South-Asia Learning Exchange Workshop on Patient's Rights and Private Medical Sector Accountability

Support for Training and Advocacy to Health Initiatives (SATHI)  
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In many low and middle income countries (LMICs) especially in South Asia and Africa, the private healthcare sector is playing a 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. There is a 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. Recognizing a need for a platform to bring together activists and practitioners, who would help to develop a discourse on accountability of the private medical sector the thematic hub on Patient's rights and private medical sector accountability anchored by Pune (India) based organisation SATHI, associated with COPASAH initiated in 2017-18. It began 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. The thematic hub works by organising global thematic webinars, networking and alliance building in South Asia, regional consultations, and capacity building of activists. As part of its networking, strengthening social accountability practices and learning from different experiences the thematic hub, held a two day Learning Exchange Workshop on Accountability of Private Medical Sector and Patient's Rights involving civil society activists from India, Bangladesh, Nepal and Sri Lanka on 23-24, January 2018 at Mumbai.
Objective of the Learning Exchange Workshop

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. Different stakeholders together to share and learn from each other's experiences on private sector accountability existing 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.

Sessions of the Learning Exchange Workshop

Spanned over a period of two days the sessions in the workshop focused upon bringing forth different experiences from number of states in India as well from different countries as well different stakeholders.

Perspectives and Experiences of Policy Makers and Shapers on Accountability

Representing Maharashtra state government, Director of Medical Education and Research Dr Pravin Shingare detailed 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. Senior Consultant, National Health Systems Resource Centre, Government of India, Prasanth K S outlined about the The Clinical Establishment (Registration and Regulation) Act 2010 while providing details about status of implementation of Clinical Establishment (Registration and Regulation) Act (CEA) which is currently applicable in 11 states of India. Health Advisor, Delhi
Government Nimmi Rastogi discussed about steps under consideration for improving existing health services with emphasis on community involvement for health and environment. Prasanna Saligram, from Azim Premji University highlighted the Regulation puzzle, by providing examples of weak regulatory system and medical negligence as well as overcharging by the private sector hospitals. Dr. Arun Gadre a gynecologist and an in Maharashtra shared about the forum of Alliance of Doctors for Ethical Healthcare, its beginning and its position on the current practice in private sector.

**Country Level Issues and Approaches for Regulation of Private Medical Sector**

Different country representatives shared the experiences about health care systems and private medical sector and the countries represented in this panel included Kenya, Sri Lanka, Bangladesh and Nepal. Representing Independent Accountability Panel (IAP) from Kenya, Winfred Lichuma, shared experiences from Kenya and expressed that Kenya does recognize health as a constitutional right since 1990's. The policymakers and government have not paid much attention towards regulation and there has been a recent move towards corporatization in the country and the public sector is weakening. There are several problems of patient rights violations as overcharging, unnecessary investigations, malpractice etc. in private medical sector in Nepal. There is no regulation on private medical sector and overall framework and its implementation is very weak. Dr. Md Sayedur Rahman, health activist and Executive Director of UBINIG, Farida Akhter from Bangladesh shared that malpractices were rampant in the private sector in the country. Kenya and Nepal experiences highlighted that countries have the constitutional right to health, where as India, Sri Lanka and Bangladesh do not have it. The issues of patients' rights are similar across the countries with inadequate regulation, capping on pricing of health services. Bangladesh and Sri Lanka have a well laid primary health care system. Private hospitals and Clinical Research Organizations from India are making foray into these countries. The discussion led out that there was a need to have greater alliance and to learn from each other experiences in order to improve the health care systems in respective countries.

Apart from the panel session case stories of violation of patients' rights in the private health sector were also shared in the workshop.

**Lessons from Campaigns and Initiatives for Regulation of Private Medical Sector**

The sessions on campaigns laid out experiences from different campaigns across different states and networks of India. Dr. Anant Phadke outlined about the campaign for Maharashtra Clinical Establishment Regulation Bill, Jan Swasthya Abhiyaan, (JSA) the People's Health Movement network in India and Jan Arogya Abhiyaan (JAA), the Maharashtra chapter of JSA. He showcased different efforts taken by JAA like media advocacy on patients'
rights, state level conventions for patients' rights, patient's rights forum liaisoning with political representatives to enhance rights etc. Akhila Vasan from Karnataka Janaarogya 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 shared about the struggle to fight with the state to bring in force for amendments in Karnataka Private Medical Establishment Act (KPMEA). She elaborated that the story of KPME amendment is a story of citizens' battle against the exploitative profiteering private health sector. Malini Aisola from All India Drug Action Network (AIDAN) elaborated upon the campaign to regulate prices of essential medicines and medical equipments in India. AIDAN has a long standing campaign for essential affordable medicines through Public Interest Litigation (PIL). The chief focus of the PIL is on the limited coverage of drug pricing policy which covering just about 10 percent of the total medicines in the market. The other focus is on drug pricing control order, i.e. the drug pricing policy should cover all essential medicines and also pricing mechanism should switch to cost based mechanism which was in place earlier. Amulya Nidhi health activist from Swasthya Adhikar Manch, India shared about the campaign to safeguard participant's rights in clinical trials. He shared about a Public Interest Litigation (PIL) in Supreme Court to safeguard patients' rights undergoing clinical trials in the state of Madhya Pradesh about violation of rights at different levels. He elaborated that there are violations of patients' rights in clinical trials at various levels. Illiterate and vulnerable patients are selected for trials and no proper informed consent is taken, very less information is given to participants in clinical trials or to their families. There is a lack of transparency and no proper ethics committees are constituted. There is nexus between regulator, sponsor and investigator and this is all backed by a weak legal framework.

