

ENSURING PATIENTS'

RIGHTS AS A CORE

STRATEGY FOR DEMANDING

SOCIAL ACCOUNTABILITY

OF THE PRIVATE

HEALTHCARE SECTOR



Ensuring patients' rights as a core strategy for demanding social accountability of the private healthcare sector¹

Introduction

"...as Adya lay, strapped and unconscious, the only sign of change we saw was the daily SMS from Fortis accounts department indicating a change in the bill" Jayant Singh's story is emblematic of the unaccountable and non-transparent corporate health sector in India. The shocking details of the treatment of his seven-year-old daughter Adya in the reputed Fortis Memorial Hospital, in Gurgaon, Delhi made headlines in the media. Adya was admitted in Fortis on 31st August 2017, with Dengue Shock Syndrome and passed away on 15th September 2017. Fortis gave Jayant Singh a bill of 15 lac rupees (around \$21000), the particulars of which showed charges for 660 syringes and 2700 gloves which was a 1700% margin on consumables and medicines. Jayant Singh is now fighting with Fortis for unreasonably prolonged treatment, and on a more serious charge, namely that the hospital forged his and his wife's signatures on the consent form. The fact-finding panel set up by the Haryana state government has observed that the total bill was charged at a profit margin of 108%. They also made a scathing observation that Fortis overcharged Rs. 12,800 for eight units of platelets in spite of the law stipulating charges at Rs. 400 per unit. On 7th December 2017, Haryana's health minister publicly mentioned that - "in simple words, Adya's death was not a death; it was a murder." Mr. Singh is resolute to fight this battle to the point where the people who erred in treating his daughter are duly punished. He is also advocating for systemic changes so that tragedies like his daughter's death do not happen in the future.

This heart wrenching story is, in effect, a sordid piece of evidence demonstrating what is wrong with private healthcare in LMICs. Episodes like this happen frequently across the country but are seldom reported.

Indeed, the right to healthcare is inadequate without commensurate rights for patients and users within the healthcare system. A variety of social, political, philosophical factors have shaped health as a human right. The growing recognition of health as a human right led to the articulation of myriad international and domestic policies and agreements. The international human rights law is agnostic on the question of who provides healthcare services, as long as this provision is consistent with human rights obligations. Most human rights frameworks do not comment explicitly on the for-profit private health sector; the General Comment 14 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) on the Right to highest attainable standard of health is an exception to this, since it delineates the responsibility of the state to protect individuals from infringement of their rights by third parties.

Perhaps the relative neglect of private health care providers by international human rights frameworks could be the reason why the right to healthcare and responsibility of the private health sector is a relatively underdeveloped discourse. Tenets of the right to healthcare declaration have

¹ Knowledge product by COPASAH Thematic Hub on Accountability of Private Medical Sector, coordinated by SATHI, India. Drafted by Dhananjay Kakade and Abhay Shukla with inputs from Kanchan Pawar, all from SATHI.

primarily developed within the citizen and the state relationship and do not provide a viable theory or mechanism on how to protect right to healthcare in the private health sector. Existing sources of health care rights, which include international law (treaties, conventions, etc.), national constitutions, domestic statutes are still evolving to define how right to healthcare could be realised at the intersection of citizenship, state, and the private health sector. In spite of the challenges mentioned above, popular resistance to market-driven healthcare and excessive profit-seeking in the private health sector has been rapidly developing in different parts of the world.

This paper is an attempt to draw insights from the patients' rights-related policy provisions in different parts of the world and community-led campaigns in India. However, it does not claim to be a comprehensive account of patient rights and right to health care in the private sector; neither does it claim to give an overview of the private sector regulation challenges in different parts of the world. What it does seek to showcase are certain patients' rights related mechanisms that are operationalised in different parts of the world, and certain campaign strategies that have been found to be effective in demanding patient rights.

The key topics discussed in this paper are:

- A. Justification for patients' rights
- B. What are the commonly accepted patients' rights, and which are the frequently encountered violations of patients' rights?
- C. Key barriers to popular mobilisation and advocacy regarding patient rights.
- D. How are patients' rights protected? - selected country examples
- E. Towards the social regulation of the private health sector and safeguarding patient rights

A. Justification for patients' rights

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

Patients' rights vary in different countries and in different jurisdictions, often depending upon prevailing cultural and social norms. Different models of the patient-physician relationship—which can also represent the citizen-state relationship—have been developed, and these have informed the particular rights to which patients are entitled. The recognition of patients' rights flows from two fundamental premises:

- (1) The healthcare consumer possesses certain interests, many of which may properly be described as rights, that are not automatically forfeited by entering into a relationship with a physician or a healthcare facility.
- (2) Many physicians and healthcare facilities fail to recognize the existence of these interests and rights, fail to provide for their protection or assertion, and frequently limit their exercise without

recourse² (Annas and Healey). The Charters of Patients' Rights developed and implemented in different countries are the result of a growing consensus at an international level that all patients have certain basic rights irrespective of nature of healthcare providers, and the patient is entitled to certain protections to be ensured by physicians, healthcare institutions and the state.

But why do patients need rights? –

- because there is an acute power asymmetry. Doctors wield enormous power regarding patients' health-related decision-making. There is an information asymmetry unparalleled by any other sector.
- because patients are vulnerable – visit to a doctor or a hospital is only during the time of distress, and patients are critically dependent on the doctor's judgement and intention;
- because physicians make decisions for their patients, and this paternalistic view which is deeply entrenched in medical practice also needs balancing by promoting patients' autonomy and agency;
- because commercial interests often override patients' interests - there is ample evidence regarding medical malpractice and its harmful financial and health impact on patients;
- because safeguarding patients' interests is the state's responsibility- Regulation and standardisation of the private sector is an important statutory function that the state must perform to protect patients' rights; especially because self-regulation by the private sector has been mostly ineffective.
- because the private medical sector has frequently grown through direct and indirect public subsidies, it needs to be accountable to the state and patients;
- because without regulation and rights, market failure will adversely impact patients;
- because legally and ethically, without exception, all persons in all settings are entitled to receive ethical treatment and such a system is possible only when there is a universal system of patient rights and responsibilities, and an obligation on healthcare providers to ensure them.

