initiatives must:

- enable marginalised communities to assert their rights and to participate in concrete actions to improve delivery of health services and to make distribution of resources more equitable;
- give voice to peoples' perspectives;
- be an empowering process where actors related to the health system are encouraged to address power imbalances that affect people's health;
- finally, SA must be linked to an action or advocacy plan which aims to influence or change health policies and programmes.

Without these elements, SA interventions can easily be reduced to, and mistaken for, a governance quick fix meant to strengthen the supply side by activating the demand side of programmes.

References

1. Ringold D, Holla A, Koziol M, Srinivasan S. Citizens and Service Delivery: Assessing the Use of Social Accountability Approaches in Human Development Sectors. World Bank Group; 2011 Dec [cited 2020 Nov 12]. Available from: file:///C:/Users/syatirajula/Downloads/657450PUB0EPI1065724B09780821389805.pdf
2. Ackerman JM. Social Development Papers. Participation and Civic Engagement. 2005 May 2005[cited 2020 Nov 12]; No. 86, Available from:http://documents.worldbank.org/curated/en/250451468048914790/pdf/330110HR0and0SAc0paper0in0SDV0format.pdf
3. World Bank. World Development Report 2004: Making Services Work for Poor People. Washington, DC. World Bank; 2003[cited 2020 Nov 12]. Available from:https://openknowledge.worldbank.org/bitstream/handle/10986/5986/WDR%202004%20-%20English.pdf?sequence=1&isAllowed=y
4. Joshi A, Houtzager PP. Widgets or watchdogs? *Public Management Rev.* 2012; 14(2):145-62. Doi: 10.1080/14719037.2012.657837
5. Joshi A. Legal empowerment and social accountability: Complementary strategies toward rights-based development in health? *World Dev.* 2017 Nov[cited 2020 Nov 12]; 99:160-72. Available from https://www.sciencedirect.com/science/article/pii/S0305750X17302425
6. Open Society Foundations (OSF). Capacity Building for Monitoring for Accountability in Health: Issues and Perspectives. AMHI/OSF; 2013 Available from: https://www.copasah.net/uploads/1/2/6/4/12642634/amhi_cb_paper_final_april_26.pdf
7. Joshi A. Reading the local context: A causal chain approach to social accountability. *IDS Bulletin.* 2014 Aug 28[cited 2020 Nov 12]. Available from: https://doi.org/10.1111/1759-5436.12101
8. Das A. How do we know we are making a dierence? Challenges before the practitioner of community monitoring processes in assessing progress and evaluating impacts. CHSJ, India, and COPASAH; 2013[cited 2020 Nov 12]. Available from:https://www.copasah.net/uploads/1/2/6/4/12642634/how_do_we_know_we_are_making_a_difference.pdf
9. Fox JA. Social accountability: What does the evidence really say? *World Dev.* 2015 Aug; 72: 346-61. Available from: https://www.sciencedirect.com/science/article/pii/S0305750X15000704
10. COPASAH Charter and Call to Action for Social Accountability for Health, 2019. Available from: https://www.copasah.net/uploads/1/2/6/4/12642634/copasah_sa_charter_and_call_to_action.pdf

Advancing the agenda for people-centred accountability of the private healthcare sector

KANCHAN PAWAR, ABHAY SHUKLA

Abstract

*The thematic track on accountability of the private and corporate healthcare sectors during the Community of Practitioners for Accountability and Social Action in Health (*COPASAH*) Global Symposium aimed to analyse the emergence of the global trend of commercialisation of health systems, and the transition of healthcare from being a public good to a marketable commodity, at the cost of publicly funded healthcare in developing countries. It examined the implications of the lack of state regulation and oversight which has enabled the profit driven private healthcare sector to exploit vulnerable people through overcharging, malpractices and violations of patient's rights. Finally, the session addressed challenges in advocacy of patients' rights and showcased effective campaign strategies used by health activists in different countries to promote accountability of the private healthcare sector. Putting together learnings and insights from this track will help in contributing towards a powerful global counter-narrative, while providing activists with the tools to create awareness and engage with this critical issue.*

Keywords: *Accountability, private health sector, commercialising healthcare, advocacy, patients' rights*

Authors: **Kanchan Pawar** (corresponding author - kanchan@sathicehat.org), Senior Consultant in Public Health, SATHI, Aman E Terrace, Dahanukar Colony, Kothrud, Pune, Maharashtra 411 029 INDIA; **Abhay Shukla** (abhayshukla1@gmail.com), Senior Programme Coordinator, SATHI, Aman E Terrace, Dahanukar Colony, Kothrud, Pune, Maharashtra 411 029 INDIA, and Member, Global Steering Committee, COPASAH.