Parallel Sessions on Campaigns Parallel Session I

Jayeeta Verma Sarkar from Campaign Against Medical Negligence- People for Better Treatment (PBT), Kolkata, India shared the experiences of PBT, voluntary organization constantly fighting and campaigning for medical negligence by doctors both in public and private sector. She highlighted the case of Dr. Kunal Saha and its historic judgment on medical negligence wherein the Supreme Court of India found four doctors and the institute of Advanced Medicare Research Institute (AMRI) in Kolkata guilty for negligent treatment causing death of wife of Saha. Nisreen Ebrahim from Campaign for Alert Patients and their Rights, shared about the work of Rangoonwala Foundation, Mumbai, India on multi-sectoral programmes covering community services, health, education, livelihoods and disability.

Deepika Joshi from Public Health Resource Network (PHRN), Chhattisgarh, India shared about the involvement in the Monitoring and Implementation of Chhattisgarh Nursing Home and Health Care Establishment Act. Manoj Pardeshi, General Secretary of Network of Maharahstra for people living with HIV, India, shared experiences of working for rights of the people with HIV in Maharashtra as well as at country level. Jitendra Tandel from Rugna Mitra and Citizens Doctors Forum, Mumbai, India shared about the Campaign for safety of dialysis patients in Mumbai. Being on dialysis himself for more than 12 years he outlined that 90% of doctors and nursing staff fail to show concern or respect to patients.

Parallel Session II

R P Y Rao from Society for Awareness of Civil Rights, Mumbai shared about 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. Govind Bhosale from Kagad Kach Patra Kashtkari Panchayat-
(KKPKP), Pune, shared about the experiences of KKPKP, a trade union of waste pickers working for the rights of the waste pickers including the health rights of the waste pickers. It was outlined by the representative that KKPKP has 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. Shreya Nimonkar (41) narrated her story of struggle of six years against medical negligence and gross medical error in private hospital. As result of the negligence she had to undergo a number of operations including hysterectomy. Currently she is involved in to bring strict laws in medical negligence and for doctors doing malpractice. Shashikant Mane from SANGRAM, a NGO working in Sangali district of Maharashtra for 25 years 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. Advocate Jyoti Bhakare a Pune based advocate shared experiences about consumer activism in health care. She outlined about cases of medical negligence, fabrication of documents, denial of documents to the patient, as well as misinterpretation of judgments by hospital lobbies to safeguard their self-interests. Pravesh from Mareez Haq Abhiyan, Uttar Pradesh, India, involved in the Campaign to safeguard patient's rights and implementation of Clinical Establishment Act 2010 shared the case of overcharging by the private sector for normal delivery against which the organization fought the case and involvement of local elected political leader, were able to book the errant doctor. It was highlighted by him that involvement of elected political representatives as well as extensive use of RTI can put pressure on bringing private sector accountability.

Alliance Building with Rational, Ethical Doctors and Health Workers

This session focused on the experiences of the different alliances of ethical doctors and health workers working towards patients' rights. Dr. Preeti Damle from Pune Citizens Doctors Forum (PCDF), explained about the growing dominance of private sector and the relationships between doctor and patient getting worrisome. She outlined that PCDF has emerged in order to have dialogue and create awareness and building trust between doctors and patients.

Dr. Mirajkar, a surgeon doctor and associated with human rights highlighted the initiatives taken by the Mumbai Citizens Doctor Forum (MCDF). He outlined that in MCDF doctors, social workers and lawyers are committed to work and fight against the medical negligence. Susana Barria, researcher at Public Service International at New Delhi, shared experiences of accountability of private hospitals towards the workforce. She outlined that there is exploitation of the workers in hospitals and shared experiences of nurses struggle in Kerala to get minimum wages.

Way Forward and Networking

Moderated by the private medical sector accountability thematic hub anchor Dr. Abhay Shukla, this session saw summation of the deliberations, discussions, experiences of the two day workshop as well development of the way forward to ensure patient rights and private medical sector accountability. Across countries people are doing struggles. He suggested for strong foundation bases to bring private sector accountability and patient's rights in force like use of courts, official bodies media as a means to get justice as well as victim activism citizens mobilization. After much detailed discussion a consensus was arrived at to charter strategies for further action.