What is the basis for health movements to choose patients' rights as an idiom for mobilisation?

Private sector accountability issues are mostly framed either within the legal lexicon of regulation or in form of technical discourse related to quality of health care. In such a scenario, patients' rights as an instrument and entry point for accountability of private healthcare providers is an effective innovation, because it connects with values of the ordinary people and is also relevant to their experiences in a compelling manner. "Patients' Rights", in spite of the term's inherent ambiguities, can serve as an effective slogan to catch popular attention and socialise concerns related to private health sector accountability. Additionally, framing accountability 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.

2 <https://www.ncbi.nlm.nih.gov/pubmed/11662092>

B. What are the commonly accepted patients' rights and which are the frequently encountered violations of patients' rights?

The European Commission's report³ on "Patients' Rights in the European Union Mapping Exercise", in 2016, provided a useful framework and categorisation for analysing patients' rights. The report provided the following domains to categorise patients' rights:

- ⇒ **Basic individual rights**, such as the right to informed consent; to privacy and dignity; to access to medical records
 - ⇒ **Social rights**, such as access to health care; reimbursement; equal treatment
 - ⇒ **Consumer-based rights**, such as to choose one's provider, to a second opinion, to safe and timely treatment (patient safety and quality of care)
- In addition, two sets of cross-cutting rights were distinguished as follows:
- ⇒ **Procedural patients' rights**, such as the right to complain, to compensation, and to participate in decision-making are integrated in each of the domains because they help to enforce various patients' rights
 - ⇒ **Informational patients' rights**, such as the right to information about one's health, about treatment options, about rights and entitlements, including the basket of care and information about providers.

A wide variety of Patients' rights charters have been adopted in various countries across the world; yet despite extremely diverse contexts, these charters generally contain certain common or similar elements. Here we take as reference the **Indian Patients' Rights Charter which has been adopted by the National Human Rights Commission (NHRC)** and has been displayed on the Union Health Ministry's website⁴. This comprehensive 17-point charter specifies the following rights of patients, to be applicable for all medical establishments:

- Right to information, records and reports
- Right to transparency in rates, and care according to prescribed rates where applicable
- Right to emergency medical care, proper referral and transfer
- Right to informed consent, confidentiality, human dignity, privacy and non-discrimination
- Right to safety and quality care according to standards
- Right to choose alternative treatment options and right to second opinion
- Right to choose source for obtaining medicines or tests when admitted in hospital
- Right to protection for patients involved in clinical trials and biomedical research
- Right to take discharge of patient, or body of deceased, without being detained on procedural grounds
- Right to patient education, right to be heard and seek redressal

Each of these rights is accompanied by a detailed description of the right, reference documents giving justification for the same, and identification of the duty bearer responsible for fulfilling this right in context of any health care establishment. This is followed by a list of responsibilities of patients, including the obligation to provide relevant information to the doctor, and to respect the dignity of all health care providers, while never indulging in violence. Finally, the suggested

³ https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2018_mapping_patientsrights_frep_en.pdf

⁴ <https://mohfw.gov.in/newshighlights/draft-patient-charter-prepared-national-human-rights-commission>

mechanism for implementation of the charter along with a grievance redressal mechanism is described.

Needless to say, there could be varying emphasis on these rights depending on the context and the culture of the private health sector in a particular country. e.g. the right to autonomy and self-determination is one of the important cornerstones for patients' rights in the USA. Inevitably, discourse on patient rights is much more evolved and nuanced in the developed countries compared to the LMICs. Human rights advocates have also pointed out that unlike "patients' rights," which is rooted in a consumer framework, the concept of "**human rights to patient care**" is broader and refers to the application of human rights principles to the context of patient care. The concept of human rights to patient care derives from inherent human dignity and neutrally applied universal, legally recognised human rights principles, protecting both patients and providers and admitting of limitations that can be justified by human rights norms. It recognises the interrelation between patient and provider rights, particularly in contexts where providers face simultaneous obligations to patients and the state ("dual loyalty") and may be pressured to abet human rights violations.

The International Dual Loyalty Working Group⁵ - a collaborative initiative of Physicians for Human Rights and the School of Public Health and Primary Health Care University of Cape Town, has elaborated on dual loyalty as follows-

*".....health professionals often have obligations to other parties besides their patients – such as family members, employers, insurance companies and governments – that may conflict with undivided devotion to the patient. **This phenomenon is dual loyalty, which may be defined as clinical role conflict between professional duties to a patient and obligations, express or implied, real or perceived, to the interests of a third party such as an employer, an insurer or the state.**⁴ The dual loyalty problem is usually understood in the context of a relationship with an individual patient. In many parts of the world, however, clinicians have responsibilities to communities of patients, for prevention, health education and clinical care. Dual loyalty conflicts can and do arise in these settings as well. In cases where dual loyalty exists, elevating state over individual interests may nevertheless serve social purposes often accepted as justifiable."* The Working Group described six common types of human rights violations that stem from dual loyalty conflicts:

1. Using medical skills or expertise on behalf of the state to inflict pain, physical or psychological harm which is not a legitimate part of medical treatment;
2. Subordinating independent judgment, whether in therapeutic or evaluative settings, to support conclusions favoring the state or other third party;
3. Limiting or denying medical treatment or information related to treatment of an individual to effectuate the policy or practice of the state or other third party;
4. Disclosing confidential patient information to state authorities or other third parties in circumstances that violate human rights;
5. Performing evaluations for state or private purposes in a manner that facilitates violations of human rights;
6. Remaining silent in the face of human rights abuses committed against individuals and groups in the care of health professionals.

