAH has forayed into working on across themes and the three thematic hubs which are- a) Reproductive /Maternal Health: The Need to Stimulate Community Action and Accountability, b) Conceptual Framework of the Indigenous People's Right and c) Accountability and Accountability of Private Medical Sector. Along with this he introduced the global symposium which is going to take place in February 2019.

The key speaker, **Mr S. C. Sinha, Hon'ble Member- National Human rights Commission (NHRC), India** could not make it, and his note was read out. National Human Rights Commission, with help of experts from civil society and academia, has formulated a draft Charter of Patient's Rights which is under active consideration of the Commission. Once it is

adopted, this would be applicable to both public and private hospitals. This charter would include key provisions for Patients' rights like- Right to information, medical records and reports Right to emergency medical care, Right to informed consent, Right to privacy, confidentiality, human dignity, Right to second opinion, Right to transparency in rates, and care according to prescribed rates wherever relevant, Right to non-discrimination, Right to safety and quality care according to standards, Right to proper referral and transfer, Right to protection for patients involved in clinical trials and biomedical research, Right to choose source for obtaining medicines or tests Right to be heard and seek redressal. NHRC believes that this Charter of Patients' Rights would be a pioneering document to ensure the protection and promotion of human rights of those who are among the most vulnerable sections of society – ordinary patients and citizens seeking health care across India. Charter of Patient's Rights which is under consideration by NHRC draws upon all relevant provisions, inspired by international charters and guided by national level provisions, with the objective of consolidating all of these into a single document, making them publicly known in a coherent manner. Apart from this NHRC has been taking serious note on patient's human rights violations. It has also recommended the State Governments either to adopt central Clinical Establishment Act (CEA-2010) or to enact similar state specific law while ensuring specific provisions to safeguard patient's rights and grievance redressal mechanism for patients who seek care in private hospitals. Finally it mentioned that it is our shared moral responsibility to promote human rights of patients, which cross the geographical boundaries of nation states and concern all of humanity.

## SESSION-I

### **PERSPECTIVES AND EXPERIENCES OF POLICY MAKERS AND SHAPERS ON ACCOUNTABILITY**

**Chair: Dr Abhijit More**, SATHI and Thematic hub on Patients Rights

**Dr Pravin Shingare**, Director of Medical Education and Research, Government of Maharashtra, India, **Mr Prasanth K.S.**, Senior Consultant, National Health Systems Resource Centre, Government of India, **Dr Nimmi Rastogi**, Advisor Health, Dialogue & Development Commission, Chief Minister's Office Govt of NCT of Delhi, **Mr. Prasanna Saligram**, Azim Premji University, **Dr. Arun Gadre**, Alliance of Doctors for Ethical Healthcare

**Dr Pravin Shingare**, Director of Medical Education and Research, Maharashtra Government shared details about the steps taken by the department to regulate private medical sector, safeguard interest of the patients and legislation to curb the commission practice by doctors. In relation to regulation of private medical sector the department has following the NEET exam (which is uniform entrance exam for existing medical colleges which includes private medical colleges) at the undergraduate and post-graduate level. It also proposed that the NRI quota (Non Resident of India) will also come under the purview of government. In relation to safeguard the interest of the patient the state has introduced number of schemes and plans such as the Rajiv Gandhi Jeevandayee Arogya Yojana (RGJAY) in 2012 and the scheme is renamed as Mahatma Jyotiba Phule Jan Arogya Yojana (MJPJAY) in April 2017, Free beds in charitable Hospitals, concessional rates for poor, mandatory to treat emergency cases, Chief Ministers fund for major Surgeries and also involvement CSR for Health sector. There is a legislation proposed by the state to curb prevalent practice of cuts and commission by the doctors. Along with this Dr. Shingare also informed that Maharashtra State Government is considering to bringing out some changes within Maharashtra Medical Council through legal amendments.

**Mr. Prasanth K. S.** “The Clinical Establishment (Registration and Regulation) Act 2010” he provided details about status of implementation of Clinical Establishment (Registration and Regulation) Act (CEA) which is currently applicable in 11 states (includes all UT). The act includes registration and regulation of public and private medical establishments. It covers all

facilities public/private, all levels, and for all practices. He explained the scope of Clinical Establishments Act in which it includes Registration, Regulation, Facilities and Services, All recognized systems of Medicine, Public and Private, Exception – Clinical Establishments of Defence forces, Minimum standards, Registries (National/State). There are institutional mechanisms proposed under the Act. He explained the procedures for provisional registration based on self declaration as well as the procedures for permanent registration. Provisional registration application can be done by post, online or by person and the validity period is one year. If there is any change of ownership or change of category/location/ functions then it has to be informed to the respective district registry authority. One of the important flaws of provisional registration is that there is no enquiry prior to registration. For applying permanent registration the application has to be submitted with the evidence of standards compiled and there is 30 days period for public to file objections if there is any and there is 45 days period for response to any objections. The validity for permanent registration is five years and the renewal application has to be given before six months of expiry date. He explained the uses of the act in terms having reliable database for Clinical Establishments, Categorize and classify types of clinical establishment, helps government in obtaining data for various public health interventions, determine standards and bringing in uniform standards etc. Further he explained the functions of National and State Councils of Clinical Establishment in which it is to Compile and publish a National Register of Clinical Establishments within two years from the date of the commencement of this Act, Classify the clinical establishments into different categories, Develop the minimum standards and their periodic review, Collect the statistics in respect of clinical establishments, Compiling and updating the State Registers, Representing the State in the National Council, etc. There is district registry authority in which there are different officials are authoritative persons which includes District Collector is the Chairperson, District Health Officer is the Convener, Superintendent/city commissioner – Police, Local self government and professional medical association. There are various conditions for registration such as minimum standards, personnel, infrastructure, maintaining records etc. He detailed explained the post registration issues, register of clinical establishment, various penalties, miscellaneous and the status of national register. At the end he requested civil society activists to follow up CEA in their respective states.

**Dr Nimmi Rastogi** Health Advisor, Chief Minister's Office, Delhi Government discussed about steps under consideration for improving existing health services with emphasis on community involvement for health and environment. She briefly explained and provided the overview of the health service delivery system in Delhi with some figures of existing clinics, hospitals, multi-specialty hospitals and teaching hospitals, public and private. She also briefly gave overview of improvement in the existing health service delivery in Delhi.