To cite: Pawar K, Shukla A. Advancing the agenda for people-centred accountability of the private healthcare sector. *Indian J Med Ethics*. 2021 Oct-Dec; 6(4) NS: 281-85. DOI:10.20529/IJME.2021.075

Manuscript Editor: Sunita VS Bandewar

Peer Reviewers: Bijoya Roy

© Indian Journal of Medical Ethics 2021

Background

This paper draws on the interactions, perspectives and practices shared in the thematic hub on "Patients' rights and private medical sector accountability" during the COPASAH Global Symposium on Citizenship, Governance and Accountability in Health, held in October 2019.

Around 28 practitioners from 10 Asian and African countries shared their experiences about community and civil society action to address challenges faced by the unchecked growth of the private health sector and its implications for the changing nature of healthcare. The thematic hub focused on possible approaches and models of engagement with state and other actors to introduce accountability mechanisms to ensure effective regulation of a dominant and rapidly growing private healthcare sector in Asia and Africa.

The global emergence of a growing "for profit" private sector in healthcare, and the increasing commercialisation of healthcare across most low- and middle-income countries (LMICs), have critical implications for the future of healthcare. In many LMICs, underfunded public health systems are overwhelmed due to inadequate staff, facilities and supplies. Large sections of people, especially the poor, often have no other recourse but to turn to private healthcare providers and have to reckon with unaffordable healthcare and widespread malpractices such as unnecessary procedures, tests and overtreatment in the form of irrational medicines.

The dominance of the medical-industrial complex is compounded by a lax regulatory framework and lack of accountability and oversight, which paves the way for private healthcare providers to get away with malpractices and violations of patients' rights. The impact of commercialisation in the private healthcare sector has proven disastrous for ordinary people. For example, in India alone, where the private health sector accounts for more than 70% of healthcare provisioning, 63 million people fall below the poverty line every year due to catastrophic health costs (1). In Uganda and Kenya, the private healthcare sector is mostly unregulated and has almost monopolised certain domains of health services, while Sri Lanka is also witnessing an upsurge of market-based tertiary private care. Out of pocket expenditure on drugs is a major cause of impoverishment in many countries.

Though there is a major discourse around various frameworks of social accountability in healthcare, the discussion focused on approaches adopted and challenges faced by community practitioners in various Asian and African countries to promote accountability in private healthcare.

Impact of corporatisation of healthcare on access to quality care

Across LMICs, most social accountability practices so far have focused on the public health sector with comparatively little attention directed towards accountability of the private healthcare sector, even though it dominates healthcare markets in many countries across Asia and Africa.

The structural adjustment and economic reforms programme from the 1990s onwards, flowing from a neo-liberal discourse, has shrunk resource allocation for public health services (2) and favoured expansion of the private health sector. Healthcare was transformed from largely being a public good, into a market-based commodity. A public health researcher from India pointed out that India has amongst the lowest spending on public healthcare in the world – a mere 1.02% of its GDP, largely stagnant over decades. The private healthcare market is however expanding at 22% per annum, with scant regulation in medical education, drugs and diagnostics (3).