⁵ <https://phr.org/wp-content/uploads/2003/03/dualloyalties-2002-report.pdf>

Although this is an important step forward to understand human rights violations that stem from dual loyalty, the report of the Working Group does not provide a concrete mechanism to analyse and resolve commercial exploitation of patients' in the private health sector, which is perhaps the most important patients' rights related conundrum in LMICs. As such, some important violations noted in countries like India⁶, Kenya, and South Africa are -

- ⇒ Not providing proper information about illness, diagnosis, proposed treatment, expected outcome, estimated expenditure
- ⇒ Not giving details of the treating physician
- ⇒ Denial to share medical records of the patient
- ⇒ Denial to give itemized bill and lack of transparency in rates
- ⇒ Not taking informed consent of patient/ caretaker or taking blanket consent
- ⇒ Refusal to share documents for second opinion
- ⇒ Denial of basic emergency care to accident victims
- ⇒ Compulsion on patient to buy medicines/ obtain diagnostic tests in a particular hospital
- ⇒ Violating human dignity, privacy and confidentiality of patients
- ⇒ Discriminating against HIV positive patients
- ⇒ Holding patient or dead body of a deceased patient as a hostage for settlement of bills
- ⇒ Non adherence to standard treatment guidelines for ulterior motives; usually profit motives

Not surprisingly, each of these ongoing violations are mirrored in existing Charters of Patients' Rights such as the Indian charter mentioned above; for every common violation, there is a corresponding right intending to prevent such violation.

C. Key barriers to popular mobilisation and advocacy regarding patient rights

"...both progressives and reactionaries have to navigate the same narrative terrain, but the meanings and consequences of their stories could hardly be further apart. Both narrate a vision for "the people" and both point fingers "at the establishment," but one punches up at structured injustice while the other punches down at the most vulnerable people of society." - Jonathan Smucker⁷.

Nobody in principle can oppose patient rights or private sector accountability; however, contestation is over the meaning and value of these terms to different stakeholders. It is almost impossible to miss the coercive power of the powerful private health care industry, but it is much harder to see when this power operates as a narrative. This narrative power manifests itself in repeated broadcasting of messages which reinforce certain unsubstantiated beliefs. For example, "the private sector is synonymous with high quality of medical service", "regulation means License Raj", "medical profession is already over-regulated", etc. Although there is widespread public discontent about practices of the private sector, above mentioned dominant narratives also shape public opinion, normalises the status quo, and obscure alternative options. Additionally, this narrative power assists transformation of healthcare into a commodity.

"Medical care is an area in which crucial decisions — life and death decisions — must be made; yet making those decisions intelligently requires a vast amount of specialized knowledge; and

⁶ <https://sathicehat.org/images/download/webinar-patients-rights.pdf>

⁷ Foreword to 2nd edition- Re:imagining change, PM press, Oakland 2017.

often those decisions must also be made under conditions in which the patient is incapacitated, under severe stress, or needs action immediately, with no time for discussion, let alone comparison shopping. That's why we have medical ethics. That's why doctors have traditionally both been viewed as something special and been expected to behave according to higher standards than the average professional.”- Paul Krugman⁸.

Above lines by a noted economist aptly summarise inherent power dynamics between doctors and patients. Krugman, in the same article, has also warned against reducing the doctor-patient relationship to sellers and consumers.

Common assumptions about enabling preconditions that catalyse an effective campaign, like a constituency of people who are affected by unaccountable behaviour; for example, displaced populations affected by development projects, a group of people deprived of their livelihoods, etc. are not easily applicable while seeking accountability from the health sector. There are at least three peculiarities⁹ of the health sector that sets it apart from other social sectors, which also has implications for mobilising people and campaigning.

- ⇒ **Lack of clear supportive constituency-** Unlike other social and commercial sectors, organised and collective agency of the affected population i.e. patients is limited in case of the healthcare sector. Healthcare is mostly an “off-on” priority; so, it becomes a topmost priority only in situations of illness. This shifting nature of illness and episodic nature of healthcare seeking makes the development of sustained solidarity and mobilization difficult.
- ⇒ **Knowledge and power asymmetry-** As noted by Krugman in the note above, medicine is a specialized domain of knowledge, and the decision-making power of physicians may have consequences in terms of life and death. This acute power asymmetry is a pivotal challenge to bring in equilibrium in the doctor- patient relationship and to build a campaign on patient rights.
- ⇒ **The popular belief that medicine is an exalted profession-** Irrespective of political regime, throughout history, the medical profession has enjoyed a higher social status and privilege than any other profession except perhaps the priesthood. The high status of the profession has given rise to some popular beliefs, for example, assumed goodness and justness of the medical profession. Even though this belief system is now being challenged, societal reverence for doctors is still mostly intact. So, a normative assumption that if we could inform people about the accountability issues and give them the information they are lacking, they will join the campaign does not work in the health sector. Facts alone are not enough to persuade; assumptions, emotions, and preexisting attitudes get in the way of facts making sense.