Delhi Nursing Home Act which is enacted in 1953 gives power to state government to issue\renew\cancels license, regulate & inspect hospitals\nursing homes, and also to demand compliance for Economic Weaker Section scheme and other schemes, increase or decrease number of sanctioned beds, collect data & report epidemic check for biomedical waste\ death & birth registration issue notice for any irregularity reported.

The Economic Weaker Section (EWS) scheme which is applicable to societies and trust hospitals who have given land at subsidized rate (one rupee for one acre). These hospitals are mandatory to provide free health care services to EWS people.

Controlling gross profiteering in consumables by private hospitals for which GNCTD established a committee for capping profit margin in private hospitals. This move came after the incidences of medical negligence and overcharging in the big corporate hospitals like Fortis and Max in national capital region.

**Mr. Prasanna Saligram**, presented on "The Regulatory Puzzle In India" He provided the brief background of the weak regulatory system and the medical negligence as well as over charging by the private sector hospitals through few examples. He raised a question on can Clinical Establishment Acts (CEA) be the panacea for the irrational practices? He argued that "*CE Acts are necessary but not sufficient. It caters to 'hardware' and not necessarily 'software'*". The judicial proceedings are slow and costly also the legal measures make regulation/governance government centric and do not provide scope for active community participation/governance/regulation. There are serious implementation gaps as it focuses only on infrastructure, silence on processes and outcomes (Quality of Care for eg. Standard Treatment Guidelines).

The way forward in which he theorized responsive regulatory pyramid in which he discussed about the regulatory levels which includes voluntary, market mechanisms, self regulation, meta regulation, command and control. Domains of regulation which includes, cost of care, quality of care, conduct of providers and accessibility of care. He analyzed these regulatory levels and domains of regulation with text book approaches of regulation and policies availability in India. He showed that most of the policies availability in India is absent.

He specifically emphasized on Community Governance or Regulation and discussed the importance of Charters and Rights. He said, while Charters are a first step, they are only voluntary, but it is a useful first step for a system to move systematically towards realization of Rights. The larger umbrella of a 'Right to health care' is absent and should be pressed ahead. This has great promise to bring in such processes as grievance redressal mechanisms, Community monitoring (community action) and 'patient's rights'. It also brings in entitlement based system response than scheme based system response. Till the time the Rights are achieved another important tool to be utilized is the 'monopsony power' of the state to drive down costs and improve quality. This is the promise of the 'Universal Health system' where the state demands better adherence to regulations through the 'carrot' of volumes. E.g. Canada

A Universal Health System moves away from the dichotomy of public and private and moves towards a singular system. Also holds the promise of moving on the path of 'health' in terms of more preventive, promotive than curative 'medical care', but by design of neo-liberal forces the current system is made 'Coverage' based on fee-for-service payment mechanisms (purchaser-provider split) to suit the needs of private sector, e.g. Narayana Hrudayalaya getting away with both medical tourists and government schemes. Through such a Universal mechanism, the system can introduce systematically the Evidence Based Medicine, Standard Treatment Guidelines, performance audits, prescription audits etc., Another important consideration should be for the push towards complete decentralization/devolution (with all the three F's – functions, functionaries and funds – devolved) which again would empower communities' actions.

**Dr. Arun Gadre** is a gynecologist who had private practice in Maharashtra. He shared about the forum of Alliance of Doctors for Ethical Healthcare, its beginning and its position on the current practice in private sector. The emergence of ADEH is started from his published book called

“Dissenting Diagnosis” in which he interviewed 78 doctors across India. Among this 35 doctors agreed to reveal their name. ADEH is a gathering of doctors who are heart, angry, frustrated and vulnerable. ADEH is trying to develop “software” (here it is considered human mind) which is essential to make regulatory hardware functional in the medical fraternity. He reiterated that there is power inequality between doctor and patient and in this relationship patient is most vulnerable. Doctor can circumvent and take the benefit of his knowledge. ADEH is trying to achieve to raise the voice from within and the central point is self regulation. It is against corporatization and against pharma industry problems. It does try to solve the practical problems of the doctors because in the regulation one thing cannot be ignored that is corruption. ADEH is in support of CEA but there has to be provision for minimizing the chance of corruption. ADEH along with the other five support organization demand for resolving MCI but also have critique for NMC bill. It submitted report on the commission practice in Maharashtra to Directorate of Medical Education and Research (DMER) to Dr. Shingare. This forum sees it as advocacy engagement with the policy makers as a sensible rational voice from within the medical fraternity who are not in denial mode. The important aim is to have Universal Health Care for All in India. To achieve this aim it started promoting UHC in India, now started Ethical Practice Watch and have organized first national level conference for doctors for ethical health care at AIIMS Delhi on 23<sup>rd</sup> April 2018.

There was a vibrant discussion with comments and questions from the participants which ranged from the weak implementation, weak political will and nexus of the erring doctors and patient rights.

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## **SESSION-II**

### **INTERNATIONAL PANEL DISCUSSION ON VARIOUS COUNTRY LEVEL ISSUES AND APPROACHES FOR REGULATION OF PRIVATE MEDICAL SECTOR**

**Chair- Dr Amar Jesani**, Indian Journal for Medical Ethics

**Ms Winfred Lichuma**, Independent Accountability Panel (IAP) Kenya, **Mr. Telge Sirimal Wijitha Peiris**, Public Health Consultant, Sri Lanka, **Dr. Manuj Chrishantha Weerasinghe**, University of Colombo, Sri Lanka, **Dr. Madhur Basnet**, B. P. Koirala Institute of Health Sciences, Nepal, **Dr. Jagadeesh Chandra Bist**, Health Activist, Nepal, **Dr. Md Sayedur Rahman**, Health Activist, Bangladesh, **Ms. Farida Akhter**, Executive Director, UBINIG, (Policy Research for Development Alternative), Bangladesh

**Dr. Amar Jesani** set the ground for discussion where he welcomed all the international participants. He set the background where he mentioned the campaign on patients rights which started way back in 1980's when consumer protection act was enacted in India. Now the politicians are also coming to a stage where they are ready to bring some law or regulating the medical sector. It is good sign in a sense people are pressurizing to political system to do something. It is necessary to learn from other countries what is happening in their countries.