Mapping the shift in the nature of medical practice over the past three decades due to the entry of the private medical sector, a public health researcher presented findings from a study on the impact of corporatisation of healthcare on doctors in Maharashtra, India (4). The presentation highlighted the change from individual private practice in the seventies, to small and medium hospitals in the nineties, to the emergence of multi-specialty and corporate hospitals in the new millennium. High fees of private medical colleges, competition from corporate hospitals, patients' expectations, and high investment costs are factors causing many small and medium sized hospitals to shut down (5). On the other hand, corporate hospital chains offer lucrative employment options to medical professionals in terms of monetary benefits, access to infrastructure, technology and prestige. However, corporate hospitals pose challenges to doctors as well. Senior doctors with market credibility are offered hefty remuneration packages, while junior doctors are underpaid. Hospitals are run on the profit principle, where doctors need to fulfill targets and are assessed on their ability to generate revenue. The pressure to meet corporate targets undermines the professional autonomy of doctors and the doctor-patient relationship, leading to malpractices and inflated cost of healthcare for patients (5).

Health rights activists shared similar accounts of lack of effective regulation and oversight mechanisms by the state, unimpeded practice of for-profit medicine and exploitation of the information asymmetry that exists between doctor and patient. In Uganda, failing public health systems push poor, dispossessed people towards private clinics, which at the primary care level, function as referral points for large corporate hospitals. Observing that accountability in healthcare is as much a challenge in Uganda as in India, activists stressed that the success rate of prosecution in medical negligence cases is minimal, and State medical councils are ineffective in curbing malpractices.

A physician activist from Nepal presented an overview of the evolution of healthcare in the country. In Nepal, the 1990s was an era of political and economic liberalisation, following the abolition of the monarchy. Neo-liberal pro-

market policies dominated, leading to phenomenal expansion of the private healthcare sector. Today in Nepal, the distribution of the healthcare workforce between the public and private sector is skewed, with more than one third of the total healthcare workforce serving in the private sector which also dominates medical and dental education. The implications of the skewed distribution of services and medical personnel are manifold, including the high cost of healthcare services, unnecessary hospitalisations, and irrational use of medical technology. Hospitals and healthcare workers are concentrated in urban areas. State regulation of the private healthcare sector, including price control is very weak, causing an imbalance of power between people and healthcare providers and leading to catastrophic costs of healthcare.

Enabled by funding and influential political lobbying, the private sector has rapidly expanded and captured healthcare markets in many developing countries, facilitated under the banner of "universal health coverage". The narrative of universal health "coverage", where all individuals are provided health services through government funded insurance, private health insurance or a combination of both is preferred over universal health "care", which provides assured access to healthcare services through government owned hospitals There are examples of Kenya and South Africa where health insurance was a major political promise, enabling opportunities for the private sector to not just provide services, but also influence decision making at policy and governance levels. The trend of privatisation is visible in the approach to public-private partnerships (PPPs). A panelist from Africa commented that despite lack of clear evidence of its efficacy, governments of many African and Asian countries are introducing the PPP model into not just the health sector, but also into fields directly impacting the social determinants of health like agriculture, education, infrastructure and transportation, while weakening public provisioning.

The presentations underscored the global spread of corporatisation and privatisation of healthcare, despite clear evidence that in the absence of effective regulation, a privatised healthcare sector threatens access to affordable and quality healthcare for all. Close attention needs to be paid to the commercialisation of social determinants of health such as water and nutrition, further reducing access for a large vulnerable population.

There is an intersectional aspect to the trend of privatisation and commercialisation of healthcare, contributing to gender inequality and exploitation of women through unaffordable and frequently unnecessary sexual and reproductive health services. These for-profit processes distort equity and are exclusionary in nature as exemplified in Nepal, where deliveries in government hospitals are free of cost, but the poor quality of services forces women to turn to exorbitantly priced private hospitals, as mentioned by a participant Families who must borrow money or sell assets to access private reproductive and maternal health services often make the difficult decision to not seek healthcare or put it off until too late, thus putting women's lives in danger.

Patients' rights advocacy: a strategy to promote social accountability of private healthcare

With increasing public frustration has come the demand for reform in the private health sector to make it more accountable. Healthcare however is an episodic concern for many, and it is challenging to engage with and mobilise communities on a sustained basis on issues of accountability and regulation of healthcare, given the inherently abstract nature of such demands. Here, a focus on patients' rights could mobilise the community to raise their collective voices and draw attention to the lack of regulation in the private health sector, and its impact on quality and cost of healthcare.