At a macro level, erosion of health care as a public good, and aggressive promotion of health care as a commodity is one of the key challenges. Under neoliberal regimes the presumption that markets are the most appropriate basis for organizing economic and social life has also engulfed health systems. The laissez-faire liberalism adopted by various governments led to a change in the role of the state from serving public provision to promoting and supporting the private health sector. In India, Pakistan, Kenya, South Africa and other African countries, growth of the private sector has taken place at the cost of the public health sector, and with active support from the state. In a dominating policy trend of privatization and reliance on the private health sector, governments are using their power to protect capital and private interests. In such situations, budget cuts in public expenditure on health and weakening role of the state as a regulator are usually concurrent

⁸ <https://krugman.blogs.nytimes.com/2011/04/20/patients-are-not-consumers/>

⁹ Adapted from Healthcare Corruption: Responses from People’s Health Movements, Abhay Shukla, P.481, Healers or Predators.

developments. There is dissonance between deeply entrenched neoliberal policies in the health sector, and the discourse on human rights and private sector accountability. In such a situation, a campaign has to not just deal with hostile and highly organized private health interests, but also must deal with apathetic or ineffective public institutions of health governance.

D. How are patients' rights protected? - selected country examples

At a macro-level, annexure 1 lists internationally and regionally recognized rights relevant to patients, along with applicable treaty provisions and examples of violations.¹⁰ The section below is a snapshot of selected country level provisions to protect patient rights, presented as examples.

1. United Kingdom- NHS Constitution¹¹ and Handbook

The National Health Service in UK provides the foundation for ensuring a Right to health care, within which patients' rights are embedded. England, Scotland, and Wales all have their own patients' charters. These charters emphasize that the NHS belongs to the public, and people have a right to know what to expect. The charter sets out seven existing rights in the NHS. For example, the charter states the right "to be given a clear explanation of any treatment proposed, including any risks and any alternatives before you decide whether you will agree to the treatment." The Welsh charter goes slightly further, stating that a patient may expect "to help choose appropriate care and treatment."¹² Another theme running through charters is the right to information about what health services are available locally and to what standards these will be delivered. Patients have the right to have their complaints about NHS services investigated promptly, and to receive a written reply from the chief executive or general manager. This emphasis on providing information is welcomed by people, since poor communication and lack of information are patients' common complaints about the NHS. The charter then goes on to give nine "charter standards," which are more intentions than rights.

2. A new California law¹³ to ensure transparency to patients

The first of its kind in the United States, this law requires doctors to tell new patients if the state medical board has placed them on probation for activity involving patient harm. Activities that must be reported under the Patients' Right to Know Act include sexual misconduct, drug misuse that has harmed or could harm patients, a criminal conviction involving harm to patients, and inappropriate prescribing. In California, disciplinary actions against doctors are already public, since the Medical Board of California has an online registry that lists when physicians are on probation and the reasons for the disciplinary action. However, patients had to research a doctor's record. The law affects all of the

¹⁰ <https://www.hhrjournal.org/2013/12/human-rights-in-patient-care-a-theoretical-and-practical-framework/>

¹¹

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/480482/NHS_Constitution_WEB.pdf

¹² <https://www.bmj.com/content/bmj/303/6811/1148.full.pdf>

¹³ <https://www.fiercehealthcare.com/practices/first-its-kind-law-california-doctors-sexual-misconduct>

roughly 140,000 “licensed physicians” in California, a category that also includes osteopaths, naturopaths, chiropractors, podiatrists, and acupuncturists, who are regulated by their own state boards. Any new patient of a doctor on probation must be given a written notification, which patients must sign to show that they have read it. Previously, the burden was on the patient to look up such information on a rarely visited state government website.

3. No fault fund system in Austria and New Zealand

The No fault fund system separates professional liability from compensation in cases of negligence. In Austria, the fund is financed by a patient fee per day of hospital stay, and is administered by the regional patient advocate. An independent commission decides on redressal for individual cases. There is a limit of approximately 22000 € for redress from the fund in individual cases. In New Zealand¹⁴, the no-fault system replaced the tort system in 1972. Initial problems included compensation shortfalls, lack of accountability of doctors, and the definition of medical misadventure (used in place of medical negligence). In 1992, a reformed act was passed to address some of these criticisms and laid heavy emphasis on disciplining doctors at fault. The scheme seems to work well in the field of medical litigation. However, the minimal cover provided by the act and complete bar on the right to sue remain unique to New Zealand.

4. Hungary Commissioner for Fundamental Rights – A system of effective redressal

The Commissioner for Fundamental Rights in Hungary is an ombudsman-type institution responsible for the protection of fundamental rights in Hungary, covering the spectrum of fundamental rights. The Commissionerate was established in 1993, along with a compulsory social health insurance scheme that funds the Health Insurance Fund. Anybody whose health rights have been violated as a result of an action or omission by caregiver can approach the office of the ombudsman. It is noteworthy that the ombudsman office has proved to be an institution that is accessible to individuals. One of the hallmarks of the ombudsman office is a robust redressal system. Patients have the right to file complaints; complaints usually entail requests aimed at extinguishing individual grievances of any rights or interests. Anyone is entitled to file complaints to the authorities having the competence to decide on the matter at hand. The healthcare provider and the financing organization are legally bound to launch an investigation into all complaints filed and inform the patients on the results thereof no later than within 30 business days. Importantly, the patient has a right to turn to different bodies for their complaints to be investigated as prescribed by law. Detailed rules of investigating complaints are set forth in the internal regulations of the healthcare provider.

The National Center for Patients’ Rights and Documentation (OBDK) can be contacted in case of questions regarding patients’ rights (in case of any violation of patient rights). The OBDK assist the complainant in finding the patient rights advocate assigned to the concerned healthcare provider, who then puts together the complaint and files it through the appropriate channels. The OBDK houses and operates the national bureau of complaints. Additionally, the Office of the Chief Medical Officer (OTH) can be contacted with (primarily medical-professional) service-related issues. The OTH operates a system of specialized physicians in every specialty field. The OTH conducts an official inquest, then informs the complainant about the result.

