

March 2022



Patients' voices during the Pandemic

Stories and analysis of rights violations and overcharging by private hospitals



Published by
SATHI

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About SATHI

Support for Advocacy and Training to Health Initiatives (SATHI) is an action-research center of Anusandhan Trust (www.anusandhantrust.org) based in Pune.

It has nationally pioneered health rights approaches in India since 1998, fostering accountability of public health system, private health sector and inter-sectoral community action through partnerships with civil society organizations. For more information about SATHI, please visit the website: <https://sathicehat.org>

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Foreword

by Shreya Milind Nimonkar

It was not easy to fight a decade long legal battle in the consumer court against medical negligence by the private hospitals. On 21st October 2021, when the State Consumer Commissioner directed erring doctors to pay a compensation of 28.66 lakh rupees, all the traumatic memories of fighting this tough battle with the powerful medical lobby, along with my late husband, whom I recently lost to COVID-19, came back to me from the oblivion. Although very late, this compensation will help me continue treatment for my permanent disabilities caused by medical negligence. Besides my husband, my family, and the advocate who fought this legal battle on my behalf, stood by me throughout this uncertain journey as strong pillars; without them, I would not have persevered in this distressing battle with little hope of winning.

In March 2010, I was operated for a hysterectomy during which both ureters were permanently damaged, leading to prolonged complications, more surgeries, continuous medical expenses and agonising discomfort that I will have to bear throughout my life. Initial two years post-surgery went into consulting various doctors to treat the damaged urinary system and understand the nuances of my case. My husband and I met many doctors to seek expert opinion and confirm whether there was medical negligence in my case and whether I can legally challenge it? Although it was evident to most doctors that the case involved irrational care and medical negligence, they refrained from giving expert opinion in writing. Finally, two doctors agreed to provide it after one and a half years. In parallel, we tried to find out about various legal protections available to patients. What followed was relentless and tiring follow up with various authorities, including consumer court, police stations, district medical officer, municipal health department, J.J. Hospital, etc. However, almost all authorities have pointed out that as original records of the surgery are missing, my case will be untenable. We then approached the Maharashtra Medical Council and the Medical Council of India. But they, too, failed to get the original records from my consulting doctors. It was a painful realisation that proving medical negligence is extremely complex for a layperson like me. Perhaps that's the ordeal of many people fighting to prove medical negligence. In my case, the key issues were-

- *The consent process was incomplete since I was operated upon without*

permission and without being explained the risks involved.

- *My family and I was kept in the dark and a doctor from outside was called to carry out the procedure.*
- *I was operated on without fitness report issued by the anaesthetist.*
- *There was a lack of communication and non-disclosure of a complicated condition to my family. They were kept in the dark about the major damage to my other organs during the procedure.*
- *A consultant surgeon neglected me despite repeated complaints about frequent pain following surgery.*
- *My original case papers were withheld by the consulting doctors for years.*
- *Professional misconduct of failing to follow basic pre-operative protocol such as not maintaining an anaesthetist's report, missing surgery notes, and demonstrating post-operative carelessness by not attending the patient's medical complaints.*

Many patients' rights were clearly violated in my case. But for the sake of legal battle, the case was framed entirely on the critical issue of "valid and complete informed consent" which was crucial for proving medical negligence. Later, the Judge had carefully crafted his observations and reasonings about informed and valid consent as well as shortcomings on the part of the doctor.

During the COVID-19 pandemic, private hospitals overcharged thousands of patients with false billing, false reports, irrational care etc. 'SATHI' has compiled testimonies of such patients from different parts of Maharashtra. The stories included in this compendium illustrate how patients and their families suffered unjustly at the hands of private hospitals that violated their patients' rights. SATHI has taken on the very important task of amplifying patients' voices and creating awareness regarding patients' rights.

I hope my struggle for justice and accountability will inspire other patients who suffered because of overcharging and medical negligence during the pandemic. May this compendium help catalyse much-needed positive changes related to medical practice and transparency and accountability of private hospitals in the future.

Shreya Milind Nimonkar,

Patient-activist who won a decade-long legal battle against medical negligence by a private hospital.

Mumbai.





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Preface

“The issue which has been raised in the petition concerns a wide strata of society consisting of patients and their relatives who have been overcharged during the COVID-19 pandemic and the issue which has been raised would merit serious attention”- The Supreme Court of India, October 13th, 2021.

Not everyone suffered during the pandemic. All emergencies create opportunities for profiteering and overcharging, and the pandemic was no exception. From people's point of view, this time, the epicentre of overcharging was corporate and private hospitals. There are also examples where private doctors and hospitals have played an exemplary role in performing their public health duties, but this compendium is not about exceptions.

Twenty-three testimonies in the compendium vividly illustrate what really happened to people while seeking healthcare from private hospitals, showcasing the scale and magnitude of overcharging, how blatantly the private hospitals ignored state rate capping order, and how hastily created grievance redressal system crumbled. These stories emerge from telephonic interviews with individual patient victims and or their relatives, clearly showing how rights were violated and overcharging took place while accessing private healthcare services in urban and rural parts of Maharashtra. We documented most of these testimonies between October to December 2020.

This compendium is not exhaustive documentation of patient testimonies; the attempt here shows patterns of overcharging and financial unaccountability of the private health sector. Additionally, the document breaks the myth that overcharging is primarily restricted to metropolitan cities and shows that this has been a generalised phenomenon and needs to be addressed as an urgent policy issue.

It is worth noting that outrage about overcharging was so overwhelming that the Government of Maharashtra was forced to issue a rate capping order on COVID-19 treatment to safeguard patients from overcharging in private hospitals. Indeed, it was an unprecedented policy step, in contrast to the government's traditional laissez-faire policy-making perspective. However, the government's repeated reassurances regarding patient protection from overcharging and subsequent orders on rate capping did not materialise to its full extent as systems for grievance redressal were fraught with insufficiencies. A study from Pune, one of the worst affected cities in India during a pandemic, showed that a scant 1.86 % of total numbers of bills were audited, with a large number of patients still awaiting scrutiny of their bills. Studies also showed that a mere

4% of COVID-19 patients benefited from the MJPJAY (state insurance scheme) due to lack of awareness amongst beneficiaries and red tape.

At a macro level, these cases provide a grassroots perspective to develop a much-needed counter-narrative to challenge national and global euphoria on harnessing the private health sector in achieving public health goals like Universal Healthcare and the Sustainable Development Goals. Whereas, at the national and the state level, it points to an urgent need to put a robust people-centric regulatory system for India's private health sector.

Anonymised testimonies in this compendium resulted because people who spoke to us wanted their grievances to be visible and in the public domain. Many of them have lost their loved ones to the pandemic. Still, their stories are not about death, but rather about how private health hospitals that they trusted and depended on for healthcare used their desperation as an opportunity for overcharging and profiteering, how grievance redressal systems failed, and how benefits of highly publicised state insurance schemes were concealed and denied. They spoke to us because they are still hopeful that their grievances will be heard and resolved.

I believe this compilation of patients' stories could serve as an important reference document for civil society networks, individuals and academics who work on patients' rights and private sector regulation related issues. Further, I sincerely believe this collective web of real stories will compel the government to no more procrastinate regulating the private health sector. And, as an immediate step, there is a state-wide systematic enquiry into instances of overcharging and financial unaccountability in the private hospitals, and people who have been overcharged are duly compensated.

I want to express my sincere gratitude to Ms Shreya Nimonkar, who agreed to write a foreword for this compendium. Shreya's story exemplifies how resolute individuals can still win a battle against a powerful medical lobby with sheer determination and resilience in a profoundly adversarial environment.

I express my deepest gratitude towards all the respondents- patients and or their relatives for sharing their traumatic experiences in private hospitals during the pandemic.

This compendium wouldn't have been possible without my colleagues Shakuntala Bhalerao, who anchored and coordinated data collection and liaising with patients, and Shweta Marathe, who concretised the idea of compendium and coordinated for developing it. I also want to take this opportunity to thank Dr Kanchan Pawar and Dr Abhijit More for conducting interviews and writing cases.

Thanks to Shripad Kondhe, Ravi Desai, Santosh Jadhav and Ms Vaishali Gaikwad for their support in coordinating the data collection. I express my gratitude to Programme Development Committee and Institutional Ethics Committee for guiding and approving this documentation. Focussing on the pandemic experience, the last section of the compendium is drafted by Dr Abhay Shukla. He has outlined key steps necessary to protect patients' rights and enhance the accountability of the private health sector. Lastly and importantly, I acknowledge the financial support from Funds for Global Human Rights (FGHR) for undertaking this important initiative.

Dr Dhananjay Kakade,

Head of the Institute,
SATHI, Pune

Introduction and methodology

Section I





Introduction and methodology

Introduction

The COVID-19 pandemic re-exposed scale and magnitude of the private sector accountability crisis in India. At the pandemic's peak, innumerable instances of overcharging and profiteering were reported from different parts of India, including the focus of this compendium- the state of Maharashtra. Many newspapers published articles related to overcharging, the inadequacy of hastily created grievance redressal mechanisms, and the apathy of private hospitals to comply with the government's rate capping order. Pandemic was a double whammy for patients- they had a choice of treatment between fund-starved, poorly maintained, understaffed public health institutions or expensive and non-transparent private hospitals. Equitable access to healthcare is an essential tenet of India's aspiration for universal access to healthcare; pandemic demonstrated how distant we are from that goal. Particularly striking was how the private health sector, particularly corporate hospitals, used the COVID-19 pandemic as an opportunity to extract profits through non-transparent overcharging. Notably, unabated overcharging continued despite Maharashtra Government's order to put a rate cap on COVID-19 treatment. Moreover, positive policy steps by the government, like instituting audits of the private hospital bills which exceeded rate ceiling and expanding provision of free and cashless insurance protection from 85% to 100% for poor people under the flagship program *Mahatma Jyotiba Phule Jan Arogya Yojana* (MJPJAY), were poorly implemented due to range of governance and coordination glitches.

Why the compendium?

The protagonist of this compendium is 'patient'. Twenty-three anonymised case stories in this document will resonate with readers of this compendium. It is not an exhaustive analysis, but it certainly provides a glimpse into patterns of overcharging, non-transparency, and in worst cases, complete apathy. There have been a plethora of academic papers and research briefs on marketisation, commercialisation, privatisation, and corporatisation of healthcare; however, there is a dearth of patient's narratives, focussing on patients and their perceptions and experience of interfacing with private healthcare. As we documented patients' experiences, we realised how desperately people want to share their stories of seeking healthcare during the pandemic and build a collective web of shared narratives. This is an opportunity to

strengthen patients and ordinary people as an important constituency and key stakeholder in shaping the regulatory landscape for the private health sector. In many ways, this compendium is a unique contribution to strengthening and amplifying demand for patient's rights and better regulation of the private health sector and encouraging other organisations to document and analyse instances of overcharging.

What is in the compendium?

Succinct case stories presented in this document show various ways in which private hospitals violated patients' rights with impunity. Some notable and illustrative patterns of overcharging, non-transparency, and illegal practices were-

- Overcharging for COVID-19 treatment and diagnosis and not adhering to the government's order on rate capping.
- Denial of treatment in COVID-19 designated hospitals, particularly concealing information about the government schemes.
- Keeping patient relatives in the dark about treatment and estimated cost of the treatment.
- Demanding huge deposits or advance money to admit patients.
- Withholding dead body of patient to extort payment.

Lastly, the compendium ends with a very important way forward section. We believe that sharing people's experiences is not sufficient, but those experiences should shape advocacy strategies and crystallise new ideas for better regulation of the private health sector. With that expectation, the way forward section offers some much-needed insights into what has not worked as regulation until now and what needs to change and reconceptualised.

Methodology

This documentation aims to amplify the voices of patients and caregivers, especially from marginalised communities, who have suffered during the COVID-19 pandemic by systematically documenting instances of denial of Patients' Rights in the dominant for-profit private healthcare sector. This exercise used a narrative approach to solicit first hand testimonies from individual patient victims and their immediate family members, who have experienced denial or outright violation of their patient's rights while accessing healthcare services in private hospitals in Maharashtra during the COVID-19 pandemic through interviews.

