THEMATIC HUB ON PATIENTS' RIGHTS AND REGULATION OF THE PRIVATE MEDICAL SECTOR
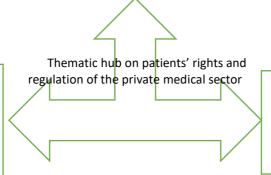## -POLICY BRIEF

CONTEXT -

Reliance on private healthcare and the neglect of public healthcare has been a policy-making trajectory in various LMICs, particularly South Asian and the African countries, with severe consequences for the patients. India allocates only a little over 1 % of the gross domestic product on public healthcare and has the dubious distinction of a poorly functioning public health system and dominant unregulated private health sector among its South Asian peers. Elsewhere, Sri Lanka is deviating from the solid public health foundations that they had for the last one hundred years and is witnessing an upsurge of market-based tertiary private care. In Kenya, the private sector is mostly unregulated and has almost monopolised certain domains of health services, with the burgeoning health insurance industry. In other parts of Africa, there are signs that the for-profit private sector is expanding, and as a consequence of poor regulation, there are huge distortions in the type, quantity, distribution, quality of price of health services. This dominance of the private sector and the privatisation of the public health services as a policy prescription by the World Bank, USAID, and some of the other funders has negatively impacted health systems in various LMICs.

Given this context, SATHI-as the COPASAH thematic hub on "Patients' rights and private medical sector accountability", is involved in developing an action-oriented discourse among African and South- Asian organisations on safeguarding patient's rights and making the private healthcare sector accountable. The hub is promoting networking among civil society organisations and networks on issues related to private health sector regulation and patient's rights, with a focus on South Asia. These efforts areintended to further support and complement existing networks like the People's Health Movement. The thematic hub is engaged in relevant knowledge generation through publication of papers and policy briefs. It is expected that this hub would help to orient activists and civil society members, enabling them to raise key issues related to the private healthcare sector, such as accountability and rights.

ROLE OF THE HUB-

Knowledge and technical resources creation – academic and popular writing on patients' rights and private sector accountability for a diverse group of people.

Thematic hub on patients' rights and regulation of the private medical sector

Strategise and implement innovative campaigns, create interactive forums between private health sector and community at the national level.

Dissemination of practice-oriented knowledge products through convenings, webinars, symposiums, workshops, and website and create national and regional discourse.

Within the broader agenda of patient's rights and private health sector accountability, SATHI has so far managed to elicit the interest of different civil society groups from countries like Sri Lanka, Bangladesh, Nepal, South Africa, Kenya, and various other African organisations. The four key strategies that the thematic hub has adopted are –

- o understanding the contextual challenges of private sector regulation and patient's rights in the LMICs, with focus on South Asia and some African countries;
- o enhancing the knowledge base of citizens, academicians, CSOs and doctors regarding specific accountability deficits that exist in private health sector;
- o identifying strategies and policies that can mitigate the impact of the private health sector on patient's rights and overall right to healthcare;
- o putting patients' rights at the centre of the UHC and the privatisation debate.

Until now the thematic hub has organised webinars which played a crucial role in networking and alliance building in South Asia, held regional consultations, and built capacity of health activists.

KEY ILLUSTRATIVE ACTIVITIES CONDUCTED BY THE HUB-

January 2018- South Asia Learning workshop on patients' rights and private medical sector accountability:

Jointly organized by SATHI and CHSJ, the two-day workshop was attended by representatives from Kenya, Nepal, Sri Lanka, Bangladesh, along with India. This unique workshop brought together around 60 activists from diverse campaigns, organizations and networks, united by their concern regarding gross commercialization of healthcare and its disastrous impact on people.

The first session was focused on perspectives and experiences of policy makers on accountability. In many ways, this was a multi-stakeholder dialogue, inclusive of some higher state-level officials from Maharashtra and Delhi who spoke about the steps undertaken by the government to regulate private medical sector and safeguard the interest of the patients through legislation such as the Clinical Establishment Act, Introduction of charitable schemes and plans for the poor, and Initiatives on community involvement for health and environment, capping profit margins In private hospitals.

The second session of theworkshop was an international panel discussion on country-level issues and approaches to regulate the private medical sector. Countries represented in the panel discussion were Kenya, Sri Lanka, Bangladesh and Nepal. Based on the respective country experience, panellists shared insights on the following three questions:

- From a citizen's point of view, the frequent violations of patient's rights in the private sector and nature of medical malpractice;
- A regulatory framework for private hospitals and its effectiveness and responsiveness to people's concerns;
- Key lessons and experiences regarding regulation of the private health sector.