Activists involved in the campaign for patients' rights in India presented diverse strategies used for advocacy in India. These include documentation of patients rights, documentation of patient's rights violations, and denial of service in the private healthcare sector, awareness campaigns and advocacy with the state and central governments.

Campaign actions to increase awareness included organising "People's ballots" in Maharashtra where people voted on their health rights and expectations (6). Advocacy related to the Patient Rights Charter formulated by the National Human Rights Commission included online petitions and "Satyagraha" marches (7) demanding that the Union Health Ministry adopt and implement the charter. Sustained advocacy resulted in circulation of a shorter charter of rights and responsibilities to all states for implementation in 2019 (7).

Patients and their caregivers, who have borne the brunt of denial of their rights, have turned to activism and are fervent advocates for the concept of Patients' Rights. One such activist talked about his personal journey, highlighting the failure of the Medical Council of India, the apex regulatory body for doctors, and the State Medical Councils to curb corruption or investigate patients' complaints (8). Lack of stringent punitive measures has given rise to a culture of impunity, where doctors are emboldened to engage in corrupt unethical practices with no fear ofrepercussions. Patient victims and their families who decide to seek justice have to contend with red tape, inordinate delays in resolution, multiple redressal forums and an opaque system heavily biased towards doctors.

A health rights activist in India shared insights about the campaign run by his organisation for patients' rights in the context of clinical trials. Multiple clinical trials were conducted in India by multinational pharmaceutical companies between 2005 and 2010 without proper enrollment and documentation (9). The campaign mobilised

patient victims and used litigation along with media advocacy to seek redress. The most common violations were lack of informed consent being sought from participants. As a consequence of a public interest litigation filed in the Supreme Court of India in 2012 (10), it is now compulsory for clinical research organisations to provide product information sheets to patients and video record the informed consent process. The campaign continues to focus on two major demands – ensuring that the government pays retrospective compensation to those harmed in clinical trials before 2013, and inclusion of the Patients' Rights Charter in the Drugs and Clinical Trials Rules, 2019.

Activists from Uganda outlined the challenges they have been facing in their fight for national health insurance as budget cuts for healthcare lead to drug stock-outs, sale of expired drugs and an ever-shrinking national list of essential medicines. Since economically vulnerable patients are powerless to negotiate with private hospitals, Uganda sees a number of patient detentions linked with non-payment of dues, denial of information, and lack of transparency. The campaign is asking the government to include the Right to Health in the Constitution, with health services becoming enforceable. The law should institutionalise the Patient Rights Charter, while empowering patients to hold health services accountable. Other strategies include translation of the Charter from text to graphics to make it more accessible to community members, and enabling them to negotiate standards of care with their hospitals.

Experiences shared by practitioners underscored the urgent need for patients' rights to become a global movement within international frameworks for social accountability. The struggle to legally enshrine patients' rights in countries like India and Uganda shows the need for collective action and sustained advocacy, considering strong pushback against any form of patient centered regulation from the powerful private healthcare lobby.

Organising citizens' voices and using litigation

The Peoples Health Movement in Sri Lanka has consistently advocated for the Right to Health since 2002 (11) and its current campaign is focused on bringing this issue onto the political agenda, while introducing a law to cap prices of vital drugs like insulin. Using their learnings from their decade long struggle for access to essential medicines, they focused on the lack of regulation in the rapidly expanding private health sector in Sri Lanka. However, their struggle to regulate the private sector has had limited success, since the influential private health sector lobby ensured that the government agency functions only as a registration agent with no powers to enforce accountability.

In Uganda, practitioner efforts are focused on introducing regulation in public- private partnerships (PPP) in health. The Access to Information law does not apply to private entities in Uganda (12), and the law stipulates that only information in possession of the state can be provided to the complainant. A Ugandan health activist cited the example of a woman who lost her baby due to negligence in a private hospital on a government grant. She was denied access to her medical records. It was argued that if public funds are being given to a private entity, the government is accountable to share information, as the private agency has to be held as acting on behalf of the government. Community advocacy campaigns are focused on a Bill on patients' rights and responsibilities to protect vulnerable patients in PPPs, while bringing them within the scope of the Access to Information Act.