Data collection

Patients or their families residing in Maharashtra, who have experienced denial and/or violation of their patient's rights while seeking COVID-19 and non-COVID care during the COVID-19 pandemic and are willing to speak about their experiences voluntarily were selected for the documentation. Potential respondents were identified through referrals from health activists and allied health networks who are active in COVID-19 relief work, particularly with people from vulnerable or marginalised backgrounds in urban and rural Maharashtra. Cases included in this documentation belong to first wave of COVID-19 from March 2020 to December 2020 and are from various districts including Pune,

Yavatmal, Kolhapur, Nashik etc. In-depth interviews of patients or immediate family members were interviewed over the phone. The research team interviewed 30 respondents during November 2020 to January 2021. Respondents were explained the purpose of the interview and its anticipated outcomes, so as to manage the expectations of the respondents beforehand.

Informed consent was taken for participation in the documentation while giving assurance about maintaining privacy, confidentiality and anonymity of respondents, as per their stated preference, from stage of participation in the documentation to its final dissemination. Interviewers reassured respondents that all personal information, names of treating doctors, hospitals, places and other identifying information will be strictly confidential and removed or disguised in the final narration, depending on the stated wish of the respondents. Interviews were conducted following the interview guide which broadly covered patient's experience in the hospital, billing issues, impact of hospitalisation and denial of patients' rights on their health. All the interviews were conducted in Marathi and were audio recorded with prior consent of the respondents. Audio-recorded interviews were first anonymised and transcribed for carrying further analysis. Proxy names are mentioned in the stories to protect identify of the respondents.

Profile of respondents

Total 30 respondents were included in the study. Of these, we have included 23 distinct cases in this compendium. Of the 23, seven were women while the rest were all men. The respondents ranged in age from 24 to 85 years. Of the total respondents, majority were COVID-19 positive. Their experiences were during the period of July 2020 to December 2020. Barring a few exceptions, the majority of respondents belonged to a lower-middle class background. Two respondents were admitted in big charitable hospitals, three in big private-corporate hospitals, nine in medium sized and the remaining nine in small sized private hospitals. Patients' hospital stay ranged from 2 to 25 days, and the total bill amount varied from Rs 75,000 to 14,00,000 with ten patients owing bills exceeding Rs 3,00,000 and two patients having bills above Rs 14,00,000. There were 11 deaths among the total respondents. Only five respondents had made a complaint and all were up to the district level authorities (for more details, please see annexure no. A)

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Patients' stories

Section II



Victims of non-responsive private hospital My struggle to avail the publicly funded health insurance scheme In our country, only wealth can help bring health back Unending demands for money and unanswered questions till the end Desperate and futile struggle against COVID-19 and hospital Inflated charges and incomplete information No avail of publicly funded health insurance scheme, despite being eligible and despite massive efforts Did my mother really die of COVID-19? Laissez Faire attitude of hospital and disappointment with grievance redressal forum No COVID-19 scheme benefits, no beds in government hospitals COVID-19, chaos and fake reports We were cheated by a corporate hospital Debt and disease go hand in hand in my village Advance cash deposits first Advance deposits were compulsory despite cashless mediclaim Cash and connections for COVID-19 care Debt and disease go hand in hand in our country No schemes for critical patients Can only those who can afford to pay hospital packages get treatment? I was never COVID-19 positive but treated for COVID-19 COVID-19 care – unnecessary, expensive Mediclaim – License to loot patients The price of my father's hospital stay was our ancestral land

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1 Victims of non-responsive private hospital

Case synopsis

Manali Kuchekar's ordeal is emblematic of the experiences of thousands of people in Maharashtra who were forced to pay exorbitant advance deposits and dues for COVID-19 treatment in private hospitals, which despite being empanelled with MJPJAY, did little to nothing to facilitate these entitlements to scheme beneficiaries and flouted state directives on price capping for COVID-19 treatment. When her husband passed away, Manali also experienced patient's rights violations such as the hospital's refusal to hand over the body of the deceased till dues were paid, refusal to hand over a proper bill and medical records of the deceased.

“ Testimony

My husband, Suryakant Kuchekar (name changed to protect identity) was a 48-year-old teacher in a primary school in a village near Kolhapur. In the beginning of September 2020, all of us started to feel unwell with symptoms like fever and body ache. While we all recovered in a few days, Suryakant's fever persisted. He consulted a MBBS doctor in the vicinity for treatment and was taking medicines for a few days, but to no avail. On September 11th, early in the morning, his fever suddenly spiked. I immediately admitted him to the government COVID-19 Care Centre in their village, where he was put on oxygen and given intravenous fluids. Initially, he felt better after all this treatment.

Though he had given his sample for COVID-19 testing on the same day, he had still not received the test report even on the 13th of September. Late that night, he started to complain of breathlessness and cough. We decided to shift him to Kolhapur in the morning of the 14th where a HRCT scan confirmed that he had COVID-19 changes in his lungs. Desperate and worried, we took him from one hospital to another, but there were no beds available for admission. Finally late in the evening, we were able to admit him in a private multispecialty hospital on paying an advance deposit of Rs 1,50,000. With his oxygen saturation level sinking to 87%, Suryakant was immediately taken to the ICU and put on the ventilator. After some days, he was given non-invasive ventilation.

MJPJAY scheme empanelled hospital didn't inform patients about the scheme, thus denying scheme benefits to eligible beneficiaries

This particular hospital was empanelled with the government MJPJAY scheme for provision of COVID-19 care and was expected to provide free treatment to critical patients. However, when I along with other family members enquired about the scheme, the hospital did not provide us any information about the MJPJAY scheme nor did it make any effort to facilitate the process of entitlement. Instead, they insisted on an advance of Rs 1,50,000 on admission and collected an additional amount of Rs 2,40,000 from us at regular intervals during his hospitalization. We had no idea how to go about applying for this scheme in the midst of the chaos and tension.

Refusal to issue a proper bill, medical records and detention of dead body till dues were paid

Suryakant's condition continued to deteriorate till he passed away on the 8th of October, 2020 on the 25th day after his admission. After his death, **the hospital administrator verbally informed us that the total bill had come up to Rs 14,21,000 instead of providing the detailed bill in writing. We were also told that my husband's dead body would not be handed over to us until the complete dues were settled.**

Shocked at the stance of the hospital, I reached out to relatives and friends for help. We held multiple rounds of discussions and meetings with the hospital administration, trying to make them understand that we did not have the funds to settle the bill at that moment. Finally, after protracted negotiation and payment of Rs 2,00,000, the hospital released my husband's body after eleven hours in the evening at 6 pm. The hospital only issued a death certificate which stated that the cause of death was Acute Respiratory Failure in case of Bilateral Pneumonia with COVID-19 with Septicemic Shock. **It refused to hand over other documents like the patient's medical records, test reports, detailed death summary and the hospital bill, even when we requested them a number of times.** We ended up paying Rs 5,90,800 in total, in addition to paying for all the investigations and the medicines.

It is noteworthy that despite being empanelled with the government MJPJAY scheme for COVID-19 care, the hospital didn't provide this information to beneficiaries and refused to provide free treatment to MJPJAY scheme beneficiaries like Suryakant. The hospital also did not adhere to the price capping measures for private hospitals which the government had announced and flouted all regulations by charging exorbitant amounts for treatment.

No transparency in billing

On repeated follow up over the next three months, the hospital finally gave us my husband's medical records and a proper itemised bill for Rs 9,42,057. The bill breakdown was Rs 72,202 for lab tests, Rs 20,000 for X-rays, and Rs 5,64,155 for medicines. I pointed out that we were asked to pay Rs 14,21,000 on 8th October but were given a bill for an amount far less than that. The hospital was unable to explain the difference of Rs 4,80,000 between the quoted and printed bill.

A grim future after loss of the bread winner and loans to be paid back

When our savings were exhausted, I was forced to borrow money from our relatives to settle the hospital bill. Widowed with two small children, I not only have to fend for myself and my children, but also figure out a way to pay back the money that I owe to different family members. I feel that the government should have done much more to ensure effective implementation of MJPJAY and other schemes in private hospitals as family members are in no frame of mind to figure out the red tape and engage with indifferent hospital staff in the middle of a health crisis.

”

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2 My struggle to avail the publicly funded health insurance scheme (MJPJAY)

Case synopsis

The Maharashtra state government claimed that free treatment for around 996 procedures would be provided to all residents under the state MJPJAY insurance scheme, but many eligible beneficiaries faced an uphill struggle to avail of scheme benefits in reality. When Pramod's aged mother tested positive for COVID-19, her son managed to admit her in one of Pune's charitable trust hospitals, as government hospitals were fully occupied. He submitted all documents for free treatment under the MJPJAY scheme the very next day but was shocked to hear from the management that his claim was denied as his mother had tested negative for COVID-19 after her admission. Despite the fact that his mother was admitted on the basis of an ICMR approved COVID-19 positive test report and was being treated for COVID-19 in the COVID-19 Care Unit of the hospital, the management was adamant on its stance and asked Pramod to pay the hospital expenses of Rs 1,00,000 immediately. What transpired was a long saga of red tape and frustrating arguments with the management as Pramod pleaded his case with various government representatives. His perseverance paid off as his claim was finally approved by the hospital, but he still ended up paying Rs 20,000 to the hospital for the first two days of her treatment along with an additional Rs 70,000 for medicines.

“ Testimony

My mother and I live in Pune. My worst fear came true as she tested positive for COVID-19 on 18th July, 2020 during the second lockdown. She is 65 years old and suffers from Diabetes and Hypertension and her health has deteriorated rapidly just in two days. I wanted to admit her right away in a government hospital and went in person to all the four corporation hospitals but there were simply no beds available anywhere. I was at my wits ends. I was turned away like many others and asked to seek admission somewhere else.

“Make your own arrangements, there are no beds available”

With oxygen levels hovering between 70% to 80%, my friends said I had to take my mother to a hospital before her condition turned critical. In desperation, I finally took her to one of the city's largest charitable trust hospitals, where after a lot of pleading, they agreed to treat her temporarily in the casualty, while I looked for alternative arrangements. I dashed to the divisional corporation office for assistance. The Medical Officer there flatly informed me that all government hospitals were overwhelmed, with people even paying for their own oxygen there and I should make my own arrangements.

“Pay the advance deposit if you want to admit your mother”

Extremely worried, I returned to the Trust hospital, where after an entire day, with the help of some contacts, I was able to admit my mother in the COVID-19 isolation facility. I was right away asked to deposit an advance of Rs 25,000 at the time of her admission, but could manage to pay only Rs 10,000.

Red tape and denial by hospital management for MJPJAY eligibility on flimsy grounds amidst desperate hunt for medicines

The *Aarogya Mitra* (Staff for coordinating the MJPJAY entitlements) in the hospital assured me that I would be able to avail of free or subsidised COVID-19 treatment under the MJPJAY and/or *Sheheri Garib Yojana* (scheme for urban poor), which was a huge relief. When I submitted all necessary documentation the next day, I was told to update the ration card, for which I had to then rush to the ration card office.

The management then informed me that the COVID-19 test conducted on my mother after her admission was negative, and therefore her treatment costs would not be covered under any scheme, even though she was admitted on the basis of a positive ICMR approved test report. I was asked to immediately pay a deposit of Rs 1,00,000, as that was the cost incurred for her treatment till then.

I was completely confused with this information, because she was being treated as a COVID-19 patient and was even shifted to the COVID Critical Unit (CCU). I was told to get seven Remdesivir injections for her, which I had managed to procure with great difficulty, spending entire days going from pharmacy to pharmacy in the city.

Looking for explanations, I presented my mother's case to medical experts and even the head of the CCU in the hospital. I was told that even though my mother had tested negative, she was suffering from post COVID-19 sequelae and her treatment was based on her symptoms and condition and not on the basis of a test. I asked the doctors to convey their observations to the hospital management, because they were refusing to accept that my mother had COVID-19, based on the test results.

“A protracted battle for my health rights with an indifferent hospital management”

I was at loggerheads with the hospital management which refused to accept my explanations and kept on asking me to pay up. I was so frustrated with their stance that I threatened to share my experiences with the press, and even uploaded some videos on social media. I also submitted my case to the MJPJAY district co-ordinator and complained to other corporation officials and political leaders.

Based on advice from health rights activists, I asked the hospital management to give me an official statement rejecting my application for MJPJAY, which they refused to issue. My efforts finally paid off when my application was approved during a scrutiny of pending applications by a team of MJPJAY officials. This entire process had taken over ten very stressful days. I had to spend out of pocket for everything till then, but felt relieved that at least the hospital stay would be covered by the scheme. My mother was discharged on the 15th day and the hospital bill had come up to Rs 1,12,000. Again, to my shock, I was informed that I had to pay Rs 35,000!!!