The countries are represented in this panel are Kenya, Sri-Lanka, Bangladesh and Nepal which have different characteristics of health care system. Like Sri-Lanka always used as one of the real example for what developing country can do in order to make health care accessible. It is not only in modern medicine but also how to use non modern medicine in this endeavor. In last 20 years lot of turmoil going on with India is becoming liberalized and there are exerting pressures on them. It has impact upon neighboring countries. Sri-Lankan experience may give idea about how and what way it is affecting them. Bangladesh where NGO's are prominent and NGO's are the state within the state. Many people are working in the NGO sector so it is important to see how a private non profit NGO delivery system interacts with the for profit delivery system which is emerging there. Nepal is the only nation where left movement and left politics is prominent.



Kenya where we do not have much experience but looks more organized and regulated society and quite authoritative society.

So in this context Dr. Jesani set the three major areas for all the participants for the discussion.

- What are common violations of patient's rights and nature of medical malpractices in your country/region, from citizen's point of view?
- What kind of regulatory framework for private hospitals is operational in your country/region? To what extent, is it effective and responsive to people's concerns?
- What are the lessons and experiences of people's health movement, civil society organisations towards regulation of private medical sector in your country/region?

**Ms Winfred Lichuma**, Independent Accountability Panel (IAP) from Kenya, has expressed that Kenya does recognize health as a constitutional right since 2010. It promotes right to health which also includes reproductive health. No one should be denied of emergency care. It provides right to life includes safe legal abortion. At one side there is public health care system which is decentralized. There is national government and 47 county governments. Policies, regulation and standardization mostly remain at the national level whereas the actual implementation is at the county government. On the other side it does recognize the private health care providers which includes private companies, private insurance companies etc. There are many problems with the implementation. For implementation you have to go to court of law to get it implemented. Government doesn't allow public to make demand pro-bono- lawyers to defend citizens. So citizens have to claim their own claim.

Private sector has come in and almost monopolized health care sector. There is a vibrant public sector whereas private sector is unregulated or very minimally regulated. In last two years there are strikes going on from the doctors, nurses, clinicians. There are cases of medical negligence in the private sector. However the bottom line is the citizen and nobody is concerned about what citizens want.

Medical tourism is highly unregulated. Doctors from India come to Kenya and process starts to get the patients in India. There is urgent need to regularize the medical tourism. She pointed out

that in 1980-90 health insurance was less and now has flourished. Needs to study how many private insurance companies are there because public servants are insured by private insurance companies and hence there is need to be regulated.

Self regulation alone won't solve the problems and there is a need to involve non medical doctors on board. She suggested using of different government bodies and using various government mechanisms, National Human Rights Bodies, National Gender Inequality Bodies, and Ombudsman etc. in order to bring accountability in the private sector. Citizen voice can only be done by civil society organizations. Regulation must be supported with action and commercialization of health care must be stopped.

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

**Dr. Manuj**, mentioned that in Sri Lanka health is not a fundamental right in the constitution. The Supreme Court judgment in 2010 considered right to health under the right to life. In Sri-Lanka 50 percent people access outpatient care (OPD) in the government sector and 50 percent in the private sector. 95 percent patients access in-patient care (IPD) in the government sector whereas only five percent patient access IPD services in private sector.

He provided the brief overview of the violations of patient's rights at various levels. He mentioned that even though the literacy rate is 95 per cent still there is asymmetry of information when it comes to health or illness. Hence there are many unnecessary investigations as people also belief on number of investigations, questionable procedures, expensive brand prescriptions, unregulated fees in which there is huge variations in the fees for example there are huge variations for c-section procedures, medicalization of physiological conditions, etc. All these issues matters when it comes to patients rights. There is a growing private sector in Sri-Lanka and majority of health work force prefers to work in the private sector as doctors employed in the government hospitals are allowed to practice in private hospitals. Different organization are working on promotion of generic drugs however people feel branded are better and its difficult to counter those notions. Even the government has promised a drugs policy but it never came into reality. There is no legislation to control the drugs trade; they are sold in the open market under several trade names. Private Medical Institution Regulatory Act drafted over a decade however

there is no enforcement. Three times it went to Supreme Court but still there is no enforcement. The private medical sector regulatory framework is very weak. There are many serious flaws and the medical industry takes advantage of it. He mentioned that “having a good health system, we are derailing from the foundation we used to have.”

Efforts are being made by **People’s Health Movement-Sri Lanka (PHM-SL)** to advocate Right to Health as a constitutional right, to work towards eliminating corruption in health sector and defeat move towards privatization, to voice against military actions disrupting healthcare provision, to advocate for a National medicinal Drug Policy, to establish a people centered health / medical education system, to work against trade agreements negatively influencing health and to provide recognition to alternative medical systems. It had discussions with medical, sociology and political science university professors and also a healthy dialogue has been commenced with the leaders of trade unions, politicians, civil society members and with the prominent individuals. PHM has formulated to propose following section to be included in the constitution

*“Each and every citizen has a fundamental right to receive quality and quantitative and un-biased free medical attention for treatment in case of a disease, ailment or accident and preventive and consultative services regarding communicable and non-communicable disease under state expenditure”.*

There have been continuous efforts by the PHM-SL to campaign for right to health as a constitutional right.

**Dr. Madhur Basnet**, B. P. Koirala Institute of Health Sciences and **Dr. Jagadeesh Chandra Bist**, Health Activist, Nepal.

From 2015, Nepal’s constitution addresses health as fundamental rights however the way present health care system practices and the way it is implemented is an issue. There are contradictions and hence the present system does not guarantee fundamental right. The wave of privatization in Nepal came in 1990 and that is the time when democracy came along with the liberalization. According to the policy the regulation of private sector will be the integral part of the liberalization however after the liberalization the policymakers and government didn’t paid attention to regulation. The recent move is also towards corporatization and there is weakening of public sector. Due to weakening of public sector people do not have option to access private

hospitals. The Public system is undermined over the private sector. There are similar problems of patient rights violations as overcharging, unnecessary investigations, malpractice etc. in private hospitals. There is a growing dominance of private medical colleges in which merit is ignored. Currently in Nepal there are 18 private medical colleges as against four in government sector. There are also protests going on against this private sector growth. Nepal does have National Health Insurance however in that there is a provision that private hospitals can be service providers. Hence there is worry that regulation will be poor and the public money is going into the private sector. Another conflict of interest is that the physicians who are working in the government sector are allowed to do private practice. Hence the government sector is not going to improve due to this conflict of interest. There are huge under-staff in government sector hospitals. There is no regulation on private medical sector and overall framework and its implementation is very weak. Hence the patients' rights get violated.