14 <https://www.bmj.com/content/326/7397/997>

Importantly, Hungary also has an effective system of Patients' Rights Advocates¹⁵, who have a clean criminal record, a degree of higher education, and are not prohibited from engaging in healthcare activities. Patients' Rights Advocates are tasked with the protection of patients' rights specified by law, and they assist patients in getting to know and exercise these rights. As such, key functions that Patient Rights advocates perform include- assistance to patient in accessing medical records and documentation, and in posing relevant questions; assistance to patient in putting complaints into words and initiate the investigation of these claims; informing healthcare workers on rules relevant to patients' rights etc.

5. Punjab (Pakistan) health care commission

The Punjab Healthcare Commission (PHC) is an autonomous health regulatory body that regulates the hospitals, clinics, laboratories and other health centres in Punjab province of Pakistan¹⁶. It was established by the Government of the Punjab under the Punjab Healthcare Commission Act 2010. The PHC is responsible for developing and enforcing Minimum Service Delivery Standards (MSDS) at all levels of healthcare, to improve the quality of healthcare services and foster a culture of Clinical Governance. All Healthcare Establishments are required to implement MSDS to acquire a License to deliver healthcare services in Punjab. The Directorate of Patient Rights and Complaints is constituted to hear complaints regarding- adherence to service delivery standards and standard protocols; violation of charter of patients' rights; malpractice and medical negligence; harassment of medical professionals/staff; violence in hospitals, etc. Importantly, PHC is one of the few statutory bodies in the SAARC region to comprehensively regulate healthcare service delivery.

(For a snapshot overview of the patients' rights in the European Union- <https://publications.europa.eu/en/publication-detail/-/publication/8f187ea5-024b-11e8-b8f5-01aa75ed71a1/language-en>)

E. Towards social regulation of the private health sector and safeguarding patient rights

In India, private health care providers play a major role in the provision of health services. At the time of independence, only about 7% of all qualified modern medical care was provided by the private health sector. Now the private sector contributes nearly 75% of the outpatient care and over 60% of the hospitalization services. With weak regulatory oversight and failure to self-regulate, the trajectory of the private sector has been to aggressively maximise profits through the healthcare market. Sordid stories of medical malpractice, irrational procedures, overcharging are persistent, and have led to a communication breakdown and extreme trust deficit between doctors and patients.

Unfortunately, the institutions of health governance in India, which are primarily responsible for enacting and overseeing regulation of the private sector and also safeguarding patients' rights, have done an abysmal job in fulfilling their mandate. Some of the regulatory bodies, like the erstwhile

¹⁵ <http://www.patientsrights.hu/exercising-patients-rights.html>

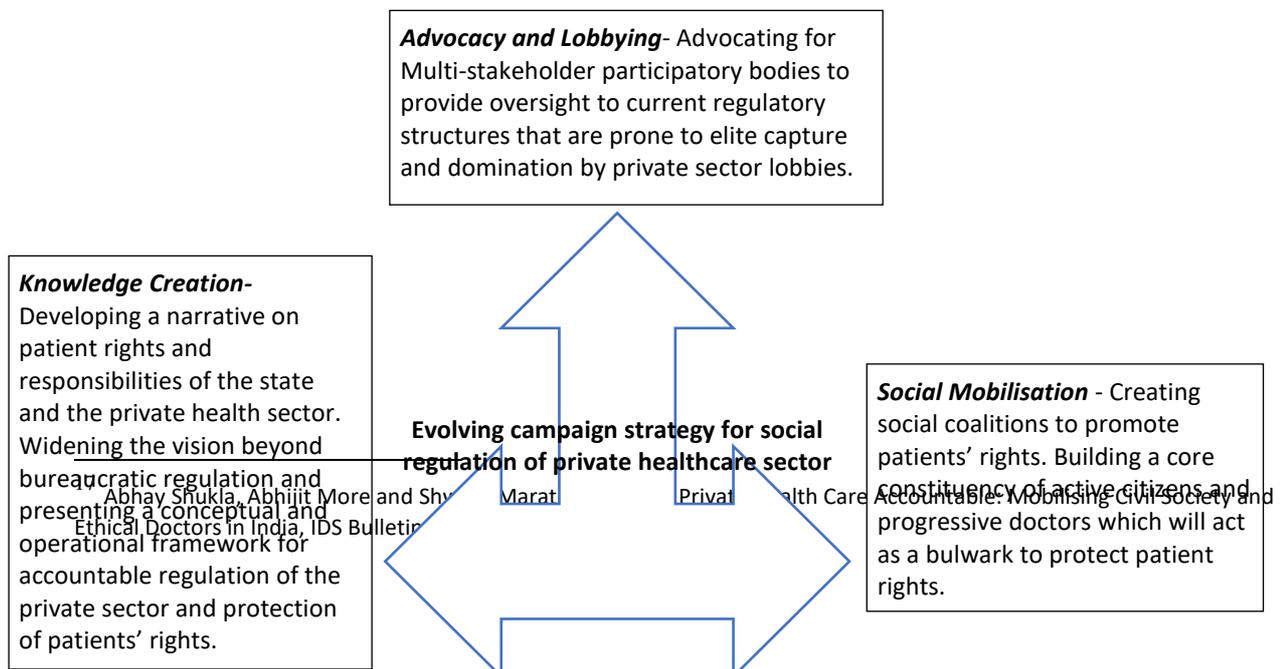
¹⁶ https://en.wikipedia.org/wiki/Government_of_Punjab,_Pakistan

Medical Council of India (MCI), themselves turned into Augean stables of corruption. This was particularly alarming since the state medical councils and the MCI were for a long period de-facto the only authorities who were allowed to take action against the private health sector. Moreover, such action was restricted only to disciplinary proceedings. Prevention of Corruption Act is limited to the public sector and does not criminalize bribery in the private sector. Even the Consumer Protection Act-1986 does not have a provision to investigate bribery and fraud charges in the private health sector. Besides the lack of political will, past legislations- like the archaic Bombay Nursing Home Regulation Act 1949- amended in 2005, and even the newly enacted Clinical Establishment Act -2010, lacked the provision for a grievance redressal mechanism and did not articulate patient rights in depth.