“I conceded defeat and paid up”

It turned out that the management had approved my MJPJAY application from the 23rd July onwards and had billed me for the first two days. I again explained to the management that I had submitted all my documents within 12 hours of my mother's admission and it was not my fault that they had processed my application two days later. We kept on going back and forth over the next few days till I finally reluctantly gave in and paid the hospital Rs 20,000 because they just would not stop hounding me. I was aware of all the irregularities but I was exhausted from all the arguments over the past 18 days and did not feel equal to another protracted war of words.

The total hospital bill was Rs 1,12,000. **After MJPJAY subsidy - I ended up paying an additional Rs 20,000 to the hospital and Rs 60,000 to 70,000 for the medicines, out of which Rs 40,000 was for Remdesivir alone. So I paid around Rs 90,000 out of my own pocket. I used all my savings and borrowed the rest from my friends.** I am still paying these loans back.

“Hospital management are just intent on looting patients”

I saw that everyone from the security guards to the ICU doctors was working sincerely and doing their best for all patients in such a risky environment with exception of the hospital management who were absolutely ruthless, intent on extracting every rupee possible from all patients, indifferent to the plight of helpless patients.

“Why can't hospitals help patients to avail of the government schemes? In the end, they just remained on paper”

The whole experience of applying for the MJPJAY scheme was extremely stressful; I simply wanted the government benefits that were promised to citizens in the pandemic, it was not like I expected the hospital to pay for my mother's treatment. **If the government has offered such a scheme, all we expect is that this process should have been facilitated for eligible beneficiaries by all hospitals.** However, the on-ground implementation was extremely poor and the hospital management did not seem to care about the schemes, they were just interested in profiteering and billing patients as much as they could.

My bill for three days included PPE of Rs 12,000!! When I pointed out that the state health minister had said that PPE Kits should be provided free, the admin told us that they had not received any such Government Resolution to that effect and had to bill the patients for it.

I am aware that I have not suffered as much because I was aware of my rights and I was being advised and supported by health rights activists and doctor friends. Most importantly, my mother recovered from this crisis. **I ask myself, what would someone do - who had no access to a support system, to legal guidance, to contacts, to generous friends to lend money? I saw so many people weeping in front of the hospital management, pleading for help, begging for some time to be able to collect funds.**

The government should ensure that citizens can easily avail of such schemes and not be made to run around in circles. I persisted because I was aware of my rights, many would have just given up.

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3 In our country,
only wealth
can help bring
health back

Case synopsis

Sandesh (40 years) developed COVID-19 like symptoms in August 2020, but tested negative for it even though his chest X-rays and CT scan of the lungs confirmed COVID-19 changes. With government hospitals there insisting on a positive test, he was therefore admitted in the ICU of a government approved private COVID-19 Care Centre in a nearby village. Even when he was on the ventilator and struggling to breathe, Sandesh was worried about the cost of his treatment and if he would be able to afford it. Though he was charged at government capped rates, the hospital bill for his 22 day long stay in the hospital was around Rs 3,00,000 due to additional costs of PPE, investigations and medicines. He was not able to claim any MJPJAY entitlements since the hospital he was admitted in was not empanelled during his stay there. Like thousands of other patients, Sandesh settled his hospital bill in cash, using his savings and personal loans from relatives. Small villages in rural Maharashtra did not have audit facilities for people who were overcharged for COVID-19 treatment and people hesitated to complain about local hospitals, as they did not want to be in the bad books of the doctors there.

“ Testimony

I work in a cooperative society that gives microloans to farmers. We were working throughout the lockdown with all possible precautions but there was a slip-up in August 2020. There was a colleague in our office who had COVID-19 like symptoms, but did not disclose them to the management and continued to come to office. After he became really unwell, he did get tested and turned out positive. We were all concerned about possible exposure then after we found that he was positive.

A week after this incident, sometime in mid-August 2020 - I started to feel unwell and developed a mild cough and fever. After taking medicines and rest, it seemed like I recovered from both; we even had a five day *Ganpati Pooja* (festival) at home, but after

some days, I again developed high fever and a hacking cough. A doctor friend advised me to get tested and also get an X-ray. Though the test came negative, the X-ray did show typical signs of COVID-19 infection. I was also feeling worse and was struggling to breathe. My oxygen levels were steadily decreasing. I knew I had to be admitted. So, I went to a private hospital in a nearby village that had been approved as a COVID-19 Care Centre by the government. I also knew the doctor, so felt that I would be in safe hands there. When the doctor examined me, he said the same thing that even though my test was negative, I had all COVID-19 symptoms, the infection seemed to have reached my lungs. He advised me to get admitted immediately as time was of the essence. It was the 29th of August, 2020. I was admitted right away into the ICU.

Constant worry about the cost of treatment even when critical

The next day, I was sent to Pune in an ambulance to a diagnostic centre for a CT scan which confirmed the doctor's diagnosis. The COVID-19 infection had spread to my lungs. I was constantly worried about the money; the CT scan had costed me Rs 8000 and the ambulance Rs 2500. I hoped that since the hospital was a government approved COVID centre, the stay would not cost me that much. As my condition was not really good in the first week, I was put on the ventilator for three days and stayed in the ICU for 12 days. I received expensive Remdesivir injections. I was being given oxygen daily. When my condition stabilised, I was shifted to the general ward where I stayed for another ten days. Though I was able to talk, I was extremely weak, so much so I did not have the strength to get up from the bed. But even in that state, I was constantly fretting about how much the stay in the hospital was costing me and how would I be able to arrange for the funds.

I was satisfied with the treatment I got in the hospital, as I was personally acquainted with the doctor. They did take good care of me. **But it was extremely crowded with almost 60 patients admitted for treatment. Beds were hardly kept three feet from each other. Hygiene and sanitization of the hospital premises was infrequent.** Once in the general ward, we could talk to our relatives and family on the phone, but nobody was allowed to come inside the hospital premises. I was worried about my son who had also tested positive and was in home quarantine.

MJPJAY wasn't applicable, settled the entire bill in cash

I was finally discharged after 22 days on the 18th of September. The bill for the hospital stay had come up to Rs 3,00,000, even though I was charged at government stipulated rates. The PPE bill alone had come up to Rs 44,000 at Rs 2200 per day! The medicines from the hospital pharmacy costed another Rs 1,27,000 on which they gave me a 5% discount. Lab investigations costed another Rs 25,000. When I enquired about the MJPJAY scheme, I was informed that it was not approved for this particular hospital during the time of my stay. I found out that the hospital got the approval for MJPJAY a week later after my discharge. But that was of no use to me at all. I had to pay the whole amount in cash. I used all my savings and also borrowed the rest from my in-laws to settle the bill.

No auditors in rural areas and no options to raise a complaint

There was no auditor there to audit the bills in our small town. I was able to somehow arrange for the money, but what are the poor to do in a time like this? **If government hospitals are all full or reject admission on technical grounds because the COVID-19 test is negative, there is no option for people like us in rural areas, but to go to private hospitals and pay what they ask for.**

We cannot even afford to argue or file a complaint against the hospital or doctor, because we might need their services again in the future. How can we be in their bad books?

Expectation of quality affordable treatment

If the government approved private hospitals for COVID-19 treatment, they should also ensure that subsidised treatment is available to everyone there at the same time. So many of us who were admitted there thought that the hospital stay would be free of cost or subsidised because it was government recognised. We were not prepared for these bills at all and have had no option but to incur debt to settle these bills. But do we even have a choice in the matter?

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4 Unending demands for money and unanswered questions till the end



Case synopsis

In October 2020, Altaf Javed, a 30 year old shop owner from a small village near Kolhapur district fell ill with COVID-19 like symptoms and was admitted in a local hospital. Dissatisfied with the quality of care and his worsening condition, his family shifted him to another private hospital in Kolhapur, where they were asked upfront about their ability to afford the treatment. Desperate to give him the best treatment possible, Altaf's family borrowed money from relatives to be able to admit him in a hospital with ICU facilities and spent more than Rs 1,50,000 in two days. But Altaf's death on the third day left them shattered. They have spent the past three months; trying to pay back all the money they borrowed by selling household assets. Embittered by the attitude of hospitals and their money making priorities, Liyakat Javed (a brother of the patient) is one of the many people who were forced into debt due to out of pocket catastrophic medical expenses during the lockdown.

“ Testimony

A part of our joint family, my younger brother Altaf had a small footwear shop and I have a small store that repairs watches. On 10th October 2020, I took my brother to a local hospital in our village as he had been feeling unwell for the past few days and had started to cough.

COVID-19 was just another opportunity for private hospitals to make money

We were taken aback when the doctor said his condition was serious and he had to be admitted immediately as he seemed to have COVID-19. Confused and anxious, we agreed immediately and he was admitted in the general ward. Even before his admission, we were given a long list of medicines, which came up to almost Rs 30,000!! He was tested for COVID-19, many other blood tests, X-rays and given Oxygen.

The COVID-19 test came back negative two days later but he was already being treated

for COVID-19. In the three days that my brother was there, we saw that they were labelling all patients as COVID-19 patients. The staff did not pay any attention to the patients. My brother had to call the nurse himself to stop the IV drip when it got over. The only time that the doctors or the staff talked to us and other relatives was to ask us to pay more money. I felt it was just money first, patient's life later. We paid Rs 40,000 to the hospital, including the cost of the drugs.

The struggle to find a good hospital that cared about patients, not money

On the third day, my brother pleaded with us to take him to another hospital. His condition had worsened and he said the oxygen being given was insufficient, he was feeling out of breath. We agreed and asked for his discharge, since he was just being given a lot of medicines. We then took him to a small hospital that was run by a *madrasa* in the neighbouring village, thinking that he would be cared for there, without unnecessary medication. But to our great dismay, the hospital had no facilities, not even oxygen and so after a day and a half, we decided to shift him to Kolhapur, to a good hospital with a proper ICU. We then took Altaf to a medium sized private multispecialty hospital in Kolhapur. The distance from the village to the hospital took just ten minutes, for which the ambulance charged us Rs 3000.

“Can you afford treatment here? You have to pay a deposit first”

When we reached the hospital, we told them Altaf's condition was serious and he needed immediate attention. **But we were told upfront that if we didn't have the money, we should not even bother coming to the hospital, saying their minimum package costed a Rs 1,00,000 for three days. The management made it clear that we had to pay an advance deposit of Rs 50,000 for ICU admission for Altaf. Right away, they gave us a list of medicines that came up to Rs 56,000 in the hospital medical store.** Having no choice, we agreed to all their terms. We just wanted to get Altaf admitted as soon as possible.

“We called up everyone we knew to borrow the money for Altaf's treatment”

We literally begged all our relatives, friends and contacts to lend us the money and somehow gathered the amount to pay the hospital deposit. Altaf lay on a stretcher in the hospital foyer for some four to five hours, while we were running around to arrange for the money. He was talking to everyone though he was feeling breathless.

He was finally admitted to the ICU at 7 pm in the evening. The nurses took his blood and urine samples and he had an X-ray. That was the last time we saw him. We were not allowed to enter the hospital premises and had to wait outside the gate the whole night. We prayed that he would recover.

Just endless demands for money and no idea what was happening with our patient

The next day in the morning, we were again asked to pay Rs 50,000. It was at this point that my father said that we would not be able to afford this treatment and it would be

better to take Altaf home. When we communicated our inability to pay the bill to the hospital and asked them for a discharge, they said we still had to pay the outstanding dues, which were Rs 20,000, otherwise they would not discharge Altaf! Again, we had to run around trying to arrange for this money; like a Godsend, some relatives came to our aid in this crisis and vouched for his treatment costs. With their help, we paid the hospital Rs 20,000 and an additional Rs 15,000 for his medicines. We had no contact at all with Altaf, we just knew he was in the ICU and on the ventilator. No doctor talked to us at this time, except the staff which approached us only to ask for more money. We had no idea what was happening, but put all our trust in God and the doctors.

On the morning of 16th October, we received a call from the hospital, informing us that Altaf had passed away. We were given his body around 3 pm in the afternoon that day; it was all wrapped up in plastic.

“The hospital didn't give us his records even after his death”

Ironically, we never got a confirmed COVID-19 report – Altaf passed away before we got the test results. We were never given any of his hospital records and files. The hospital bill had come to Rs 1,68,000 for two days.

Over the next three months, we had to pay back our debts by selling all of Altaf's footwear stock at a loss for some Rs 1,75,000.