In terms of regulation it mentioned that there is no separate framework to protect the rights of the patients. Health as a right became constitutional right just two years back and hence the mechanism to provide it as right is yet to develop. Patient can go to court to get the constitutional right but overall framework and the mechanism to ensuring it as right is yet to develop. There is consumer protection act and centrally that is governed by consumer council which is represented by different ministries and NGOs. Patient can file their grievances in this consumer council. At the district level there are compensation committees that are led by chief district officer where patient can file their grievances. In terms of health professionals regulation there is Nepal Medical Council, Nursing Council, Health professionals Council. These councils regulate the professionals and their code of ethics. Under the National Health Insurance Scheme there is committee under which patient can file their grievances related to violation of patients rights in Insurance scheme. As private sector is part of industry so some regulation is done by ministry of industry but it's not very well led out. There is no coordination between MOH and MOI hence the regulatory framework is very weak.

The nation is into reshuffling and transitory phase. Ensuring basic health care has been incorporated in right to health. The member and activist of people's health movement have been active and played a prominent role in the development of National Health Policy 2014 amendment which is yet to pass by the parliament. The sub-committee on public private

partnership has been in the move to promote PPP model. In this case the movement is making ensure that providing basic health care is the government responsibility and it has to be provided by the government as it is right under the constitution. It is also trying to make national health insurance pro people and it should be based equity form, based on income of person. It is also trying to make sure that insurance is not being exploited by private sector. There is hunger strike to regulate the private medical education as well.

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

In Bangladesh, health is not considered as fundamental right. Constitution just says provision of basic health care by the state in addition to food, clothing etc. It does not have strong guidelines. After independence there was a focus on the preventive and primary care and it did built the excellent primary care set up covering the whole population. However there is transition to tertiary curative care in which the private sector comes in and the profit becomes important. There is an impact of India's development towards privatization of healthcare and focused on high end tertiary curative care in Bangladesh. The transition from preventive and primary care to focused high end, capital intensive, less required but profitable tertiary care is mainly impacted by the India's interaction with Bangladesh.

In Bangladesh, there are 65, 000 practicing doctors out of which 18, 000 are employed in the government sector and they are distributed all over the country. Every unit has at least one or two physician with having support staff.

Over the last decade, Government hospitals did not increase as much as the private sector hospitals grown with no regulatory framework. Even at the government owned sub-district hospitals there are agents hired by the private clinics to recruit patients. There is unholy alliance between public and private. Mostly the malpractice does take place in private hospitals. Lots of cases of malpractice in private hospitals got media attention. There is question of use of ICUs, use of life support technology, withholding dead bodies if the payments are not done etc. Now, Apollo has reached to Bangladesh and it has a very bad name in the country.

In terms of Private sector regulation there are three areas- one is private medical education, second is clinical research and third is care. There are three layers of regulation as one one is

medical council, second Health Ministry and the third is policy for establishment and management of private medical colleges. Under this policy in last two years nine medical colleges were closed down and there will be some bar on admission and management of private medical colleges. Bangladesh entered in a clinical research scenario there is a competition with China and India. There are individual efforts to protect the people in clinical trial research. Since 2009 there is Consumer Protection Act in place but care law similar to Clinical Establishment Act in India is in pipeline for 7 years. There is also Patient and Medical Practitioner's Protection Act under which the case of attendant is not bail able and in case of practitioners it is bail able, hence it shows the bias and influence of practitioners. There is high court ruling that doctor's handwritten prescription should be readable.

**Ms. Farida Akhter** suggested that there should be more focus on the community level health care and it can be given to people at low cost. We have lost our focus on community level health care in recent decades. There is a Shastra Andolan for demanding patient's rights and higher budget allocation on health. There is few doctors' organization who does talk about malpractice in private hospitals. Health journalists are active in Bangladesh. Some human rights activists discussing about right to privacy of patients data and whether it can be pushed. Health care is a political issue and it has to be discussed at political platform only.

In Summary, Kenya and Nepal mentioned that they have the constitutional right to health, where as India, Sri-Lanka and Bangladesh did not have it. The issues of patients' rights were similar, with inadequate regulation, capping on pricing of health services. Bangladesh and Sri-Lanka have well laid primary health care. Private hospitals and Clinical Research Organizations from India are making foray into these countries. The discussion led out that there is a necessary to have greater alliance and to learn from each other experiences in order to improve the health care systems in respective countries.

## **SESSION-III**

### **LESSONS FROM CAMPAIGNS AND INITIATIVES FOR REGULATION OF PRIVATE MEDICAL SECTOR**

**Chair: Prof Jaya Sagade**, Senior Legal Expert, ILS Law College, Pune, India

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

**Ms Akhila Vasan**-Campaign for amendments in Karnataka Private Medical Establishment Act-Karnataka Janaarogya Chaluvalli (KJC), India

**Ms Malini Aisola**- Campaign to regulate prices of essential medicines and medical equipments-, AIDAN, India

**Mr. Amulya Nidhi**-Campaign to safeguard participant's rights in clinical trials- Swasthya Adhikar Manch, India

**Dr. Anant Phadke**- briefly gave overview of the Jan Swasthya Abhiyaan, (JSA) and Jan Aarogy Abhiyaan (JAA). JAA is the –Maharashtra chapter of Jan Swasthya Abhiyaan, (JSA). JSA is the People's Health Movement network in India. From its inception in 2000, JAA has been advocating regulation of private health care. He explained the outcome of unregulated private health care sector where there is huge commercialization of health and it has impacted upon violating patients rights. The number of factors which led to the unregulated growth- that is not having legal framework, no political will, fear of babu-raj, powerful doctors lobby and growing influence of Corporate players in the healthcare sector.