Regarding key areas where maximum patients’ rights violations take place – like commission practice and kickbacks, overcharging, unnecessary and irrational treatment or surgeries, etc. - provisions are either missing from CEA or the related regulations remain unimplemented. In spite of its relatively sanitized orientation, even the current CEA has faced considerable backlash from the private sector lobbies. Against this backdrop, it was a conscious strategy to sensitise and mobilise people on patients’ rights besides continuing to advocate for better regulation of the private health sector. As mentioned, regulation of the private medical sector is often seen as a bureaucratic function of the state and apparently has little to do with the aspiration of people in terms of quality of health care. However, Patients’ Rights campaigns have consistently articulated the view that regulation is a form of social accountability writ large, and hence, regulators must be accountable to people, and their aspirations should reflect in any regulatory mechanism. Adding further, the campaign also proposed that the demand for patients’ rights could be an important fulcrum for social mobilization related to regulation and social accountability of the private medical sector¹⁷.

Reorienting the standard model of regulation, placing emphasis on social regulation of the private health sector and protection of patients’ rights

Discontent regarding the private health sector in India is now at a tipping point, and yet even a moderate attempt to mobilise patients is met with vociferous opposition from the medical fraternity. Nevertheless, some steps have been taken towards private sector regulation and patients’ rights issues in India, through three interrelated strategies which are as follows-



Annexure 2 enlists some illustrative activities related to building initiatives around patients' rights in India.

Conclusion

The dream of reason did not take power into account. – Paul Starr

The rise of scientific medicine in the 20th century must be counted as one of the major achievements of humanity. This has been accompanied by major expansion in the knowledge, power and prestige of the medical profession, and more recently, growing domination by a profit seeking, corporatised health care industry. The emergence of these immensely powerful entities with their inherent profit-and power – seeking goals cannot be assumed to translate into protection of the interests of ordinary patients. Hence the increasingly relevant discourse around patients' rights.

Diversity of patient rights in different countries is significant. In some countries, e.g. Brazil and Columbia, courts became the primary arbitration mechanism for patients and primarily dealt with issues like insurance coverage and higher copayments. In other countries such as South Africa, the Treatment Action Campaign (TAC) successfully addressed structural problems and brought forward Right to Healthcare and patients' rights on the political agenda. Given context-specific social and political factors, Collen Food and Aeyal Gross¹⁸ provide clear differences in the role of the right to health, including patients' rights, among three categories of countries.

- High-income countries which have relatively strong, predominantly tax-financed health systems. These are modern welfare states where health was a part of policy, and where rights are well embedded in the health system. e.g. UK, Netherlands, Canada, etc.
- High income countries with stronger health insurance systems, where decisions or decision-making processes concerning the defined basket of benefits may be subject to judicial review. Some of the significant litigations in these countries were directed at the insurers and providers rather than state.
- LMICs with major gaps between a poor public health system and a well resourced private one, where one is most likely to find an explicit constitutional right to health care, or that the right to health care is inferred from other provisions. e.g. South Africa, India, etc.

This is a useful categorization to understand the global context of the patients' rights and right to healthcare, to understand variations in the impact of rights depending on their modes of enactment-international, constitutional, statutory and de-facto. While patients' rights have an unmistakable individualistic connotation, there needs to be a careful balance between the individual and community, and the struggle for Patient Rights should also be guided by a commitment to public health values like solidarity, equality and universality.

¹⁸ Contexts for the promise and peril of right to healthcare, P. 468, The Right to Health at the Public/Private Divide- A Global Comparative Study

The struggle for private health sector accountability and patients' rights has a long arc, and has to navigate its way through a maze of adversarial forces- well organized private health sector lobbies, the tremendous influence they wield on policy makers, neoliberal ideology that has a deleterious effect on social services, and the inherent knowledge asymmetry between medical profession and patients. Our primary attempt is to mobilize ordinary people, patients and progressive voices within the medical profession in a manner that the state is forced to respond. Although patients' rights discourse in LMICs is still in a nascent stage, some significant gains have been made. This is a perilous journey, but what used to be just a whisper is now becoming the amplified voice of a united people.

Annexure 1

Table 1¹⁹ lists internationally and regionally recognized rights relevant to patients, along with applicable treaty provisions and examples of violations.