Formation of collectives of citizens and ethically inclined doctors are also an important approach to engage and involve key stakeholders in the campaign for ethical rational healthcare. The Alliance of Doctors for Ethical Healthcare in India is one such network formed due to the need to promote and support patient-centred rational medical practice (13), free from commercial influences. It serves as a platform for doctors who actively voice their concerns regarding the corporatisation of healthcare, regulation of drug prices, the equipment and consumables industry, honoring patients' rights, and transparency in pricing. Another participatory initiative undertaken in the city of Pune, India is the Poona Citizen Doctor Forum (PCDF). Founded to promote rational medicine, universal healthcare and improve doctor-patient relationship, the PCDF organises awareness sessions and posts videos on healthcare and policy issues. PCDF operates a twitter handle (https://twitter.com/PCDForum) where it crowd sources doctors in Pune whom patients have perceived to be patient-friendly and responsive (14).

A public health activist presented the evolution of the Karnataka Private Medical Establishments (KPME) Act 2017 for regulation of the private healthcare sector. Since 2002, many social health insurance schemes have been introduced in Karnataka in which the private sector has a significant role in implementation. Strong linkages between politicians, private hospital associations and doctors' associations ensured a united front to represent their interests. In this context, when the state government attempted to introduce more effective regulation through KPME amendments, there were major protests by the medical fraternity against pro-patient amendments, which were diluted as a result. While rate regulation could not be introduced, transparency of rates and Patients' Rights Charter was ultimately included in the modified Act (15).

A leading consumer rights advocate and practising lawyer from India presented his experience of using litigation to cap the prices of cardiac stents in India which were being sold at exorbitant rates. Using public interest litigation (PIL) to exert pressure on the government, he was successful in his efforts to cap prices of cardiac stents and make them affordable by their inclusion in the list of essential drugs (16). He made a strong case for use of the judiciary as a strategy to introduce accountability and transparency in the healthcare sector.

Overall the participants recognised that there is a need to build strong popular alliances to counter the hegemony of the influential and organised private healthcare sector. Rights can only be enshrined in law, when a broad social coalition comes together and demands change collectively. It is equally important to marshal evidence through academic research and documentation of the impact of weak accountability in the health sector, instead of relying solely on opinion-based advocacy. Civil society needs strong advocacy coalitions, actively supported by research and evidence, to fully utilise opportunities for policy engagement.

Conclusion: Need to strengthen accountability movement at all levels

As community practitioners shared diverse and innovative approaches to engaging with and mobilising people on this issue, it became clear that uniting voices, sharing learnings, networking with allied citizen groups across regions and countries is critical to counter powerful private health sector lobbies. Certain concrete strategies emerged through the presentations which could be used to initiate and sustain community action:

- Health researchers, activists and civil society organisations need to analyse the transnational linkages fueling the growth and influence of the private health sector in LMICs, aided by supportive policy frameworks. Public health professionals need to recognise and hold accountable actors beyond the government sudonors and financial institutions like the World Bank, which promote public-private partnerships in healthcare.

- Health rights networks should use patients' rights as a fulcrum to mobilise and sustain community participation in the movement for accountability of the private health sector through awareness building and advocacy with he government to protect patients' rights by defining and institutionalising them.

- Another strategy that emerged was the use of litigation that focused on pinning the liability on a system with failed checks and balances, which enables the private healthcare sector to put profit above patients.

- Lastly, community practitioners across LMICs could form a powerful and well-organised global advocacy initiative backed by research, to demand protection of patients' rights and effective regulation of the private healthcare sector, and of public private partnerships in the health sector.

- The movement can be strengthened by well-designed media outreach initiatives to generate awareness and sustained engagement amongst the public, while preventing the mainstream discourse on healthcare from being dominated by the influential private healthcare lobby.

The prevailing policy framework which treats healthcare as a marketable commodity must be replaced, with the widespread acceptance by the State and society that health and healthcare are fundamental human rights.