He explained the various flaws under the Bombay Nursing Home Registration Act (BNHRA)-1949, in which it is mostly applicable only in a few big cities, mostly mere registration of nursing homes. He mentioned that JAA had played an active role for advocacy for amendments to BNHRA. It got amended in 2006 however the amendments were perfunctory, hence JAA campaigned for further amendments in the Act and Rules-Inclusion of patient's rights in rules. Under this, many activities undertaken such as signature campaign for patients rights in

BNHRA, Pamphlet demanding approval of BNHRA rules and patient's rights, writing in news paper articles. It has conducted state level convention, started patient's rights forum, Media coverage, Liaison with selected MLAs to raise the issue of pending approval in the Vidhan Sabha, E- Petition for patients' rights etc. JAA's Media advocacy on Patient's Rights was well covered by print and electronic media.

Central Government enacted Clinical Establishment Act in the year 2010. JAA prepared a critique of CEA-2010 and launched a campaign for an improved version of Maharashtra specific CEA bill. He explained the positive features of this bill and the problems of this bill from public health point of view as well as from doctor's perspective and patient's perspective. JAA Campaigned for "No for Central CEA and Yes for Maharashtra CEA". Due to JAA's advocacy, Maharashtra Government appointed Expert Committee in December 2013 for drafting Maharashtra CEA. JAA representative played a leading role in this draft. Expert Committee submitted draft Bill in June 2014. JAA's also gave proposal for rate regulation under which it specified the regulation of professional fees and regulation of charges for services. However, Maharashtra CEA Bill-2014 has not been tabled in the assembly for three years.

**Ms Akhila Vasan**-Karnataka Jan Arogya Chaluvali (KJC), a people's movement for health rights, dignity and well-being of all citizens, with a focus on the most disadvantaged and marginalized communities. She has shared the struggle to fight with the state to bring in force for amendments in Karnataka Private Medical Establishment Act (KPMEA).

She explained the experience with KPMEA was that it was woefully inadequate. All complaints and representations made detailed demands regarding amendments to the Act of 2007. There was citizen's core demand for the protection of the patient's rights.

In October, 2016 Justice Sen committee established to look into the bill and to make it citizen centric in which the committee was dominated by private hospital representatives and there was only one citizen included as citizen's representative. There was half hearted response to KJC's demand to include 20 sanghatans/ individuals in the committee. In the four meetings Citizens groups constantly raised objections against attempts to include government facilities under the Act. There were serious efforts being made by the private sectors doctors lobby to derail the process for enacting the bill. In April 2017, The Justice Sen Committee excludes citizens' groups



and finalizes recommendations. In response to this action in May, 2017 there was efforts being made by the KJC for building public opinion against the Sen Committee report while focusing on citizens' demands. To create public opinion there were efforts being made for mobilizations of various constituents led by Dalit sanghatans in 16 districts, Meeting the Health Minister that Jt. Sen Committee had violated the government brief, Meeting Members of Legislative Assembly (MLAs) across parties to raise questions in the upcoming Assembly session on KPME. In response to this there was campaign and protest conducted by the Indian Medical Associations and by the private practitioners lobby. In June 2017, the Amended Bill was presented in the Assembly where there was Six hour debate on the Bill and MLAs cutting across party lines welcome Bill as being 'pro-poor' and 'pro-citizens' but express concern about its 'consequences on doctors'. Hence referral was being made to have Joint Select Committee. After this Joint Select Committee there was huge struggle being made by the KJC to make the bill pro-people and hence it has actively campaign and put it into public opinion. Against this there was also active campaign by the doctors on social media. The political party BJP's support to the protesting doctors made the campaign more vibrant.

Finally she mentioned that, "the story of KPME amendment is a story of citizens' battle against the exploitative profiteering 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 when drawn into the health rights discourse".

**Ms Malini Aisola**-gave a brief introduction of All India Drug Action Network (AIDAN) which is an independent network of several individuals and non government organizations who are engaged in issues related to affordable access to medicines, safety of medicines, rational use of medicines and various medico legal issues. AIDAN has a long standing campaign for essential affordable medicines through Public Interest Litigation (PIL). It is actively involved in the Campaign to regulate prices of essential medicines and medical equipments in India. The chief focus of the PIL is to the limited coverage of drug pricing policy which is at the moment covering just about 10 percent of the total medicines in the market. The second one is on drug pricing control order which is drug pricing policy should cover all essential medicines and also

pricing mechanism should be switched to cost based mechanism which was in place prior to it. AIDAN is also working on the issues of medical devices and explained the deep rooted exploitation in the system because there is severe vacuum in the regulatory mechanism. There are artificial inflated prices of medical devices which keeps MRP high.

She appealed that we need to equip ourselves with knowledge of all technical as well as market based strategies as how it works. She also discussed about the outcomes and lessons of this campaign as the prices of stent and knee implant has been capped however there is no any further move to cap prices of other medical devices. So the issue comes of huge trade margins. AIDAN is demanding broad based price mechanism across medical devices or at least minimum in 19 essential medical devices which are in most need.

**Mr. Amulya Nidhi**-Health Activist from Jan Swasthya Abhiyan- Madhya Pradesh (JSA\_MP) talked about “Campaign on Securing Rights of Clinical Trials Participants in India”. He shared insights into his Public Interest Litigation in Supreme Court to safeguard patient’s rights undergoing clinical trials in Madhya Pradesh and also shared violation of rights at different levels. He said that the clinical trials are necessary for developments of new drugs but need to assess whether they are Ethical, Safe and Legal. There are violations of patients rights at various levels such as regulatory approval in which there are lack of expertise, inadequate manpower, corrupt practices, illiterate and vulnerable patients are selected and there is no proper informed consent being made, in this case, very less information given to clinical trial participants or to their families. There is a lack of transparency and also not having proper ethics committee (Institutional vs Independent). There is nexus between regulator, sponsor and investigator. This is all backed by a weak legal framework. He mentioned that there is a need to have pro-longed action by using following approaches- Advocacy through political, administrative and judicial channels; victim mobilization; gather information which is absent in public domain (Using Right to Information Act); connecting with government organizations and networks.

He explained that Swasthya Adhikar Manch had filed a complaint against medical practitioners in the Medical Council of India for conducting illegal drug trials on patients. As a result, Medical Council of India suspended the license of eight doctors for three months (July 2017). Chief Minister of MP had done departmental enquiry on 11 doctors in the year 2012, in which it was

confirmed that the illegal clinical trials were conducted on the patients by them, but in spite of this, the government has not taken any action. Public Interest Litigation filed in the Supreme Court by Swasthya Adhikar Manch vs Union of India in 2012. Multiple states became respondents and Human Rights Commission intervened into this PIL.