¹⁹ Source- <https://www.hhrjournal.org/2013/12/human-rights-in-patient-care-a-theoretical-and-practical-framework/>

| Right | Treaty provisions | Examples of violations |
|---|---|---|
| Right to liberty and security of person | ICCPR 9(1), ACHPR 6, ECHR 5(1) | <ul style="list-style-type: none"> • Patients are detained in a hospital for inability to pay. |
| Right to privacy and confidentiality | ICCPR 17(1), CRC 16(1), ECHR 8(1) | <ul style="list-style-type: none"> • Patient medical information is open to all staff. • Patients are forced to disclose their medical diagnosis to their employer in order to obtain leave from work. • Medical examinations take place in public conditions. |
| Right to information | ICCPR 19(2), ACHPR 9(1), Council of Europe Framework Convention for the Protection of National Minorities (FCNM) 9(1), European Convention on Human Rights and Biomedicine (ECHR) 10(2) | <ul style="list-style-type: none"> • A state fails to provide information on health care services. • Physicians fail to provide patients with information about treatment options and the potential risks and benefits of each procedure. • Patients are denied access to their medical files. • Information services are unavailable for people who speak certain languages. |
| Right to bodily integrity | ICERD 5(b), ACHPR 4, FCNM 6(1), CRC 19(1), ECHR 5 (The right to bodily integrity is not specifically recognized under the ICCPR, ICESCR, ECHR, or ESC, but has been interpreted to be part of the right to security of the person, the right to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health.) ¹³ | <ul style="list-style-type: none"> • Physicians fail to obtain “free and informed” consent from patients before performing medical procedures. • Patients are not allowed to switch physicians or health care providers. |
| Right to life | ICCPR 6(1), ACHPR 4, ECHR 2(1) | <ul style="list-style-type: none"> • Due to inadequate reproductive health and prenatal care, complications from pregnancy are a leading cause of death for young women. • Ambulances fail to arrive at certain communities or for certain individuals in a timely manner, leading to patient deaths. |

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| Right to the highest attainable standard of health | ICESCR 12, ICERD 5, CRC 24, CEDAW 12(1), ACHPR 16, ESC 11, ESC 13 | <ul style="list-style-type: none"> • Maternal and reproductive health services are lacking. • Doctors and health facilities are not located near neighborhoods of certain communities. • Social policies disproportionately exclude patients from certain communities from access to health insurance. • Patients are given inferior care. |
| Right to freedom from torture and cruel, inhuman and degrading treatment | ICCPR 7, Convention against Torture, ACHPR 5, ECHR 3, European Convention for the Prevention of Torture | <ul style="list-style-type: none"> • Prisoners are denied adequate medical treatment. • Women are sterilized without their consent while giving birth by cesarean section. • National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain. |
| Right to participation in public policy | ICCPR 25, ICERD 5(c), ACHPR 13(1), FCNM 15, CEDAW 7, CEDAW 14(2) | <ul style="list-style-type: none"> • Citizens lack an opportunity to comment on and participate in the setting of public health priorities. |
| Right to non-discrimination and equality | ICCPR 21(1), ICCPR 26, ICESCR 2(2), ICERD, ACHPR 2-3, ACHPR 19, FCNM 4(1), ECHR 14, ECHR 3 | <ul style="list-style-type: none"> • Mothers belonging to certain ethnic groups are forced to stay in separate wards when delivering a baby. • Doctors refuse to provide care to people living with HIV, sex workers, or people who use drugs. • Reproductive health services for women are not addressed in national policy. |
| Right to a remedy | ICCPR 2(3), ICERD 6, CEDAW 2, ACHPR 26, ECHR 13 | <ul style="list-style-type: none"> • The state takes no action to address any of the violations described above. |

Table 2 provides a listing of three key clusters of rights relevant to providers, along with applicable treaty provisions and examples of violations.

| Right | Treaty provisions | Examples of violations |
|------------------------------------|---------------------------------|---|
| Right to decent working conditions | ICESCR 7, ACHPR 15, ESC 2-4 | <ul style="list-style-type: none"> • Nurses are paid less than the national minimum wage. • Medical staff are exposed to dangerously high levels of radiation due to faulty equipment. • A nurse is infected with HIV due to improperly sterilized medical equipment. • Medical staff are threatened by violent patients. |
| Right to freedom of association | ICCPR 21, ACHPR 10, ECHR 5, 11 | <ul style="list-style-type: none"> • A professional medical association is not approved by the Ministry of Health because its president is a leading member of an opposition political party. • Authorities prevent a rally for improved work conditions for health workers without justification. |
| Right to due process | ICCPR 14(1), ACHPR 7, ECHR 6(1) | <ul style="list-style-type: none"> • A nurse facing disciplinary proceedings is unable to obtain access to all the evidence presented against her in advance of the hearing. • A doctor facing a medical negligence suit has still not been given a hearing date five years after commencement of the proceedings. |

Annexure 2 – Illustrative Activities to promote Patients’ Rights and responsiveness of the Private health care sector in India

Public hearing on Health rights by People’s Health Movement-India and NHRC

Jan Swasthya Abhiyan (People’s Health Movement – India) proposed in 2015 to organise a series of regional public hearings on the right to healthcare across the country, to be conducted in collaboration with National Human Rights Commission (NHRC). Over 30 preparatory workshops preceded the hearing process, and health activists were oriented regarding the documentation of denial of patients’ rights in public health services as well as private hospitals.

The first hearing was planned at Mumbai in Jan. 2016 involving three states from Western India. Around 25 cases of serious violations of patients’ rights were documented in the western region of India. The first hearing in Mumbai in January 2016 was attended by more than 650 participants where NHRC heard cases related to the public health system, but declined to hear the cases related to private hospitals on procedural grounds. While this was a setback for the campaign, this event received extensive media attention and coverage and laid the foundations for further documentation and campaigns around patients’ rights in context of the private sector.