While Kenya and Nepal have the constitutional right to health, India, SriLanka and Bangladesh do not. The issues of patients' rights were similar, with inadequate regulation, capping on pricing of health services. While Bangladesh and Sri Lanka have a well-developed primary health care

system,corporate hospitals and Clinical Research Organizations from India are making forays into these countries. The discussion concluded with the understanding that alliance building, knowledge and experience sharing is necessary to improve transparency and regulations inprivate health care systems across LMIC countries.

In other sessions of the workshop, there was a productive discussion on lessons from the campaigns and initiatives by civil society for the regulation of the private medical sector in India, and possible strategies to safeguard patients. In the words of AkhilaVasan, who recounted the struggle of Civil Society organisations to introduce citizen friendly amendments to the Karnataka Private Medical Establishment Act (KPMEA),the lesson was about the immense possibilities when the health rights discourse is democratized, of what ordinary citizens can do when drawn into the health rights discourse. Besides strategy discussions, there were also testimonies from people who have taken a stand against corrupt private hospitals.Patient victims like Jayant Singh, Kunal Saha, Jayati Varma, Shreya Nimonkar from India who are victims of medical negligence/overcharging are fighting for justice andshared their struggles.

The key points that emerged from the workshop were summarized by Dr Abhay Shukla at the end, who observed that the struggle to ensure private health accountability and safeguarding patient's Rights could be based on petitioning the judiciary and other official bodies, effective use of media to increase the visibility of campaigns, patient victim activism and mobilising CSOs.

In conclusion, the workshop enables participants to formulate strategies such as
- The formation of a National level Forum to coordinate the campaign for accountability from a citizen centred view point.
- Intensifying efforts to ensure regulation of prices of implants and other medical devices
- Launch a campaign in Maharashtra and other states for adoption of the Clinical Establishment Act,
- Provide active inputs in reform of State medical Councils, with emphasis on protection of patient's rights in private hospitals

(for details seehttps://www.copasah.net/uploads/1/2/6/4/12642634/pvt._sector_learning_exchange_report.pdf)

April 2018- Webinar:PATIENT'S RIGHTS – Fulcrum for accountability of private medical sector

This webinar was attended by various activists in different parts of the world. The webinar provided a justification to why should patients have rights related to private medical providers, and also enlisted different policy mechanisms opted by various countries to protect patients' rights. Based on the Indian experience, following campaign options to regulate the private health sector and safeguard patients' rights were discussed in detail in the webinar:

- Promoting widespread literacy among citizens regarding patient's rights and awareness aboutmalpractices.
- Developing a framework for accountable, social regulation which includes patients' rights charter
- Promoting forums for dialogue and collaboration among active citizens and ethical doctors
- Designing standard treatment guidelines by groups of rational doctors
- Moving towards a system of Universal Health Care which makes available free, quality healthcare for all
  (for details seehttps://www.youtube.com/watch?v=p-Xaq644bvs&feature=youtu.be)

On 17th November 2018, a workshop was jointly organised by SATHI and CFSJ to identify and discuss action and advocacy strategies that could mitigate the harmful impact of an unregulated private health sector on patient's rights. This workshop was an attempt to initiate a process of exchange around common areas of concern, for discussing campaign strategies to challenge unaccountability in the private health sector, with a focus on protecting Patients' rights. The second objective was to bring together institutions and networks, who may be willing to undertake collaborative activities on this issue at national and regional levels in the coming years.The workshop was well attended by representatives from India, South Africa, Kenya, Sri Lanka, Nepal, and Bangladesh.

In the workshop, participating panellists from LMICs (mostly South Asia) shared their observations about the dominance, spread and impact of the for-profit private health sector in their respective countries. It emerged from the discussion that there were common challenges like medical malpractice, poverty due to out of pocket expenditure on healthcare, lack of effective regulations to contain the cost of private healthcare, Increasing corporatization, trend towards public private partnerships without requisite accountability mechanisms.

Panellists also presented their attempts to garner support and generate awareness about these critical issues through the use of various Innovative campaign strategies such as by the PHM in Maharashtra, India, to demand legislation to protect patients' rights and participatory regulation of the private healthcare sector. In South Africa, there was a campaign that compiled evidence of very high prices and lack in quality of care. This information was submitted it to the government, which acted upon It using competition laws to Introduce some regulations.