Over the years, he is continuously campaigning against unethical clinical trials across the country. He expressed that to get justice need to approach court without which it is not possible to have pro people agenda.

## **DAY-TWO (24<sup>TH</sup> JANUARY 2018)**

### **SESSION IV: TWO CASE STORIES**

#### **ADV. BIRENDRA SANGWAN-ACTIVIST AND PETITIONER FOR CARDIAC STENT PRICE CAPPING, INDIA**

A young, Delhi based advocate and activist shared his experiences of series of petitions in the high court of Delhi on cardiac stent price capping, India. PIL against 38 hospitals was filed in Delhi High Court (HC) for overcharging cardiac patients by hospitals in the name of angioplasty procedures. Due to his continuous petitioning the prices of stents were reduced from INR 80,000 (about USD 1350) to INR 28,000 (approx. USD 400). He shared campaign strategy about how civil society can check gross profiteering by private hospital. Giving example of his famous and successful Public Interest Litigation (PIL) intervention for capping the cardiac stent prices by whopping 80%, he appealed to use instrument of PIL in more constructive and effective manner.

#### **Jayant Singh, Campaigner against Fortis Hospital, Gurugram, Haryana, India**

Father of seven year old girl who died because of dengue in Fortis Hospital which is corporatized hospital in Gurgaon, Haryana. He narrated his tragic story about medical negligence and greed for profiteering took life of his beloved daughter. Hospital slapped huge bill of Rs. 16 lakh which later on proved that it was highly inflated bill with 108% profit margin in medicines and astonishingly upto 17.37% profit margin in consumables! He narrated the horrifying experiences of dealing with the hospital, the apathy of the staff and the manipulation of the business team in manipulating the processes without giving adequate opportunity for the patient or guardian to have a say in the process. From the experience of his daughter's death, Mr. Jayant, an Information Technology expert, has started a campaign against the exploitation of the corporate hospitals.

## SESSION V

### PANEL DISCUSSIONS ON LESSONS FROM CAMPAIGNS AND INITIATIVES TO PROTECT PATIENT'S RIGHTS (HELD IN TWO PARALLEL SESSIONS)

#### Parallel Session-5.1

**Moderator- Mr. E Premdas**, Global Secretariat Coordinator, COPASAH

**Ms. Jayeeta Verma Sarkar**-Campaign Against Medical Negligence- People for Better Treatment (PBT), Kolkata, India

**Ms. Nisreen Ebrahim**-Campaign For Alert Patients And Their Rights- Rangoonwala Foundation, Mumbai, India

**Ms. Deepika Joshi**-Monitoring Implementation of Chhattisgarh Nursing Home & Health Care Establishment Act- PHRN, India. **Mr. Manoj Pardeshi**-Experiences of working for the rights of people with HIV- Network of Maharashtra People with HIV, India

**Mr. Jitendra Tandel**-Campaign for safety of dialysis patients in Mumbai- Rugna Mitra and Citizens Doctors Forum, Mumbai, India

**Ms. Jayeeta Verma Sarkar**-There are many Civil Society Organizations who are coming forward and fighting and demanding for patient's rights. Among them the People for Better Treatment (PBT) is the voluntary organization that is constantly fighting and campaigning for medical negligence by doctors both in public and private sector. The famous Dr. Kunal Saha case and its historic judgment on medical negligence, the Supreme Court of India found 4 doctors and Advanced Medicare Research Institute (AMRI) in Kolkata guilty for negligent treatment causing death of his wife. Jayatee Verma shared her experience of the negligent death of her father and seeking help in her quest for justice for her departed father. Over the past six years she has not only launched a recent-less fight against the powerful hospital and doctor, has also joined PBT as an ardent volunteer to help other victims of medical negligence. The organization is helping and guiding patients to file complaint procedures who are victim of medical negligence.

**Ms. Nisreen Ebrahim**-Rangoonwala Foundation (India) Trust, Mumbai, works on multi-sectoral programme which covers community services, health, education, livelihoods and disability. She shared her experiences on campaign for alert patients and their rights.

**Ms. Deepika Joshi**-Public Health Resource Network (PHRN),Chhattisgarh, India actively involved in the Monitoring and Implementation of Chhattisgarh Nursing Home & Health Care Establishment Act.

**Mr. Manoj Pardeshi**-General Secretary of Network of Maharashtra for people living with HIV, India, shared his experiences and his active involvement in working for rights of the people with HIV in Maharashtra as well as at country level.

**Mr. Jitendra Tandel**-Rugna Mitra and Citizens Doctors Forum, Mumbai, India actively participated in the Campaign for safety of dialysis patients in Mumbai. He himself was on dialysis for more than 12 years and felt that 90% of doctors and nursing staff failed to show concern or respect to patients.

## **PARALLEL SESSION-5.2**

**Moderator- Dr Shakeel**, Jan Swasthya Abhiyan, India

**Mr R P Y Rao**-Campaign To Regulate Prices Of Implants, Catheters- Society For Awareness of Civil Rights, India

**Mr. Govind Bhosale** - Campaign To Avail Free Healthcare For Poor Patients In Charitable Trust Hospitals-, Kagad-Kach-Patra-Kashtakari Panchayat, Pune, India

**Ms. Shreya Nimonkar**- Fight Against Medical Negligence –Citizens Doctors Forum and Setu Pratishthan, Mumbai, India

**Mr. Shashikant Mane**- Experiences Of Working For The Rights Of People With HIV- SANGRAM, Sangli, India.

**Adv. Jyoti Bhakare**- Consumer Activism In Healthcare-, University of Pune, India.

**Mr. Pravesh**- Campaign To Safeguard Patient's Rights And Implementation of Clinical Establishment Act 2010- Mareez Haq Abhiyan, Uttar Pradesh, India.

**Mr R P Y Rao**-Society for Awareness of Civil Rights, Mumbai and he is actively involved in the campaign for 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 Kashtkari Panchayat-(KKPKP), Pune, is a trade union of waste pickers and works for the rights of the waste pickers which includes the health rights of the waste pickers. They have initiated number of programmes for the health of the waste pickers

which primarily includes the health insurance of the waste pickers. The union is also actively involved in the Campaign to avail free healthcare for poor patients in Charitable Trust Hospitals and it continues to fight to ensure that members eligible for treatment under the scheme receive their rights. He shared one of patient's case in which the members of KKPKP fought against the trust hospital to have free health care treatment.