Publication of ‘Dissenting Diagnosis’ and formation of ‘Alliance of Doctors for Ethical Healthcare’:

Published in May 2016, "the popular book Dissenting Diagnosis" authored by two medical doctors associated with SATHI was a cornerstone in highlighting malpractices in the private health sector in India. It was based on interviews with 78 practicing doctors, who were courageous enough to speak about medical malpractice. This book was reviewed and highlighted by various periodicals, as well as print and electronic media. Importantly, this book gave agency to non-conforming doctors who were frustrated with the current state of affairs in the private health sector. In a concurrent development, SATHI took the lead in the formation of the Alliance of Doctors for Ethical Healthcare (ADEH)- a national network of doctors supporting ethical and rational healthcare. Following its formation, ADEH intervened in some important policy-making spaces. Notable among them were demands for major reorganisation and reform of the Medical Council of India (May 2016), submission of a range of suggestions to NITI Aayog regarding the draft National Medical Commission Bill (October 2016), etc.

Innovative campaign activities by Jan Arogya Abhiyan (People's Health Movement, Maharashtra)

People's poll for patients' rights- Voting for better health care

Under the broad heading of "Patients' Voice, Citizen's Initiative Campaign," we organized voting for patients' rights in different parts of Pune District, from 15th June to 30th June 2017. Each ballot paper reflected what people want; it was an exercise that gave us a glimpse of how strongly people feel about patient' rights and the exploitation in the private sector, and how much they aspire for better public health services. Here is a snapshot of the voting-

- 21351 votes were cast.
- The voting was conducted at more than 80 places in the Pune district.
- 670 people voted online.
- People from various residential societies, slums, villages, companies, colleges, self-help groups participated. Cross-section of society voted- there were government employees, doctors, nurses, IT professionals, unorganized workers, waste pickers, farmers, farm labourers, sex workers, people belonging to nomadic tribe community, truck drivers; all voted with fervor.
- In this voting exercise, the three questions were asked. Should the Maharashtra Government regulate and standardize private hospitals to check commercialization? Should the Maharashtra Government take concrete steps to improve quality of care in public hospitals? Should the Government immediately enact legislation to protect patients' rights?
- Out of the 21351 people who voted, an overwhelming 21067 (98.7%) voted in favour of bringing private hospitals under regulatory framework while 21247 (99.5%) agreed that government should take concrete measures to improve quality of care in public hospitals. 21225 (99.4%) people demanded the enactment of a legislation to protect patients' rights. This indicates that people from all walks of life are dissatisfied with current healthcare options and they strongly demand reforms in the healthcare system.

The context of the voting, the sheer number of people who voted, underscored the importance of engaging with the ordinary people. The campaign culminated into a public event, and the results of the voting were announced on 1st July 2017. The uniqueness of this event did not go unnoticed, almost all leading newspapers and electronic media reported about voting and results.

What are the key learnings?

- Many people who voted, were not just there to cast a vote, but had personal stories of denial, negligence, and exploitation.
- Voting as an idiom had struck a chord with people. They found agency and meaning in the voting and came out in large numbers. In a process, we also got a sense about the magnitude of discontent regarding the private health sector.
- This social churning did not go unnoticed; media covered details regarding the voting and the public event in great detail.

National protest to demand protection of patients' rights

Jan Swasthya Abhiyan (People's Health movement – India) held a national consultation on 24th January 2019 at Delhi, where various health activists and patients shared their experiences and violations faced by them especially in private hospitals. The consultation was organised by SATHI, Pune and Sama Resource Group for Women and Health, and was attended by patients' rights groups and health activists from seven states across India.

A key issue discussed was the **Charter of Patient's Rights** which has been developed by National Human Rights Commission (see above). In August 2018, the Ministry of Health and Family Welfare (MOHFW) announced its plans to implement this Charter, which was placed in the public domain for

inviting comments up to 30th September 2018. A decision was taken by the JSA to launch a large-scale campaign for adoption of this patient rights charter before the parliamentary elections. Health activists also pointed out that several states have adopted or are in the process of adopting the national Clinical Establishments Act. However, there is a complete absence of implementation in some states, and wherever it is adopted, patients' rights do not feature in the CEA.

The first step of this campaign was the decision to start documentation of cases of patient right denial and violation across India in collaboration with JSA activists from different states. This data will be compiled in the form of a book and shared online to highlight the extent and impact of Patient Rights violations in the country.

The second step was the launch of an online petition on www.change.org in February 2019 to the union health minister, demanding the immediate adoption of the Patient Rights Charter. The online petition was circulated heavily amongst social networks and covered in the media as well.

On 26th Feb. 2019, over four hundred patients, their family members and health activists from six major networks gathered at Jantar Mantar, New Delhi to launch a unique protest. These 'medical victims' and health activists from Delhi and other states demanded that malpractices, gross overcharging and violation of patients' rights in private hospitals must be brought to an end.

Women from low income communities, patient victims, people living with HIV-AIDS, health professionals and activists from Delhi, Maharashtra, Gujarat, Odisha, Tamil Nadu, Uttar Pradesh, Madhya Pradesh, Chhattisgarh and other states of India shared their stories of discrimination, violations, loss, suffering and fights for redressal. They participated in the day long protest and formed a human chain. Later, JSA representatives met senior officials from the Union Health Ministry and handed them a copy of the online petition along with 1500 signatures. Key demands of the protest were:

- 1. Immediate implementation of National Human Rights Commission's Charter for Patient Rights, to be done by Union Health Ministry**
- 2. Regulation of rates in private hospitals - care in private hospitals to be made affordable**
- 3. Creation of a Patient friendly and time bound grievance redressal mechanism to deal with complaints in private hospitals**

The Jantar Mantar demonstration was unique, as it brought together people from varied walks of life with a common demand for accountability in the private health sector and patients' rights. A senior doctor from AIIMS, the country's premier public hospital as well as a senior medical specialist from a top corporate hospital spoke about the urgent need for accountability in the health sector. There was a street theatre performance by students from Delhi University. The event was covered extensively in national print and news media.