References

1. Shukla A, More A, Marathe S. Making private health care accountable: Mobilising civil society and ethical doctors in India. IDS Bulletin.2018 Mar [cited 2021 Jul 10]; 49(2). https://doi.org/10.19088/1968-2018.140.
2. Sparke M. Neoliberal regime change and the remaking of global health: from rollback disinvestment to rollout reinvestment and reterritorialization. Rev Int Polit Econ. 2020; 27(1): 48-74. Doi: 10.1080/09692290.2019.1624382
3. Press Information Bureau, Govt of India. NITI Aayog releases report 'Investment Opportunities in India's Healthcare Sector'. New Delhi: PIB; 2021 Mar 30[cited 2021Sep 11]. Available from: https://www.niti.gov.in/sites/default/files/202103/InvestmentOpportunities_HealthcareSector_0.pdf
4. Berman P, Ahuja R, Bhandari L. The impoverishing effect of healthcare payments in India: new methodology and findings. Econ. Polit. Wkly. 2010;45: 65–71.
5. Marathe S, Hunter BM, Chakravarthi I, et al The impacts of corporatisation of healthcare on medical practice and professionals in Maharashtra, India, BMJ Global Health. 2020;5:e002026.
6. Sandilya S. Residents vote for reforms in healthcare system. Indian Express, Pune ed. 2017 Jul 2[cited 2021 Sep 11]. Available from: https://indianexpress.com/article/cities/pune/pune-maharashtra-residents-vote-for-reforms-in-healthcare-system-4731409/.
7. Shukla A. A charter of patients' rights will address power asymmetry between them and doctors. Indian Express. Pune ed. 2019 Oct 23[cited 2021 Sep 11]. Available from:https://indianexpress.com/article/opinion/columns/a-legal-remedy-for-patients-mental-health-6082726/
8. Pattanaik S. Delay, Harassment, uncertainty: The rocky road to justice against medical negligence. News18.com. 2020 Jan 7[cited 2021 Sep 11]. Available from; (https://www.news18.com/news/india/delay-harassment-uncertainty-the-rocky-road-to-justice-against-medical-negligence-2447647.html).
9. Nidhi A. Unregulated clinical trials. Frontier Weekly.2015 Feb 1-7[cited 2021 Sep 11] ;Vol 30. Available from:https://www.frontierweekly.com/archive/vol-number/vol/vol-47-2014-15/47-30/47-30-Unregulated%20Clinical%20Trials.html.
10. Kay M. Indian Supreme Court demands clarity on clinical trial approvals. BMJ. 2014; 349 :g4383 doi:10.1136/bmj.g4383
11. Peris S. Defending the free health service. Peoples' Health Movement Srilanka Newsletter. 2020 Jul [cited 2021 Sep 11]. Pg 4. Available from: https://phmovement.org/wp-content/uploads/2020/08/PHM-Newsletter-July-2020-English-and-Sinhala.pdf
12. Uganda Access to Information Act, 2005[cited 2021 Sep 11]. Published in Uganda Gazette no. 42 on 19 July 2005[cited 2021 Sep 11]. Available from: https://ulii.org/akn/ug/act/2005/6/eng%402005-07-19
13. Gadre A, Marathe S. First National Conference on Ethical Healthcare (NCEH) 2018, Alliance of Doctors for Ethical Healthcare (ADEH). Natl Med J India. 2018 Jul-Aug;31(4):239-240. Doi: 10.4103/0970-258X.258228.
14. TNN. Forum to rebuild citizen-doctor trust. Times of India. 2018 Jul 23[cited 2021 Sep 11]. Available from: https://timesofindia.indiatimes.com/city/pune/forum-to-rebuild-citizen-doctor-trust/articleshow/65109843.cms
15. Chandrashekhar S, Putturaj M, Bhojani U, Rao NV. Stakeholder participation analysis in healthcare regulation: The case of amendment of Karnataka Private Medical Establishment Act, 2017. HSTP; 2020 Nov 6[cited 2021 Sep 11]. https://www.hstp.org.in/wp-content/uploads/2021/03/stakeholder-participation-analysis-for-amendment-of-kpmea-2017.pdf
16. Pawar NJ. Lawyer with a heart. Deccan Chronicle. 2017 Mar 26[cited 2021 Sep 11]. Available from: https://www.deccanchronicle.com/sunday-chronicle/headliners/260317/lawyer-with-a-heart.html