We didn't think of asking the hospital for the government insurance scheme benefits. **We found out about the scheme for subsidised treatment in private hospitals later, but by that time, it was too late and hospital never informed us about it.** Altaf was already dead. We were so dejected and crushed by his sudden demise; no one was in the frame of mind to follow up with the hospital. And that's what I wanted to share. Our struggle to give Altaf good treatment and the way we were treated in all hospitals. It really felt like hospitals were just focused on making money in this lockdown and we could not ask any questions because it was COVID-19.

Note: the family does not have any documents or files from the hospital, the mother threw the records away in a bout of grief and anger.

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5 Desperate and futile struggle against COVID-19 and hospital



Case synopsis

Prakash, a father of three, had developed COVID-19 like symptoms in July 2020 and was quarantined for three days in the government COVID-19 Care Centre in his village till his test report came back positive. As his condition had deteriorated there, his family moved him to a private multispecialty hospital in the nearest city where he was admitted immediately in the ICU on paying an advance deposit of Rs 50,000. The family was not allowed to enter hospital premises and lost all contact with Prakash, as had become the norm during the pandemic. Prakash's brother procured Remdesivir and even plasma with great difficulty, but his condition did not stabilise. With many members of the family having tested positive, Prakash's aged father passed away in their village due to COVID-19 related complications on 11th of August and Prakash too passed away a day after. The hospital refused to release his body till the pending dues of Rs 1,15,000 were settled. The family had to borrow money from their friends and relatives to pay back what was possible. The management refused to give them Prakash's medical records and a proper itemised bill, till they settled the pending amount. Hospital also gave them no information about eligibility for publicly funded health insurance scheme (MJPJAY) scheme despite they being empanelled on the scheme nor did it comply with the government capped rates for private hospitals.

“ Testimony

We are a joint family, living in a small village in Kolhapur district. My elder brother, Prakash (38 years), was married and had three children. He was a labour contractor for the MIDC (Maharashtra Industrial Development Corporation). He was in good health, even though he had diabetes and hypertension.

Around July 22nd 2020, Prakash started to feel unwell. He complained of body ache, cold and developed a dry cough. We took him to a local doctor who gave him medicines and

advised him to rest at home. When his health did not improve after two days, the doctor ordered an X-ray and blood tests. The X-ray findings were suggestive of pneumonia in the lungs so he asked Prakash to be admitted in a hospital, but Prakash did not feel comfortable with the idea. Instead, he requested the doctor to treat him on an outpatient basis. He went to the hospital twice a day to get antibiotics for three days. Initially he felt better, however after three days, his condition worsened and he developed high fever.

On July 27th, we took him to a specialist doctor, who asked him to get tested for COVID-19 immediately. We went to the government COVID Centre for the test, but were told that my brother would have to be admitted in institutional quarantine for two days till he got the results. The doctor then advised us to get an HRCT (High Resolution Computed Tomography) scan done urgently to assess his condition. We drove to Kolhapur the same evening and got his HRCT scan done at a diagnostic centre. The results were worrying. The doctor told us his score was very low (17/40) and he should get admitted and start treatment as soon as possible.

On July 30th, Prakash went for his COVID-19 test at the COVID-19 Care Centre in Kagal and stayed there in the quarantine centre till his test was confirmed as positive on the 2nd of August. We do not know what treatment he got there, but his health had deteriorated over the last four days; he complained of breathlessness. We shifted him from the government COVID-19 Care Centre to a private multispecialty hospital in Kolhapur the same night at 11 pm. We had to deposit Rs 50,000 as advance payment to the hospital prior to his admission.

No communication about brother's condition, only demands for more money

Prakash was taken immediately into the ICU and put on the ventilator. Over the next three days, we were not even allowed to enter the hospital. Along with relatives of other patients, we all waited outside the hospital gate. There was no way to contact Prakash directly. We were told that the doctor would call us twice a day to update us about our patient's condition. The nurse used to call us to the watchman's cabin every evening, ask us to pay more money, which she used to note on a card.

We did everything the hospital asked us to - procured Remdesivir and even plasma

On 3rd August, we were informed that there was no Remdesivir in the hospital pharmacy and were asked to buy it from outside. With great difficulty, we managed to procure three doses the very next day. On 5th August, they said his condition was not improving and asked us to get Plasma, if possible. We managed to get the plasma the next day. Prakash was given the plasma on 7th August. Thankfully, that evening, the doctor informed us that his condition had stabilised. This was a big relief to us, as by that time, our whole family (9 out of 13) had tested positive. We were all forced to isolate at home and Prakash's friend was now at the hospital, doing everything that was needed. On the morning of the 9th and 10th August, Prakash's condition was reported as fluctuating between stable and critical. All we could do was pray for him to recover.

We were beset by crises on all fronts

In the meantime, my 65 year old father had been admitted to the government COVID Centre in our *taluka* place as his condition had worsened as well. On the 11th August, we

received a call at 5 am in the morning from the Centre, informing us that our father had passed away due to COVID-19 related complications. While we were organizing the last rites for my father in our village, we received a call from the hospital in Kolhapur on the morning of the 12th, informing us that Prakash had passed away as well. Both the elders passed away within 24 hours of each other; it was a shock to the whole family.

Hefty bill, body held back to demand payment

Some of us went to Kolhapur with a rented ambulance to collect Prakash's body. We had to settle the hospital dues before his body was handed over. On the phone, the staff had said the pending dues were Rs 85,000 but when we reached the hospital, we were given a bill of Rs 1,15,000. The total hospital bill had come up to Rs 2,95,000. Apart from that, the bill for the hospital pharmacy was Rs 89,000. We negotiated with the hospital, paid Rs 1,00,000 in cash and brought Prakash to our village where we cremated him and my father together. We paid the bill in cash, borrowing all the money from relatives and friends.

Long protracted arguments with hospital to access his medical records for insurance purposes

It was such a stressful and chaotic time; nobody helped us because we were all positive people simply stayed away. We were not given a proper itemised bill or Prakash's medical records from the hospital even after multiple requests. We explained that we needed the record and a formal bill to claim insurance, but the hospital management asked us to pay the balance of Rs 45,000 either by cash or RTGS. **When we persisted with our demands, they kept on making excuses for days on end, till we ran out of patience and created a scene at the hospital, threatening that we would bring the media there. The next day, the hospital finally handed over photocopied case papers and the bill!**

No information about any schemes, lack of clarity regarding his condition

The hospital did not inform us about any government scheme nor was there any communication about the fact that treatment rates for COVID-19 in private hospitals were capped. We do not want to complain that we were looted or overcharged. We did not care for any scheme at that moment. We just wanted our brother to get well. We were somehow able to gather the money to pay for his treatment. But we saw many other people turned away because they did not have enough money.

We did not follow up with the hospital even after we found out that the hospital had charged us more; there simply wasn't any time as my mother had a heart attack due to the shock of her husband and son both passing away and had to be admitted for 15 days. We were just trying to cope with what had happened.

We feel the hospital authorities and the doctor did not bother to communicate with us at all. They didn't give us any idea of what was actually going on. We wondered if they were concealing information from us about my brother's real condition, just to prolong his stay in the hospital. At the end, what mattered was his demise, that he could not make it despite all our efforts.

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6 Inflated charges and incomplete information

Case synopsis

When 72-year-old Sumantai had to be admitted to the hospital for apparent heart trouble, her son was asked to pay an advance deposit by the only private hospital that had available beds. The family did not receive the reports of the COVID-19 test she gave on admission despite repeated requests. However, she was declared COVID-19 positive three days later and given Inj. Remdesivir. Despite all efforts, Suman tai's condition deteriorated and she passed away. Her family felt the doctors did not manage her sugar levels which had spiked, causing the complications that led to her death. The hospital did not hand over the patient's medical records and reports after her demise and did not even give a proper bill. Many charges included in the bill appeared to be inflated, including a two km ambulance ride to the crematorium which was billed at Rs 16,000. The family is still unsure if her death was really due to COVID-19, since the hospital did not share any positive test reports with them.

“ Testimony

Insistence on advance payment before admission

There was only one big private multispecialty hospital with available beds at that time. When we approached them, they were initially unwilling to admit her. They asked me to pay an advance deposit of Rs 80,000. I had only taken Rs 40,000 in cash with me. Only after I pleaded with them to accept Rs 40,000 and assured them that I would pay the balance the next day, did they consent to admit her. I paid the balance as promised the next day.

COVID-19 report not shown

On admission, my mother had to go for a CT scan. (every patient who was admitted there had to undergo a CT scan) The doctor insisted that the CT scan should be done in the

diagnostic lab attached to the hospital. We paid Rs 8500 for the CT scan. Then they did a RTPCR COVID test in their pathology lab for which they charged me Rs 3000, but gave me no bill for it. I asked for the test result report repeatedly thereafter but they replied that the sample was being sent to Nagpur so the result would take time. Every time I asked, they would come up with one excuse or the other. I did not get the test result report till the end.

Absence of COVID-19 segregated wards

My mother was put on oxygen from 13th August onwards. For the first two days, she felt better, she was able to talk and even have her food by herself. She was being treated in the non-COVID ward. However, suspect COVID-19 patients whose test reports were pending and non COVID-19 patients were being treated in the same ward. The doctors who came for their rounds didn't wear any masks, gloves or PPE Kits. One of the patient's relatives had complained to the administration that there was no quarantining of COVID-19 suspect patients. The administration had called the police to deal with the complainant. After that, we all kept quiet despite our misgivings.

My mother has to give blood and urine samples every day. When we enquired why the tests were necessary, we were told they were to screen for COVID-19 related complications. On the third day, I was told that my mother had COVID-19 and she needed to be given Remdesivir injections. I was told to procure six doses of this injection, which costed Rs 6000 per dose. The injections were not available anywhere in Yavatmal, so I ordered them from Akola. I also got a few doses from a friend whose relative had passed away in the night.

They started to give her Remdesivir on the 17th of August. The doses were supposed to be given every six hours. But after the fourth dose, my mother's condition took a turn for the worse. When I went to see her on the evening of the 18th, she was on oxygen, breathless, unable to even talk a few words. In the night, the doctor called me into his cabin and told me that my mother's condition was critical and he could not vouch for her recovery. I could shift her to Nagpur if I wanted to. But it was too late...my mother breathed her last later that night.

My mother was diabetic as well, but somehow they did not treat her for her high blood sugar levels in this hospital. Her sugar level had shot upto 560. She developed complications because of the high sugar levels which led to her death. We had no idea what she was being treated with. She had become so weak that she was unable to change her sari. The hospital charged Rs 1500 for providing her staff assistance to change clothes.

No medical record/proper bills/death certificate given

The hospital didn't even let me touch or look through her medical file. They did not give a death certificate or even a proper bill. All they gave me was a stamped piece of paper with the bill amount written on it. I received no explanations for any of my questions regarding the treatment she received.

Rs 16,000 for a two km ambulance ride to nearby cremation ground!

The cremation ground was just two km away from the hospital. The hospital charged Rs 16,000 to transport the body to the cremation ground in their ambulance. The ambulance driver just gave me a form to sign when she was taken out of the ambulance. I

was so overwhelmed by grief and shock at her sudden demise, I didn't realise that they were looting me even after my mother had passed away. How can a two km ambulance ride cost Rs 16,000?

I paid Rs 1,48,000 to the hospital, excluding the extra amount I paid for her medicines. There was no mention of any government MJPJAY scheme or no information given to patients about scheme entitlements and eligibility. Everyone was looted there.

Negligent attitude and poor treatment

I feel that the doctors there failed to treat my mother properly for blood sugar and heart issues. Her sugar levels were high till the last day, which exacerbated her condition and contributed to her death. There was no security or segregation of COVID-19 suspect and COVID-19 patients in the hospital. The staff too was irresponsible in its conduct and didn't wear PPE. That is why my mother was infected with COVID-19. Since I never got a positive test result from the hospital, I am still unsure if my mother really had COVID-19 or not, even though the doctor said her death was due to COVID-19. I still have not received a death certificate from the hospital.

Patients demand

My relatives and friends lent me money to help me pay the hospital bill but what are poor people to do, if their loved ones fall ill? Should they just let their patient die? These private hospitals need to be a taught a lesson. It is because of these experiences where we let such hospitals extort money from us even as our patient is slipping away that frustrated people lose their temper and end up smashing hospitals.