**Ms. Shreya Nimonkar-** A 41 years old married lady and mother of two kids narrated her story about medical negligence and gross medical error in private hospital by a gynecologist under which she has to go through to a number of operations starting from hysterectomy, removed the cracked ureters and cut 20 Inch of intestine etc. She is fighting for five to six years and she has registered a complaint against gynecologist at Consumer Court and Maharashtra Medical Council as well. She is actively involved in to bring strict laws in medical negligence and for doctors doing malpractice.

**Mr. Shashikant Mane-** SANGRAM an NGO working in Sangali district of Maharashtra for 25 years. He shared experiences of working for the rights of sex workers and people living with HIV and fight to provide free ART treatment at district and sub-district hospitals.

**Adv. Jyoti Bhakare-** Pune based advocate shared experiences about consumer activism in health care in which she shared the cases about medical negligence, fabrication of documents, denial of documents to the patient, as well as how the court judgments are misinterpreted by the hospital lobby in order to safeguard their self interest.

**Mr. Pravesh-** Mareez Haq Abhiyan, Uttar Pradesh, India, is actively involved in the Campaign to safeguard patient's rights and implementation of Clinical Establishment Act 2010. He shared the case of overcharging by the private sector for normal delivery (one lakh fifty thousand rupees) against which the organization fought and with the help of MLA the punishment was given to doctor. Involvement of MP's and MLA's as well as extensive use of RTI can put pressure on bringing private sector accountability in force.

## SESSION VI

### ALLIANCE BUILDING WITH RATIONAL, ETHICAL DOCTORS AND HEALTH WORKERS

**Chair: Dr Sanjay Nagral**, Forum for Medical Ethics Societies

**Dr. Preeti Damle**, Pune Citizens Doctors Forum, Pune, India.

**Dr. Mirajkar**, Mumbai Citizens Doctors Forum, Mumbai, India.

**Ms. Susana Barria**, Public Services International, Delhi, India

**Dr. Preeti Damle** explained about the Pune Citizens Doctors Forum. There are few local level initiatives taken by the few doctors and citizens under which the initiative emerged to form a forum of Pune Citizens Doctor Forum (PCDF). She briefly explained about the growing dominance of private sector and the relationship between doctor and patient is getting worrisome problem. She explained there are increasing incidences of attacks on doctor as well as increasing cases of victims of malpractice. Inadequate and inequitable distribution of government healthcare services and entry of Corporate Hospitals has led to increased consumerism. In the current situation there is a need where good doctors need support from society and mature patients need ethical doctors and hence the solution is rebuilding the lost trust between doctor and patient. So, there is an emergence of PCDF in order to have dialogue and create awareness and building trust between doctors and patients. The forum created a website which provides the list of 'Patient Friendly' doctors in Pune for benefit of citizens (recommended by patients themselves). The forum also conducts various discussions and seminars in order to create awareness among the society and communities. It also conducted open Seminar on "Universal Health Care – What it in it for Doctors and Patients?" She also explained the way forward where she mention that promoting the website which is [www.medimitra.org](http://www.medimitra.org), spreading awareness through social media, dialogue between renowned doctors and citizens, creating and uploading of informative and educative literature on [Medimitra.org](http://Medimitra.org), platform for Second Opinion Helpline for information about affordable medical and allied services with having ultimate aim for achieving Universal Health Care.



**Dr. Mirajkar** who is surgeon doctor and associated with human rights expressed similar initiative taken by the Mumbai Citizens Doctor Forum (MCDF). He witnessed a medical negligence case and decided to response to it and wrote an opinion piece on it which got huge critical response. With this initiative few victim of medical negligence also came forward. Later on Mumbai Citizens Doctors Forum got formed with the initiative of SATHI. He is actively associated with MCDF since its formation. There is a need to have such platform to assert our needs and demand for ethical, rational health care. He also expressed apathy in the public and private health care services and regretted that the health care services are not reaching to the rural population. In MCDF there are few doctors, social workers and lawyers who are committed to work and fight against the medical negligence. There is regular meeting in Mumbai and discusses about various issues of medical negligence, overcharging, unnecessary investigations, etc. Forum does take active role in dissemination of information about health care on social media. Forum is taking forward this movement to actually work in the field. He also highlighted on the training part of the medical students as there are many junior doctors place

Both the forum representatives shared their experiences in bringing this forum in active mode.

**Ms. Susana Barria** is a Researcher at Public Service International at New Delhi, shared accountability of private hospitals towards their workforce. She mentioned that there is exploitation of the workers in hospitals and that needs to be looked out. In this context she shared experiences about nurses' struggle in Kerala to get minimum wages.

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## **Session VII**

### **WAY FORWARD AND NETWORKING**

**Moderator – Dr Abhay Shukla, SATHI, Pune, India**

**Discussants- Mr. Gauranga Mohapatra, Mr. Ameer Khan and Activists from Other Health Movement Networks**

**Dr. Abhay Shukla**, summarized the key points that emerged from two days. On the discussions and sharing of experiences it came forward that we are not alone in struggling with this issue. Across countries people are doing struggles. Despite there is a huge challenge few case stories and civil society organizations such as KPMA, Jayant Singh case story, Birendra Sangwan, are examples of inspirations to fight for patients rights and there is wide spread visibility and popular support for accountability. In this there can be four to five pillars on which we can bring private sector accountability and patient's rights in force.

1. Using courts as a means to get justice
2. Using Different Official Bodies
3. Using Media to bring the issue in public domain
4. Victim activism.
5. Citizens Mobilization

There are number of issues such as malpractice, overcharging, negligence in private hospitals (exploitation) which is becoming a burning popular concern and part of patient rights violation. Pricing of implants and stents is a wedge to penetrate larger space. E.g. a petitioner for stent pricing also has filed a petition for implementation of CEA in Delhi.