The panel discussion was focused on the need to document stories of patients' rights violations and medical malpractices in the private health sector, as a fulcrum for demanding accountability. There was also a consensus that health activists need capacity building on this newly emerging Issue. In African and South Asian regions particularly, networking amongst CSOs, researchers, doctors to share knowledge, strategies and advocacy approaches Is necessary to create mass support for regulation of the private healthcare sector.

(A brief report of the workshop can be accessed at-
https://www.copasah.net/uploads/1/2/6/4/12642634/report_of_workshop_in_pha_4.pdf)

KEY CONCEPTUAL AND CAMPAIGN INSIGHTS

1. The vision of UHC should also include a comprehensive plan to regulate the private health sector.

As demand for universal health coverage has amplified, almost concurrently, voices demanding regulation of the private health sector also have come to the fore. The very premise of universal health coverage is – those in need of healthcare should be able to access healthcare, which is effective, and without financial hardship. However, in the absence of effective regulatory framework leading to arbitrary pricing of health services, the private health sector is increasingly indulging in super-profits,Imposing a grave financial burden on patients. In general, there is a consensus that the

UHC discourse is also an opportunity to advocate for effective participatory-regulation of the private health sector in the LMICs.

2. Patients' rights as a popular idiom for mobilisation around the regulation of the private medical sector

The demand for the protection of patients' rights could be an important fulcrum for social mobilisation around regulation of the private medical sector. The private sector accountability issues are mostly framed either within the legal lexicon of regulation or abstractions of the right to healthcare language. In such a scenario, patients' rights as a term is effective because it connects with values of the ordinary people and is also relevant to their experiences in a compelling way. "Patients' Rights" as a unit of information; in spite of its inherent ambiguities, and also as a slogan is effective to catch popular attention and communitise the private sector accountability crisis. Additionally, framing it as a patients' rights issue is useful as it invokes the whole set of pre-existing personal and community experiences regarding malpractice, violations, or exploitations in the private health sector. Unlike issues related to land, livelihoods, and basic social services which are largely limited to lower- income sections of the population, the demand for patients' rights is of a cross-cutting nature, which can attract support from sections of the middle class who have significant voice and political leverage.

3. The sphere of influence of the private sector is transnational and to challenge its hegemony, CSOs will also require to build alliances and coalitions that have regional and global reach-

One of the key objectives behind the COPASAH thematic hub on the private health sector, is to create a dedicated space to discuss, validate and identify strategies to mitigate and challenge the unaccountable behavior of the private health sector, by facilitating mutual learning among CSOs located in different parts of the world.

4. The need for multiple platforms to work with diverse constituencies related to the private medical sector[1]

Social actors working towards greater accountability and responsiveness of the private medical sector need distinctive organisational forms for engaging with diverse constituencies. For example, Maharashtra chapter of Peoples' Health Movement (Jan Arogya Abhiyan) works with civil society organisations and citizens, the Alliance of Doctors for Ethical Healthcare (ADEH) works with sections of doctors, while Citizen–Doctor Forums combine both types of members. The SATHI team, which is also hosting the COPASAH hub, works centrally with all three groups in collaboration with many other members and organisations. This helps maintain a common thread of accountability and ethics, while developing each platform in concordance with the perspectives and priorities of concerned constituents. In many ways, these are very important social experiments offering key lessons into campaign and constituency building, and forging effective alliances.

5. Emerging concepts of participatory social regulation[2] from India and its relevance for other countries

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[1] IDS BULLETIN Vol. 49 No. 2 March 2018: 'Accountability for Health Equity: Galvanizing a Movement for Universal Health Coverage'

Continued contestation of regulation by private actors, and the danger of capture of the regulatory process by powerful elements within and outside the state form the backdrop for re-imagining regulation from a citizen-centric perspective. The current weak regulation of the private medical sector in many LMICs is often linked with minimal political will to regulate this sector, since the private health-care industry often has significant financial and political clout. Weak political will could also be linked to a lack of organised popular demand for accountability of the private medical sector, despite widespread yet diffuse discontent about malpractices. Overall weak accountability of the state for enforcing regulations is an additional barrier to effective regulation. Hence, unless regulation is buttressed by a social accountability framework and participatory processes, in LMICs like India there isa danger of regulatory capture or ineffective regulation, which would defeat its social objectives. Given the powerful influence exerted by the organised medical sector on health policy, there is a need to ensure such participatory action not only amongst citizens, but also amongst socially responsive sections of doctors, to jointly provide inputs for developing and informing the regulatory framework. Building effective public regulatory frameworks must be complemented by the promotion of a social climate of accountability and patients' rights, while strengthening an ethos of ethical, rational care within the medical profession. The state and its policies do not function in a vacuum, but are deeply embedded in social structures and relationships. Hence, it is highly desirable that health sector transformations linked with state regulation and civil society action be interlinked and mutually reinforcing.