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7 Health insurance coverage denied to eligible patient despite efforts

Case synopsis

Neelavati Jadhav, a waste picker from Pune had to be admitted for an emergency operation in a teaching hospital in Pune during the lockdown. She also tested COVID-19 positive prior to the operation. Her family experienced great difficulty in availing subsidised treatment under MJPJAY, *Shaheri Garib Yojana* (scheme for urban Poor) and the charitable trust hospital schemes despite following up with officials with all necessary documents. Despite being eligible for the schemes, they ended up paying the hospital bill in its entirety in cash, incurring a huge debt in the process.

“ Testimony

I am a waste picker and live in Pune with my family of six. I work alongside my 65 year old mother as a waste picker. We worked throughout the lockdown, because we were essential workers. There was no break in work for us.

One day in July 2020, my mother started to feel uneasy and complained of acute pain in her lower abdomen after breakfast. The doctor in the nursing home nearby advised urgent ultrasonography. We took her to another centre to do the ultrasonography, where the doctor told us that there was some sort of a growth/twist in her stomach which had to be removed immediately. She required urgent admission and surgery. At the nursing home, we were told no operations were being conducted due to COVID-19. We took her to another private hospital, where they said my mother needed an MRI Scan. We had no money for such an expensive test.

Distant and indifferent care at corporation hospital

We decided to take her to a Corporation Hospital where we were shocked with the treatment we received. PPE clad doctors talked to us from a distance of some 16-17 feet behind a barricade. They did not even examine my mother, but just read her sonography report and said she could not be admitted there for surgery

and referred us to the District General Hospital. My mother flatly refused to go there. She was terrified of that hospital.

Another set of issues at large private hospital

We then decided to go to a large hospital associated with a private medical college. In the middle of the lockdown, even getting an auto *rickshaw* was a herculean challenge.

When we finally reached the hospital, we were relieved when my mother was immediately examined taken in the casualty. The doctor told us that she needed an emergency operation and gave us an initial estimate of Rs 35,000. We didn't know where we could raise that amount at such short notice. But a corporator we knew intervened and contacted the hospital to ask them to admit my mother without the deposit. When my mother was finally admitted, we were extremely thankful. There was still some humanity left in the world!

We were told that she was being treated as a suspect COVID-19 patient till her report results came in. The doctor told us that they would operate on her immediately if the condition became critical. The next day, she was given absolutely nothing to eat and drink in preparation for the operation.

On Monday, plans changed as her COVID-19 test came positive and she was immediately shifted to the COVID-19 ward and thereafter, we lost complete contact with her. We were not allowed to see her or talk to her. I was so distressed; she had not had a bite to eat or drink since one day and I could not help her. We pleaded with the staff to give her something to eat.

“Nobody was updating us about what was happening”

We were then informed that she would be operated the next day (Tuesday). On Tuesday morning, we were told that the operation was postponed since the operation theatre had been booked for another emergency case. We were also informed that the operation cost would now cost Rs 80,000 since my mother was COVID-19 positive!

We could only pay Rs 15,000 till then, but I pleaded with the doctors to not delay the operation. Nobody was updating us about what was happening, we felt completely lost and helpless.

On Wednesday morning, we were suddenly informed that my mother was to be operated. Completely unprepared, we begged the security and reception staff to let us talk with our mother before the operation, but they were rude, evasive and did not allow us to do so. Finally a doctor permitted us to see our mother before she was taken into the operation theatre. When it was over, we were told that the surgeon had performed a different procedure on her than the one planned initially, based on her condition.

Harrowing experience for relatives of COVID-19 patients

For the next 12 days, my wife and I took turns to stand outside the gates of the hospital the whole day. We were not allowed to come inside or use hospital facilities like the toilet or canteen as we were relatives of a COVID-19 patient even though we were paying for her treatment there. There were no shops open outside because it was the lockdown, even getting drinking water was a problem. We were treated like untouchables by the *chaiwallah* (Tea Seller), who used to keep teacups far away on the ground. It was a truly

harrowing time, to stand there all day watching ambulances drive in and dead bodies coming out.

“Not allowed to avail of MJPJAY Scheme despite several efforts”

In the meantime, we had submitted an application for the *Mahatma Jyotiba Phule Jan Arogya Yojana* (MJPJAY) Scheme. We were informed that the scheme did not cover the operation my mother had undergone. A social worker from organisation where I work, came to the hospital four days in a row to help us with the application, but to no avail. She also filed a complaint online but we were informed that even the other schemes like *Sheheri Garib Yojana*, *Rajiv Gandhi Yojana* did not cover this operation. When we tried to apply for the National Health Insurance– *Pradhan Mantri Jan Arogya Yojana* (PMJAY) scheme, we were told we were not eligible for it, because we had filed a complaint for approval under the MJPJAY scheme. We finally had to give up and accept that there was no way to avail of subsidised treatment and we were on our own.

Burden of debts

The total bill for my mother's operation had come up to Rs 1,13,000 which the hospital reduced to Rs 1,07,000 after our request for a discount, considering our circumstances. We had already paid some Rs 15,000 to Rs 16,000 just for all her medicines.

We borrowed Rs 25,000 from all our relatives, the people in the society where I was employed organised a collection and gave us Rs 32,500. I took a personal loan of Rs 60,000 from a private money lender at 10% monthly interest. I pay an instalment of Rs 6000 every month to him now. In the 15 days where I had to be by my mother's side at the hospital, I lost my job which paid me Rs 16,000 a month. We do not know how to manage our daily expenses and pay back all the debt we have incurred due to this operation.

At the time of patient's discharge, my mother was finally discharged on the 21st of July. We were waiting for her outside the main gate and they just dropped her off at another exit, she had to walk all by herself for some 300 feet. Couldn't they have provided her with a stretcher or allowed us to pick her up, considering how weak she was after her operation?

Reports were denied at the time of discharge

We were not given my mother's file or test results at the time of her discharge. It was only after repeated follow up and submission of written applications that we were given her some of her reports.

Our only expectation is that if the government announces all these schemes, big hospitals should help common people like us to avail of their benefits. There should be a special assistance desk to help poor people like us who are completely helpless in these situations. The hospital staff should communicate with the family regularly and update them about what is happening with their patients, especially in the current circumstances. I would not wish an experience like the one I underwent on my worst enemy.

Testimony by social worker, who helped the family

Cumbersome process to avail scheme

In the beginning, we were just trying for the MJPJAY scheme, but when it became clear

that the scheme was not going to be applicable, we began to try for other schemes like *Sheheri Garib* and Trust hospital Scheme, which offer subsidised treatment. This was right at the end, when it became clear that they would not be eligible for the MJPJAY scheme.

For the *Sheheri Garib Yojana* (scheme for Urban Poor), people are supposed to go to the corporation offices to submit their documents based on which they get a card that declares their eligibility for the scheme. On submitting this card to the hospital, the hospital gives the patient a duly adjusted quotation (subsidised) for the treatment/procedure. But due to the pandemic and lockdown, the corporation offices were closed and the hospitals were supposed to collect the soft copies of all the documentation, and enrol the patients in the scheme.

But the Hospital did not enrol the family in any of the schemes, even though they had submitted all the required documents and were eligible for subsidised treatment. At the end, we reached out to the supervisor (who follows up with hospitals regarding such cases) who said he would talk to the hospital authorities and try to process the case through one of these schemes in the next couple of days. However, the family was really fed up by this time with all the red tape and lack of cooperation from the hospital management and the social workers; they managed to pay the hospital bill the next morning by borrowing money from friends and relatives without informing us.

After the discharge, we continued to follow up with the district coordinator of the MJPJAY scheme regarding this case and even filed a complaint with the MJPJAY Maharashtra Committee. We then followed up with this committee for the next 1.5 months, till their grievance redressal officer told us that the hospital had replied by saying that the procedure which was conducted on the patient was not covered by the MJPJAY Scheme. It was very difficult to contact officials (MJPJAY District Coordinator, Charity Commissioner) on phone and follow up with them due to the restrictions of the lockdown but our efforts were all in vain.

It is really sad and frustrating that despite three schemes for subsidised treatment being available, the deserving wastepicker family was not able to avail any benefits. Our experience is that the hospital social workers in many major hospitals in Pune are not proactively assisting people with scheme eligibility assessment and only collect documents from patients after a go-ahead from the billing in-charge. ”

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8 Did my mother really die of COVID-19?

Case synopsis

Siddhesh had to admit his aged mother in the government hospital in Yavatmal for a bout of severe asthma. Despite having submitted her sample for a COVID-19 test on admission, the family never received any test result, not even a SMS. Since family members were not allowed to enter hospital premises, they were clueless about her treatment. As her condition worsened over the next couple of days, Siddhesh moved her to a private hospital, feeling that she was not being treated properly in the government hospital. After the mandatory advance deposit, she was treated as a COVID-19 patient with expensive drugs and injections, even though there was no record of a COVID-19 test conducted in her medical records. Siddhesh's mother passed away on the third day after her condition suddenly deteriorated. Instead of providing the family with a proper itemised medical bill and complete medical records, the hospital issued a handwritten bill with arbitrarily inflated charges.

“ Testimony

I had to take my 67 year old mother to the government hospital in Yavatmal on 11th September, 2020. My mother was asthmatic; she had to be hospitalised every year for a couple of days whenever her asthma worsened. During the lockdown, she had a bout of severe asthma which turned into pneumonia. As she was feeling breathless and had a lot of cough, we took her to a multispecialty hospital where the doctor examined her and took an X-ray. He informed us that they were not allowed to treat/admit patients for pneumonia during the pandemic and referred us to the government hospital. This was the reason we had ended up at the government hospital.

Uncertainty about COVID-19 test results

On admission, my mother took a COVID-19 test. On the 12th September, I got a SMS saying the test sample was submitted. I did not receive any other message after that. If

we had received a message that the sample was submitted, then we should also have gotten a SMS confirming her test results, but right till the end, it was unclear if my mother was COVID-19 positive or negative.

Forbidden entry into the ward, we were clueless about her treatment in the government hospital

For the initial two-three days, my mother was only given some tablets, which caused her some difficulty while urinating. She was on oxygen but it is difficult to say what treatment she received because relatives were not allowed to be at the patient's bedside. Even when my mother's condition worsened, they did not permit us to stay with her, not even for a little while. We could only enter the premises between 11 - 12 am to hand over the lunchbox to the staff. We had no idea what was going on with her. But, with her worsening condition, it was obvious that she wasn't being treated properly. So far, they had only seen her X-rays but had not conducted any other tests. We were very disturbed, there was a feeling that my mother was left alone and neglected in the government hospital.

Encountered with similar issues at another private hospitals

So after confirming that there was a bed available for her in a private hospital, we took the decision to shift my mother to the hospital. We were asked to pay Rs 1,00,000 as advance on admission, but I negotiate and paid Rs 50,000. I wanted to be sure that there was a bed reserved for her before I applied for the required NOC (No Objection Certificate) for her discharge from the civil surgeon and district health officer. After we got the NOC, she was admitted in the private hospital at 8 pm on the 14th of September.

Initially admitted in a common room with four beds, the doctor who came later declared her condition was serious and shifted her immediately to the ICU. She was given injections for pneumonia and the very next day in the evening of 15th September, my mother was also given an injection called SEBSIVAC (Tocilizumab) that costed Rs 40,545.

No access to any reports of medical investigations

We do not know if she was tested for COVID-19 in the hospital or not, but we were charged for many blood tests and urine tests, though we never saw the reports. There is no report of her COVID-19 positive status in the file even today. Even her CT scan reports are not in the file we were given. Though she was being treated as a COVID-19 patient, we were perplexed as to if these were asthma complications or COVID-19 pneumonia.

Doctors refused to give any explanations about treatment, even when we kept asking

Actually, my mother was quite well before she received the injections. She even refused the urinary catheter, saying she was able to go to the bathroom by herself. But her condition took a turn for the worse after she got the injections. There was an injection that costed Rs 6000 which the doctor had asked for, but since it was not available, he said she would have to be given the more expensive injection, which costed some Rs 9000.

We had no idea what were these injections for, neither did the doctors give us any explanations when we asked them repeatedly. But I got those two injections from

the hospital pharmacy; we were willing to try anything possible to give my mother a fighting chance. We had to buy all the medical supplies, even the hand gloves. It was so crowded in the medical store; it used to take us hours to buy all the medical supplies.