#### **Constituencies addressed by various Patient Rights Campaigns:**

- Direct victims of medical negligence & malpractice
- Mass organisations of working people
- Middle class and their discontent
- Health NGOs and activists
- People oriented doctors & other health workforce

- Activist lawyers & legal experts

**After detailed discussion, participants formed a consensus to have following strategies in action.**

- 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 citizen centric view point.
- Intervening in 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.
- Actively providing inputs in reorganization and reform of Maharashtra Medical Council and other state medical councils in India
- Following up effective capping prices of cardiac stents, intensifying efforts to ensure regulation of prices of all implants and devices across the country.
- Keeping in view, successful campaign in Karnataka and experiences of other states, launching a vigorous campaign in Maharashtra, Orissa and other states for Clinical Establishment Act.
- There are many case stories where patient becomes victims of medical negligence, overcharging, malpractice, over prescription and diagnostic tests etc...to bring all these case stories on common platform and to have common **private hospital watch** website and also to link other websites to this website such as PBT have their website which can be linked to Private Hospital Watch Website.
- Documenting case stories and come out with a book of patient stories

## **ANNEXURE-I**

### **Inaugural Address by Shri S.C. Sinha, Hon'ble Member of National Human Rights Commission of India**

Good morning to all the participants! I welcome delegates from different parts of India, Sri Lanka, Bangladesh and Nepal in this South Asia level Learning Exchange Workshop on Patient's Rights. Though I had consented to participate in this workshop, I am unable to attend due to some other commitments. Hence I am sending my address which may be read out to all the participants.

It gives me immense pleasure to inaugurate this South Asia level Learning Exchange Workshop on Patient's Rights which seeks to enhance the knowledge base of patients' rights advocates, health experts, consumer rights activists, doctors and policy makers. I believe that you would be discussing a broad range of issues related to conceptualization, awareness generation and implementation of patient's rights with focus on key South Asian countries including India. Though I could not address this gathering in person, I convey my best wishes to all of you and hope that this workshop will significantly contribute to strengthening the discourse around patient's rights especially in South Asia region!

At this juncture, I am very happy to inform that taking into account the exploitation which patients have to suffer in public as well as private Health facilities, the National Human Rights Commission, with help of experts from civil society and academia, has formulated a draft Charter of Patient's Rights which is under active consideration of the Commission. Once it is adopted, this would be applicable to both public and private hospitals. We envisage that this charter would include key provisions for Patients' rights like-

1. Right to information, medical records and reports
2. Right to emergency medical care
3. Right to informed consent
4. Right to privacy, confidentiality, human dignity
5. Right to second opinion
6. Right to transparency in rates, and care according to prescribed rates wherever relevant
7. Right to non-discrimination
8. Right to safety and quality care according to standards
9. Right to proper referral and transfer
10. Right to protection for patients involved in clinical trials and biomedical research
11. Right to choose source for obtaining medicines or tests

## 12. Right to be heard and seek redressal

National Human Rights Commission, India believes that this Charter of Patients' Rights would be a pioneering document to ensure the protection and promotion of human rights of those who are among the most vulnerable sections of society – ordinary patients and citizens seeking health care across India. Charter of Patient's Rights which is under consideration by NHRC draws upon all relevant provisions, inspired by international charters and guided by national level provisions, with the objective of consolidating all of these into a single document, making them publicly known in a coherent manner. There is an expectation that this document will act as guide for the Union Government of India and State Governments to formulate concrete mechanisms so that Patient's Rights are given adequate protection, and operational mechanisms are set up to make these rights functional.

This charter is especially important at this juncture because regulation of healthcare providers is on the anvil; some states have adopted the national Clinical Establishments Act 2010; certain other states have adopted their own state level legislations to regulate hospitals, while yet other states are in the process of adopting / developing such regulation. NHRC believes that this Charter of Patient's Rights may be incorporated by policy makers in all existing and emerging regulatory legislations concerning the health care sector. This charter could also enable various kinds of health care providers to actively engage with such a framework of patients rights to ensure their observance, while also benefiting from the formal codification of patients responsibilities.

Another role of this Charter is to generate widespread public awareness and educate citizens regarding what they should expect from their governments and health care providers—about the kind of treatment they deserve as patients and human beings, in health care settings. NHRC is confident that informed and aware citizens can play a vital role in elevating the standard of health care, when they have guidance provided by codified rights, as well as awareness of their responsibilities.

Besides this, since many years NHRC, India has been taking serious note of patient's human rights violations in Public Hospitals, many a times by taking cognizance of these in *Suo Moto* manner. Hundreds of the aggrieved patients have approached NHRC with their grievances related to public hospitals. NHRC has ordered compensations to many such victims of human rights violations in public hospitals after conducting thorough enquiry into the matter.

Further, in the month of January 2016, NHRC has conducted the Western Region Public Hearing on Right to Healthcare in collaboration with the civil society network Jan Swasthya Abhiyan. During the public hearing, testimonies regarding serious denial of right to healthcare were heard by the Commission members, in the presence of various state health officials who offered appropriate explanations and assurances. Consequently NHRC issued a set of recommendations

to Governments of Maharashtra, Gujarat and Rajasthan to ensure corrective actions. As part of this process, NHRC has recommended the State Governments either to adopt central Clinical Establishment Act (CEA-2010) or to enact similar state specific law while ensuring specific provisions to safeguard patient's rights and grievance redressal mechanism for patients who seek care in private hospitals. NHRC has also recommended reviewing grievance redressal mechanism under State Medical Councils and recommended restructuring ethics committee mechanism of such medical councils, in order to make it more effective in handling patient's grievances related to doctors. NHRC also recommended state governments to make budgetary provisions for the crucial targeted intervention programme for persons living with HIV-AIDS.

Apart from this, NHRC has taken serious note of the health rights violations of the disabled and elderly people. This section of the population is very much vulnerable to both physical and mental health problems, but often finds itself marginalized by the health system, often figuring in the lowest priorities of the system. Hence, NHRC has recommended that all State Governments in India should initiate a post graduate medical course in geriatrics (MD-Geriatrics) and set up shelter homes for the elderly people.

Finally, I trust that this workshop will carry forward the cause of protection and promotion of the rights of patients in India as well as other countries of the South Asian region. I appeal to all participants in this workshop who are from India, to create large scale awareness among citizens about the rights which they are entitled to, when they visit a hospital. If they feel that their rights have been violated, they may approach NHRC for redressal of their grievances.

I believe that NHRC-India's efforts in this direction will find resonance amongst Human Rights Commissions in other South Asian countries too. It is our shared moral responsibility to promote human rights of patients, which cross the geographical boundaries of nation states and concern all of humanity.

Once again, I extend my best wishes for this workshop!