6. Plentyhas been written regarding the problem, how do we move towards a solution? -

The hub is purposively focusing on an action-oriented agenda for the activists. This also entails sharing a concrete actionable agenda with individuals and institutions which are involved in the struggle of regulating the private health sector. Although this work is still nascent, there is a significant receptivity to the agenda of patients' rights and private sector accountability in the LMICs. Overall, the hub's attempt will be to forge new regional alliances and create a counter discourse to the dominant narrative around the private health sector.

CHALLENGES-

a. Popular mobilization on patients' rights and private sector accountability is difficult.There are at least three peculiaritiesof the health sector that sets it apart from the other social sectors, which also has implications in mobilising people and campaigning.Unlike other social and commercial sectors, in healthcare, decision-making power and the agency of patient, is limited. The knowledge and power asymmetry are a pivotal challenge to bring equilibrium between doctor and patient relationship and to build a campaign on patient rights. The core belief that medicine is a noble profession is still retained by common people; so, a normative campaign assumption that adequate information helps in mobilisation does not work in the health sector.

b. At a macro level, substitution of health as a public good to health as a commodity is one of the key challenges. Under the neoliberal doctrine, a presumption that markets are the most appropriate basis for organising economic and social life also engulfed health systems. The laissez-faire liberalism adopted by various governments led to a change in the role of the

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[2]IDS BULLETIN Vol. 49 No. 2 March 2018: 'Accountability for Health Equity: Galvanising a Movement for Universal Health Coverage'

state from serving public provision to promoting and supporting the private health sector. In India, Kenya, South Africa and couple of other African countries, growth of the private sector has happened at the cost of the public health sector, and with active support from the state. In a dominating policy trend of privatisation and reliance on the private health sector, government is using its power to protect capital and private properties. In such situations, cuts in the public expenditure on health and weakening role of the state as a regulator are usually concurrent developments. There is a normative dissonance between deeply entrenched neoliberal policies in health and discourse on human rights and private sector accountability. In such situation, campaign has to not just deal with the hostile and highly organised private health interests, but also deal with adversarial institutes of health governance.[3]

NEXT STEPS:

1. Using the opportunity of the COPASAH Global Symposium -2019
2. (See-http://www.copasahglobalsymposium2019.net/theme4.html)

COPASAH is organizing a global symposium on "Citizenship, Governance and Accountability in Health" , in New Delhi, in October 2019. Theme four of the symposium is"Setting the framework and agenda for people centred accountability of private and corporate health care sectors." The thematic sessions on this theme will aim at mapping the emerging nature of the private medical sector including trends of commercialisation and corporatisation, range of rights violations being faced by patients and citizens, and efforts done by civil society networks and patient rights groups in different parts of the world to ensure accountability of private health care actors. The symposium will also facilitate critical analysis of existing regulations for private sector, and will stress on accountability and citizen participation in concerned regulatory frameworks. It will also focus on the constructive by promotion of discourse on protecting patient's rights, and assuring good quality, rational and ethical healthcare. As such, some of the subthemes that would be discussed in the symposium are-

o Mapping changing nature of the private medical sector in low- and middle-income countries (LMICs), including trends of commercialisation and corporatisation, which impact social accountability;
o Creating community evidence regarding patient rights violations in the private and corporate health care institutions;
o Sharing initiatives for mobilising civil society and suffering communities - especially patients, to protect patients' rights and demand accountability from the private health care sector; learning from related innovations;
o Analysing existing regulatory frameworks for the private medical sector, brainstorming about developing citizen participation in accountability and regulatory frameworks.

3. Forming national and regional level forums for communication and coordination in various states for ensuring legal protection to patients' rights and regulation of private hospitals from citizen-centric point of view.

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[3]SATHI (COPASAH Hub- Knowledge Product 1) - Demanding patient rights with focus on the private health sector accountability.

4. Stories of patients becoming victims of medical negligence, overcharging, etc are abundant. The Hub will attempt to bring all these stories on a common platform and document them in a form of a book, or series of articles.
5. Liaising with international thinktanks and CSOs working on private sector accountability- This will be explored during the forthcoming COPASAH global symposium.