Sudden deterioration in health

On the second day, i.e., 16th September, the doctor again said that her condition was critical. After receiving the injections, her pulse rate dropped from 78 to 60-62. There were no sleeping arrangements at the hospital, so I left my mother around midnight and went to a friend's place to sleep. Hardly an hour later, I received a call from the hospital saying that my mother's condition was serious. I immediately rushed to the hospital. I saw my mother seated on her bed in the ICU. Another patient had just passed away in front of her. My mother was shaken with what she had just seen but was stable and conscious. She could understand what was happening around her. I waited with her for some 40 minutes, till everything came back to normal, and then left for my friend's place again. Before I left, the hospital staff made me sign a letter stating that they were not to be held responsible for any consequences as the patient's condition was critical. I reached home at 2.30 in night. At 7 am, I received a call from the hospital, informing me that my mother had passed away. What had happened in these five hours?

Incomplete file with crucial reports missing

My mother's death certificate states that she was COVID-19 positive. But I do not have any such positive test report or document in the file that the hospital gave me. Even when she was in the hospital, there was no such report because I was going through the file daily. How is it then that the doctors declared it to be a COVID-19 death is a question that still haunts me today.

Inflated billing, kachcha bill (handwritten bill) was given

The hospital gave us a 'kachcha bill' on its letterhead instead of a proper itemised bill, where they just listed all the medicines and their costs which came to Rs 73,800. They had even charged Rs 250 for diaper changes, which I know my mother had not needed.

There was no facility of MJPJAY scheme or counter in the hospital. I had heard that if you had submitted hospital expenses of a COVID-19 related death in the Collectors office, it would be reimbursed, but I was in no frame of mind to do that. I settled the entire bill in cash.

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9 Exorbitant yet negligent hospital and disappointment with grievance redressal forum

Case synopsis

When Vishal Karnik's elderly aunt tested positive for COVID-19 in July 2020, she was admitted to a corporation approved Private COVID-19 Care Centre. As she was asymptomatic, her recovery was fairly uneventful. However, when he was given a bill of Rs 2,80,000 for two weeks, he was taken aback with the inflated charges, some for services that she hadn't even needed or availed of. After determining that this was a case of clear overcharging, Vishal sought redress over the next two months in a variety of grievance redressal forums instituted by the city corporation for complaints related to COVID-19 treatment bills and continues to wait even now for a final resolution from the Technical Committee.

Even as the bill was negotiated to Rs 1,47,000, Vishal highlighted several other irregularities and the refusal of the hospital administration to give him clear explanations and all documentation related to his patient, as per his Patients' Rights.

Of more portent was the dereliction in care by the COVID-19 Care Centre during her transfer after her discharge. As a consequence of being drenched in rain, she fell grievously ill and took a long time to recover from the incident.

“ Testimony

My aunt is 85 years old and needs help with daily living activities, so she stays in a nursing home that provides round the clock assistance to elderly people. Unfortunately, one of the nursing staff tested positive for COVID-19 in July, and so the management tested all the inmates for COVID-19. My aunt tested positive for COVID-19 as well, which caused us a lot of concern. Even though she had no symptoms and was stable, we consulted with our doctor, who advised admitting her to a COVID-19 Care Centre, in view of her advanced age.

Accordingly, we made enquiries and chose a private hospital which was designated as a COVID-19 Care Facility by the city corporation. The administrator of the hospital informed us that it was approved by the corporation as an isolation facility and for treatment of asymptomatic patients. It provided oxygen to patients, but did not have other critical ICU facilities like ventilator equipped beds. I was OK with this situation as I had ensured that my aunt would immediately be transferred to another hospital with ICU facilities, should the need arise. On enquiry about the estimated costs, we were told that charges would be Rs 7000 per day, all inclusive. The costs quoted seemed steep to me even then, considering that the patient was completely asymptomatic, but this was during the middle of the lockdown and we were more concerned about sorting out her admission as soon as possible.

She was admitted to the hospital sometime in the last week of July and her hospitalization over the next two weeks passed uneventfully, barring some minor issues which we worked out with the hospital front desk. I talked to the consultant doctor, who saw her once a day and reported that she was doing well.

Inflated and Irrational charges in hospital bill

Some four days before her discharge, the hospital administrator called to let me know that the hospital bill would be higher than the initial estimate and quoted a figure of Rs 2,80,000. I was rather taken aback, since there had been no complications in her health. I requested the administrator for the detailed bill. The invoice sent to me the next day showed numbers under different headings, but did not give any details which I expected. As a layman, what struck me was the fact that they had billed me for 44 PPE Kits and 230 gloves for a routine 14 day stay, which seemed excessive. Secondly, the charges of the consultant doctor were Rs 4000 per day, which again appeared to be on the higher side. I cross checked with friends who were doctors who agreed with my observations, saying senior consultants charged Rs 1500 to Rs 2000 on an average. **We were also billed for oxygen for four days! I checked with my aunt and hospital desk, who both confirmed that she had not been given oxygen even once.**

Totally casual approach and unfair charges made me suspicious

When I raised these points with the administrator, he argued that the billing was fair - the extreme precautions did necessitate use of large numbers of PPE and consultants were charging higher than usual fees during the epidemic. When I pointed out that my aunt hadn't been given oxygen even once, he replied casually that the billing could have been a mistake and they would omit those charges. It was this dismissive casual attitude with which he brushed off the matter, which made me suspicious about all the other overheads. Who was to know if the charges were right or wrong? And because I wanted to ascertain if the charges were true or not, I wrote to the administrator, asking for the following documents,

1. The case papers (the IPD File)
2. The bills of the medicines in the name of the patient
3. Details of the investigations conducted and their results
4. Explanation for the medicines given and investigations conducted, if she was doing well and had no complications, according to my conversations with the consultant doctor.

Our exchange of messages and phone calls went on for quite some time over the next few days, till the administrator said that they had to discharge the patient and would require settlement of the complete bill, adding that the matter of the billing could be sorted out later. He said it was difficult to provide bills in the name of the patient as the medicines were procured in bulk by the hospital.

But having been associated with health rights forums, I was aware of my rights as a patient and a caretaker and pointed out to him as well that my demands were not unreasonable and well within my rights as a patient's caretaker. My aunt was discharged on the 5th August, and the hospital arranged for her to be moved back to the nursing home in an ambulance. Since our arguments were still going on, I made a part payment of Rs 80,000 to the hospital by net transfer, as a statement of good faith to settle the bill, provided the charges were just and valid.

Lack of transparency in treatment let hospitals to get away with manipulating bills

Our experience during these two weeks when my aunt was hospitalised was frustrating. COVID-19 Care Centres, both government and private, do not allow visits from caretakers. There is a lot of opaqueness, as you can't go inside to check on your patient and have to rely completely on the doctor and the hospital staff for updates. For example, my aunt, old and disoriented, could not tell us who was checking on her as everyone was wearing PPE and masks. The only giveaway was the false billing for the oxygen, which convinced me to go deeper into the case.

Multiple Grievance Redressal Forums offered resolutions and no penalties for hospitals flouting government norms and abusing Patient's Rights.

I spoke to the local MLA, whom I was familiar with due to my work, and he said he had been flooded with similar complaints in the past months and had therefore set up a special grievance cell to register the complaints and settle disputes with hospitals. So, I submitted my case to this cell, which then called for a meeting with the hospital administrator. It was clarified that the hospital had clearly overcharged in my case, according to government guidelines which had capped the prices of treatment of COVID-19 in private hospitals. **The administrator argued saying that there was a lot of pressure on private hospitals; that they were helping the government to cope with the COVID-19 burden and should not be taken to task.**

He then asked me – “Aap kitna denge?” (How much are you willing to pay?)

I stated that I was willing to pay the bill, whatever the amount, provided the charges were valid and just. A few days later I received the revised bill Rs 2,45,000. The fees for the consultant doctor were completely omitted in the revised bill which was ridiculous!! I did not agree to this revised bill and communicated to the hospital that I had not yet received any of the documents and explanations that I had requested for.

Not satisfied with this resolution, I then decided to approach the corporation directly and submitted my complaint to the Medical Officer. After some days, I was informed that the corporation grievance cell had determined that I was indeed overcharged and the hospital had revised the bill to Rs 1,47,000. However, the management had not answered any of my questions. Why was my aunt given so many injections and medicines, if there were no complications? I was being hounded by the administrator to pay the remainder of the bill. I asserted again that I would only pay the rest of the amount only if all my questions were answered and communicated the same to the corporation grievance cell as well.

When the lower-level officers did not follow up further, I met the Additional Commissioner of the city sometime in late August. During the meeting, she called the corporation officers and asked for **my case to be forwarded to the Technical Committee in Sassoon Hospital in Pune, which audits medical cases that are not resolved at the level of the corporation.** My case is still pending till date with this committee and I have not received any communication from them or the corporation grievance cell. I have also informed the administrator that I will only pay their pending bill, once I hear from the Technical Committee.

Gross negligence in patient care with grievous consequences

I would also like to mention one more incident, one that impacted my aunt far more than COVID-19. It was raining very heavily on the day she was discharged from the COVID-19 Care Centre. The hospital ambulance was supposed to take her to the care home. On her discharge, she was brought down to the entrance of the hospital in a wheelchair and then without any consideration of her health and age, she was taken across the road to where the ambulance was parked in pouring rain!! She was drenched completely and was shivering so badly, she could not lie down in the ambulance and sat next to the driver. The nursing home staff were shocked to see her in this state and changed her out of her wet clothes. Immediately thereafter, she fell sick with a bad cold and her oxygen levels decreased drastically and she had to be given oxygen for a month. Though she gradually recovered from this episode, it was very hard on her health. We could not understand if this episode was due to post COVID-19 sequelae or the consequence of being exposed to rain that day.

When I complained to the administrator about this gross negligence of care, he had no idea about it since he was never in the centre. He ran the centre like a business, he was not even a doctor. He sent me a Whatsapp message later, confirming that this incident did happen, and tried to play the whole thing down, saying that while she did get wet, she was not drenched!! I have submitted this information to the corporation and the technical committee as well, stating the dereliction in care provided and its consequences for my aunt's health.

I am very well aware that my story is an exception - it was because of my professional background, my network and contacts that I had access to all these officials, who gave me a patient hearing and I was able to make so much progress or reach this level of resolution. I know most people would probably give up or not even attempt to approach the authorities. How much time can you give to doing something like this when you have your job and your daily life to go about? I was pretty much engaged with this issue full time for over two months, and even for me, it was an incredibly stressful and frustrating

experience to follow up with so many different authorities all the time.

Later on, I was approached by a couple of people who also wanted to understand what all I had done to file a complaint as they were also overcharged by this same hospital. From what I know, one person has also filed a complaint with the corporation grievance cell. I have also been contacted by people from Nashik who had been overcharged and wanted to take action.

As of today, I am still waiting to hear from the technical committee. I do not have any great hopes that the issue will be resolved.

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10 No COVID-19 scheme benefits, no beds in government hospitals

Case synopsis

Manoj's aged mother Vimal was unwell and the family was told she had pneumonia and had to be hospitalised. The private hospital where she was taken to tested everyone for COVID-19 on admission and all reports came positive. This gave rise to some scepticism about the authenticity of the test results, especially after some people who got tested a second time in another centre tested negative. Vimal's family was forced to continue her treatment in the medium-sized private hospital after their enquiries revealed that there were no available beds in any of the government hospitals and COVID-19 Care Centres. They paid the mandatory advance deposit and had to pay money every couple of days to the hospital on faith, as there was no contact with Vimal. Vimal was directly discharged from the ICU on the 12th day. Manoj could pay the hospital bill with great difficulty after taking a loan, while skeptical about the excessive charges for PPE. The family could not claim any benefit of free or subsidised treatment under the MJPJAY scheme.

“ Testimony

My 65 year old mother Vimal was admitted to a private hospital in our Nasarapur village from near Pune on 27th July 2020. She had not been feeling well for a couple of days. She had some cough and cold and had taken treatment from our local clinic doctor. Later, he advised her to get an X-ray of her chest based on which, he told us she had pneumonia and needed urgent admission. So, we took her to a private hospital in our village.

Uncertainty regarding veracity of COVID-19 test results

As soon as she was admitted there, she was tested for COVID-19. **Along with her, all the 24 people who were tested that day also tested positive. Later on, we heard that some people were skeptical about the test results and got checked somewhere else a second time and tested negative for COVID-19. So was my**

mother really positive or were all test results manipulated? We are still doubtful to this very day. My mother used to sleep in the same room with her two granddaughters but they did not suffer from any of the symptoms or infection she had. So how come only she ended up being diagnosed with COVID-19?

Lack of options for affordable treatment; compelled to seek care in private hospital

We chose to keep her in the hospital as she was feeling breathless and needed oxygen. Worried that the treatment in the private hospital would cost too much, we did enquire in neighbouring cities like Pune and Kolhapur about availability of oxygen beds in government hospitals and COVID-19 Care Centres but found that there were none available. So, we concluded it was better to seek emergency care in the private hospital in our village instead of losing valuable time looking elsewhere.

No idea about patient's treatment and condition in ICU

My mother was directly admitted in the ICU where she remained for a total of 12 days. She was given oxygen and medicines. Family and relatives were not allowed to enter hospital premises to visit the patients; I could only go in to hand over the tiffin box.

My mother recovered to a point she was able to go to the washroom by herself. She was discharged directly from the ICU after 12 days. She was not even tested for COVID-19 on discharge.

Advance deposits, hefty bill and overpriced PPE charges

The hospital had asked us to pay an advance of Rs 50,000, but we paid only Rs 20,000 since we were slightly acquainted with the hospital owner. We kept on paying Rs 10 to 20,000 to the hospital every couple of days. The hospital bill came up to a total of Rs 1,27,000. We paid Rs 1,00,000 and got a discount of Rs 27,000 because we knew the doctor and negotiated with the hospital through a journalist friend. The medicines costed an extra Rs 80,000. We also had to pay for lab tests, investigations and some six injections. **The cost of PPE Kits for 12 days alone was a whopping Rs 26,000. There were some 20 - 25 patients admitted in the ward – everyone was charged Rs 2200 per day for PPE. All the injections and medicines that they asked us to buy everyday – were they really necessary? Were they even used? We were not sure because nobody was there besides her to check what was happening.**

I had to take loan in constrained circumstances to settle hospital bill

I had to take a loan of Rs 1,00,000 on a FD my mother and I held jointly. I could not surrender the FD as I needed my mother's signature for it. It was very difficult to manage financially without any income – my shop was closed since the lockdown. It has been a nerve-racking time – we didn't know how to raise the money to pay for my mother's treatment or to pay back the loan we took.

No benefits from government schemes for COVID-19 relief

We were not able to benefit from any of the schemes that the government announced for free or subsidised treatment of COVID-19. There was a scheme announced by the *Zilla*

Parishad (district level) and the state MJPJAY scheme. We were not able to avail of subsidised treatment under both of these schemes and had to pay all of the treatment costs by ourselves - from our hard-earned money. I think the costs in private hospitals should be regulated by the government and the schemes should be accessible to everyone. We certainly didn't see any evidence of that happening during the pandemic.

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11 COVID-19, chaos and fake reports

Case synopsis

There were many people with non-COVID-19 emergencies during the epidemic, who suffered due to lack of hospital beds and timely treatment as an overwhelmed public and private health system struggled to cope with COVID-19 patients. Ramdas, a farmer in rural Maharashtra, needed urgent blood transfusions as his hemoglobin levels were critically low. But with all hospitals in his district occupied with COVID-19 patients, his family struggled to find a hospital willing to admit him. With time running out, they managed to persuade one doctor to admit Ramdas and administer the much-needed blood transfusion. When he was tested after developing COVID-19 like symptoms a few days later, the family was informed that he was positive and asked to purchase expensive drugs and injections. As his condition became critical, he was made to shift to the government hospital with ICU facilities, but he passed away soon after. His family found out later that they were shown a fake Positive COVID-19 test report. The hospital also refused to give them Ramdas' medical records and gave them an incomplete bill, leaving them with complete confusion about the real cause of Ramdas's death and no supporting evidence to claim any state benefits for COVID-19 victims.

“ Testimony

My brother in law (55 years), Ramdas was basically a small-hold farmer and supplemented his meagre income by working on the side as a watchman. He had become very weak over the past year as he was suffering from Piles (hemorrhoids). In September 2020, we found out that he was actually anemic and his Hemoglobin had come down to as low as 4 gm %. He looked very pale and was feeling breathless. So, the doctor told us he needed urgent blood transfusion as his condition was critical. We enquired everywhere in all the hospitals in our district and even in Pune, which was the closest city, but it was the middle of the epidemic and all hospitals were packed.

No availability of non-COVID-19 emergency care and demands for advance deposits

Many hospitals had been converted into COVID-19 Care Centers and refused to admit patients for anything else. They refused pointblank to admit even critical patients. In Pune, one hospital which we approached demanded an advance deposit of Rs 4,00,000 before his admission. Dejected, we brought him back to our village, we did not have that kind of money with us.

So, we finally found one hospital in a nearby village that was willing to admit non COVID-19 patients. We pleaded with the doctor there to admit Ramdas as it was an emergency and the doctor finally conceded to admit him, even when he was not tested for COVID-19. He was admitted there on the 2nd of September, 2020. The treatment started right away, and he was given two units of blood, out of the three units we had procured for him. His Hemoglobin levels improved marginally and increased to 5.3 gm%. His breathlessness even decreased a little, which gave us hope that he would improve on further blood transfusions.

Lack of ICU facilities to handle COVID-19 Complications

Over the next few days, Ramdas was not improving as expected and developed a dry cough, though no fever or cold. The doctor advised that we should get Ramdas tested for COVID-19, as he was breathless and had a cough. So a lab technician came to get his swab on the 5th of September and the sample was sent to a private lab in Pune for analysis. On the afternoon of the 7th September, the doctor called us and showed a photo of the test report on his phone. Ramdas had indeed tested positive for COVID-19. The doctor then asked us to get these expensive injections, which he said were absolutely necessary if Ramdas was to be saved. We drove around almost the whole day and somehow managed to get three vials on the 7th September, itself and the remaining two on the 8th September, which costed some Rs 32,000 in total.

Our last recourse was the government hospital

However, when Ramdas' condition deteriorated further on the 8th September and his oxygen levels came down to 75%, the doctor told us to shift him to the government COVID-19 Care Centre for further management as his hospital did not have the necessary ICU facilities. He was only on oxygen and he needed a ventilator. As no ambulance was available, we drove to the government hospital in my car. He was conscious then and we even walked to the center. The hospital was unbelievably crowded and we had to wait for hours before he was admitted at 11 pm. When the doctors finally checked him, they told us right away that his condition was very critical and he would probably not make it. We asked them to try their best but despite their efforts, Ramdas passed away the very next morning on the 9th of September. He had barely been there for six hours.

We had to incur debt to settle the hospital bill

The bill at the private hospital came up to Rs 1,04,000 for ten days. The hospital stay costed Rs 36,000, his medicines costed Rs 50,000 and the investigations costed some

more. We paid the entire amount in cash, using our personal savings and borrowing the rest from family and friends.

No access to medical records and given incomplete bills

The hospital didn't give us any medical records after his discharge. We requested them several times and almost had fights with the hospital and the doctor. But they refused to give us any medical records of his one week stay in the hospital, so we have no proof of the treatment he received there. They gave us a receipt for only the Rs 25,000 that we owed them at the time of discharge. They gave us no receipt for the first payment of Rs 32,000. **When we demanded the records and a proper itemised bill, the doctor rebuked us, pointing out that he was the only one who had agreed to admit our patient in such a critical condition and we should be thankful that he was at least treated for a week.** We kept quiet after that, after all, who can argue with a doctor? Indeed, we owed him our gratitude for admitting Ramdas and helping us during the COVID-19 crisis. So, despite their refusal to share records or give us a proper bill, we decided not to pursue the matter further.

Fake COVID-19 reports

There is also the matter of the COVID-19 test report which we never received. I was just shown the report on the doctor's phone but never given a copy of the original report. When I asked the doctor for it, he replied that he hadn't received the reports from the Pune lab either. I then looked closely at the report, and pointed out that only the patients name was seen at the top of the report, the ID looked smudged. I accompanied the doctor to this diagnostic centre in Pune to verify Ramdas's test report, but we discovered that the reports were all faked. The ID number did not exist in the labs records and the technician was absconding.

The doctor even filed a complaint against the lab for sending him falsified reports. So at the end, I am not even sure that Ramdas died from COVID-19 or his piles related complications. There was no time to test him again at the government hospital, he died too early.

The Family's expectation

All I expect now is that the government should help such families who have lost their earning member due to COVID-19 or other causes during this epidemic. His widow should get a pension so she has some financial support to raise her family.

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12 We were cheated by a corporate hospital

Case synopsis

When 60 year old Devdas Randive, a physician, was diagnosed with COVID-19, his family made the rounds of all hospitals in Nashik till they found an available bed in a corporate hospital which asked them to pay a deposit of Rs 2,50,000 on admission even when they had mediclaim. After making them sign multiple papers in a rushed manner during a chaotic admission process, Dr Randive was admitted and transferred a few days later to the ICU as his condition was deemed critical. Even as his condition deteriorated day by day, the hospital called his son to settle the daily bill in cash and threatened to halt the treatment if dues were not settled. Dr Randive passed away after 25 days, during which the family exhausted all their savings. When his son complained about the exorbitant billing to the hospital and corporation grievance redressal cell, he found that the consent papers they had been made to sign in such a hurry during his admission stated that they were aware that their father was being admitted in the 20% (uncapped) price category of the hospital, when in fact, they were not even aware that such a state order of rate regulation existed. As no one in the hospital had informed or explained the implications of this consent, the Randive family had been misled and ended up paying exorbitant sums for irrational care.

“ Testimony

My 60 year old father, Devdas Randive was a physician; he had his clinic since the past 31 years in a suburb of Nashik.

He started to feel unwell, had intermittent bouts of fever. Then he developed a cough which gradually became more severe. We tested him for COVID-19 in a private lab which costed some Rs 1700. Two days later, we got a positive report. We immediately took him for a HRCT scan of the lungs, based on which, his condition was termed serious and he was advised admission. But my father was sure that he would recover at home. His blood pressure was under control and he didn't have any other illnesses.

Hunt for an available bed and ICU facilities

Even though he had no wish to be admitted in a hospital, we decided to start looking for available beds in nearby hospitals but they were all occupied. With options running out, we heard that there was one bed available in a prominent corporate hospital. We immediately took my father there.

Admission was conditional on ability to afford advance and pay upfront

The management had told us very clearly when we had initially called them up “Bring your patient here only if you have money to pay”.

When I went there with my father, the first thing they asked me was “Have you brought Rs 2,50,000 with you?”. I replied that my father had Mediclaim and we had cashless claim facility. The cashier shook his head, “You will still have to pay the advance deposit. You can get your bill reimbursed through Mediclaim later on. The advance is compulsory.” We paid the Rs 2,50,000.

We had reached the hospital at around 9 pm in the night. My father was admitted at around 11 pm. We were all just sitting there in the midst of the crowd for over three hours, along with some five or six other patients who were also in line for admission. There was just one person at the admission desk, processing the formalities for all these patients. Everyone was clamoring to be admitted as soon as possible. In the ensuing chaos and confusion, the hospital staff made me sign several documents, without even giving me any time to go through them.

It struck me later that all the admin staff in corporate hospitals are experts in duping patients and to exploit them in their time of crisis. They are not trained to help the sick and suffering, they are trained to loot them when they are most vulnerable.

My father was just given supplemental oxygen for the first five days. Later on, as his breathing worsened, he was shifted to the ICU and put on the ventilator. Of the 25 days that he was in the hospital, he spent 21 days in the ICU. His condition was worsening day by day and the hospital bill was proportionally increasing as well.

Consent taken for admission in uncapped price category without giving correct information

I found out later that the form I had signed in a hurry during the admission process was a disclaimer to the effect that we were aware that the state government had capped prices on 80% of bed occupancy in private hospitals and the rates for the remaining 20% of beds were fixed by the hospital. We gave our consent to admitting our father in the 20% category, even though we were not aware of such a regulation in the first place. They had rushed us through the entire admission process, without giving us any time to go through all the forms.

We only realised the implications of the form we had signed when the official to whom we complained about excessive billing later on explained the form to us. This is actually cheating. By taking consent without giving patients like us the right information, not letting us read the form, the hospital staff cheated and looted ordinary people. If we knew

about the 80/20 allotment system, we would have ensured that our father was admitted in the 80% category, so he could have been treated longer.

No treatment without settling the bill

“Come to the billing counter to pay today's bill. We will only continue with the treatment if you pay the money. Otherwise we will have to halt the treatment”-

We used to get these phone calls from hospital admin daily. It was a harrowing time as we had to keep on paying in cash daily. We had exhausted all my savings, my father's as well. The hospital did not give us a detailed bill. Whenever we asked them, they said they would give it at the time of discharge.

Hefty bills and indifferent staff

Towards the end, when my father's condition was critical, we did feel like shifting him to another hospital. As it is, all our money was over. The hospital staff was indifferent... “you can transfer him if you want to.”

The bill by then had come to Rs 14,00,000. With no money left, we were at a loss, unsure about how to proceed at this last stage, helpless because we had run out of money. We shifted him to a hospital affiliated to a medical college. But he didn't survive long. He passed away after a mere eight hours.

Inflated billing and irrational treatment

We showed the hospital bill to a lawyer who highlighted some glaring instances of overbilling in it: charges for 75 PPE Kits at a cost of Rs 1000 each and 177 masks - Did they really need that many PPE Kits and masks daily for one patient?

There was another bill for some Rs 94,000 - They had given three Remdesivir injections from the hospital and had asked us to procure another ten injections from outside as they had run out of supplies, injection Tocilizumab for Rs 40,000 and 114 multivitamin injections.

Corporation Grievance Redressal Cell dismissed the case

I approached the Grievance Redressal Cell of the municipality to complain about the exorbitant billing by the hospital. It was then that the official showed us the form in which I had to choose the admission category. “Didn't you read this form?” – That's all he said before dismissing our complaint offhandedly. There was no point in explaining how I was made to sign the form in a hurry. It had my signature on it. We could not proceed further with the complaint.

Corporate hospitals are indulging in organised loot of patients

The government needs to close attention to corporate hospitals and their management. There should be widespread advertising to ensure that people are aware about various government schemes for free or subsidised treatment. The people who work in such hospitals definitely do not bother informing people about schemes. The government should take strict action against those hospitals who do not inform people seeking admission about government schemes or make people sign consent forms under duress without complete information.

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13 Lack of basic facilities in government hospitals compelled us to seek care in the private sector

Case synopsis

Datta Patil, a farmer and a social worker from a village near Pune spent the COVID-19 lockdown working as a '*Gram Doot*' (People's Representative) assisting the local administration in critical relief work. But when he himself tested positive for COVID-19, he was forced to seek care from a private hospital due to unavailability of beds in government hospitals and had to pay Rs 2,20,000 out of his own pocket for treatment, because the MJPJAY and the *Zilla Parishad* (district level) schemes were told be not valid during the time of his admission. Along with many others, Datta Patil too ended up borrowing money to pay for his medical expenses.

“ Testimony

I am 52 years old. I am a farmer and I am also a *social worker* in my village. In March 2020 when the epidemic broke out and the lockdown was imposed, the *Tehsildar* (collector) of our village appointed me as a '*Gram Doot*' for our work. From March to June 2020, I worked tirelessly with the *Gram Panchayat* to distribute medicines, Public Distribution System (PDS) rations and food donations given by companies and NGO's for COVID-19 infected patients and to needy and suffering people. I also assisted around 650 migrant workers who were from Uttar Pradesh and Bihar and employed here in our area in companies to go back to their native place, by organizing buses with the help of the *Tehsildar*. I was even recognised as a 'COVID warrior' by the *Gram Panchayat*, who took note of all the efforts I had taken to help people during and after the lockdown.

“No beds in government hospitals left us with no choice”

I guess I must have come in contact with the virus as I was constantly on the move and meeting so many people. I started feeling unwell around the end of August and despite taking treatment from a local doctor, my health worsened. On 29th August 2020, I developed a cough and felt breathless. I got myself tested for COVID-19 at the government centre. When the result came back positive, I tried to get admitted in the

district government hospital, but there were no ventilators available there. We then tried to enquire for available beds in large hospitals attached to medical colleges in Pune, the city nearest to my village. There were waiting lists everywhere. But with my condition worsening rapidly, my family had no choice but to admit me into a private hospital in a nearby town, which still had a couple of ventilator beds available.

I was immediately taken into the ICU and given oxygen as my oxygen level was as low as 70%. I was also put on the ventilator since I was struggling to breathe. The next days were a blur to me as I drifted in and out of consciousness. I was on the ventilator in the ICU for 13 days, almost two out of the three weeks that I was in that hospital. Later on, when my condition stabilised, I was transferred to the general ward. I was finally discharged on 17th September.

“An illness of three weeks wiped out all my savings”

Faced with a bill of some Rs 3,10,000, we were shocked. The bill for the three week hospital stay came up to Rs 1,89,000; for all medicines and PPE, it was an additional Rs 1,18,000! I also had to pay extra for all the various lab tests and x-rays. How would we manage to pay this amount? As it is, all work had stopped since March 2020. We approached the doctor in-charge and pleaded with him to negotiate the bill amount. We were fortunate that the doctor was considerate and gave us a discount, considering my background of social work. We ended up with a revised bill of Rs 2,23,000. I used my personal savings to pay the bill in cash, but it wasn't enough. I was also forced to borrow money from my friends and relatives. In fact, I still owe Rs 10,000 to the chemist, whose bill I have been paying off in instalments since September 2020.

"Government schemes were of no use to us"

Two days after I was discharged from the hospital, the MJPJAY scheme was inaugurated in our *Taluka* (Block), but it came too late for me. There was also a *Zilla Parishad* scheme for subsidised treatment of COVID-19, from which I could have been reimbursed Rs 1,00,000, but it ended on the 31st of July. I had helped so many people to benefit from various relief programs, but I was unable to do anything in my case. Despite my best efforts to follow up with the *Tehsildar* and the hospital to avail of some subsidy through government schemes, I did not succeed. I managed to pay off my hospital bill somehow and I survived the COVID-19 infection, but I know of so many people who could not even get treated because they simply had no money!

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14 Advance cash deposits first

Case synopsis

Pavan, a 30 year old father of two, from a small village in Kolhapur district tested positive for COVID-19 in September 2020. Over the course of his treatment in a private COVID-19 Care Centre in a small village and then in Kolhapur, his condition deteriorated despite the efforts of his family to provide him with the best treatment possible. He passed away on the 19th of September, 2020. His brother's experience of the profiteering in the hospitals where Pavan was admitted is emblematic of the suffering of lakhs of people who had to pay through their nose for emergency healthcare during the lockdown. From having to pay deposits prior to admission, inflated billing, dereliction in quality of care, lack of communication with patient's family, refusal to hand over documents and case files, Pavan's harrowing story reflects the reality of healthcare in rural Maharashtra and a private health sector that puts profits over patients even in a public health crisis.

“ Testimony

My younger brother Pavan was 30 years old and an absolutely healthy man, someone who had not needed to take as much as a tablet in his entire life. Married with two small children, he was a farmer and also helped me in my small shop.

Advance deposits for patient treatment with no guarantees

Pavan had come down with a mild cold and fever around the beginning of September, for which he was treated by our family doctor. When he developed a cough, he was advised to get tested for COVID-19 at the government testing centre. As the swab test results would take two days, he did a rapid antigen test which came negative. However, as he was having difficulty breathing, he was told to get a CT scan of his lungs. The score from the CT scan was 30, which the doctors told us was serious and needed to be treated

immediately. So, we started making enquiries in different hospitals. There were no beds in the government hospitals in our *taluka* town. We finally found a hospital in a neighbouring village, 70 km away, which had a COVID-19 Care facility. The staff there assured us that they had beds, along with ventilators, oxygen and specialist doctors as well.

So, we took Pavan there on the 7th of September, 2020. It was only when we got there that we realised that the COVID-19 Care Centre had just opened two days ago and Pavan was one of the first patients to be admitted there. **We had to pay an advance deposit of Rs 1,50,000 before admission, which would cover his hospital stay and medicines.**

We also had to sign papers saying that the hospital was not responsible for any outcome as the patient's condition was critical. But Pavan was not critical at the time of admission. He had a cough and was slightly breathless but his oxygen saturation was 92%. They insisted that we had to sign this form, else he would not be admitted. We had no choice but to admit him there, so we did everything they asked of us.

“We had no clue what was going on”

Pavan's condition improved initially, before he started to complain again of breathlessness. The doctor asked us to get Remdesivir for him. We ran around trying to source them through different chemists and bought nine vials - each at a cost of Rs 4000-4500. With Pavan's oxygen saturation hovering between 55 to 60%, the doctors told us to buy another emergency injection costing Rs 40,000. We managed to procure that injection as well, but his condition didn't improve even after getting all these injections. Of course, we never really saw him being given all these injections, as no one was allowed to go inside the centre. The one time I asked the doctor how many doses Jeevan had been given, he had no idea at all.

Pavan had complained to my sister that the staff switched off his oxygen supply at night, due to which he was struggling. When we brought up this issue, they said he was restless at night and did not allow the nurses to put him on the ventilator. But how was he then perfectly compliant during the day? **We also found out that the hospital was only equipped with mini-ventilators, which they had misrepresented to us when we had initially called them.**

“The hospital staff just didn't bother to communicate with us about Pavan's condition”

We were unable to understand why his health was deteriorating despite all the medication and treatment and the doctors did not give us any explanations at all, even after repeated queries and requests. On the 17th September, Pavan pleaded with us to take him to another hospital. He was very unhappy with the treatment and panicked when he saw patients dying in front of him.

“We won't discharge your patient till you settle your bills!”

We also had the same feeling and informed the management that we wanted a discharge. It took them one entire day to make our bill. **On the morning of the 18th September, without any prior intimation over the past ten days, we were given a bill of Rs 86,000 for medicines!! We were completely taken aback, because the**

management had never mentioned that we would be billed separately for the medicines. They had billed us extra for everything- PPE Kits, all kinds of tests, medicines. We were in shock. But the administration was heartless; we had to pay up if we wanted to take Pavan to another hospital. Somehow, we managed to gather the funds together, borrowing from relatives and friends. Altogether, his ten days stay in that hospital cost Rs 3,00,000.

“All hospitals were the same, asking for advance deposits before even examining the patient”

We then transferred Pavan in an ambulance to a large multispecialty hospital in Kolhapur, some 20 km away. When we reached the hospital, we were told it would cost Rs 30,000 per day to treat him in the ICU. Medicines and PPE Kits would cost extra. We had to pay an initial deposit of Rs 2,00,000. I started to realise that even in this pandemic, doctors and hospitals were more interested in making money and not saving lives. They were least bothered about my brother's condition and insisted on being paid up front.

Pavan was finally admitted in the ICU in the evening after we completed all the procedures and paid the deposit. The next morning, we got a call from the hospital saying that his condition was critical. We could see that he was on the ventilator in the ICU, not responsive and completely unconscious. Pavan was already gone even though he was being given oxygen. Around midday, they declared that he was dead. We broke down in tears. How did this all happen in two weeks?

There was nothing we could do. COVID-19 meant there could be no post-mortem and the body was completely wrapped in plastic. In the death certificate, the time of death was stated as 3.15 pm, even though we were told at 12 pm that he had passed away.

At that point of crisis, do you go about enquiring about schemes or seeing to the health of your brother?

Out of the initial deposit of Rs 2,00,000, the hospital charged us Rs 63,000, billing us for two complete days, even though my brother was hardly there for a day. We were resigned to the fact that they would extort as much money as possible. I was so stressed by negotiating and arguing with the doctors and hospital management, I lost 12 kgs in that month.

In total, we were billed Rs 3,00,000 at the first and Rs 63,000 at the second hospital. We had to borrow from relatives and friends and put in all our meagre savings, whatever they were. Nobody told us about any government scheme to treat COVID-19 free of cost or that costs of treatment were capped in private hospitals by government rules. We had no idea about these schemes nor was there any information available at any hospital.

“We didn't even get a proper bill”

The hospital didn't even give us a bill for the Rs 63,000. Neither did they give us any of the reports including those from the previous hospital, in spite of my repeated requests. We were already in so much shock and grief, we didn't think of approaching them again.

Our experience has scarred us so much that I feel it would be better to die in peace at home, instead of going to a hospital, because all they want to do is extort as much money as possible from you.

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15 Advance deposits were compulsory despite cashless mediclaim

Case synopsis

The COVID-19 pandemic and the stance taken by many private hospitals on payment of hospital bills came as a rude shock for many families who thought their Mediclaim policies would help them to cover the cost of COVID-19 treatment. When Sumit's father had to be admitted to a hospital, he was taken aback when the hospital insisted on an advance deposit of Rs 2,00,000, despite the cashless Mediclaim. With time and other options running out, he had no option but to acquiesce to their demands and borrow money at the last minute to pay the deposit in cash. Despite repeated requests, the hospital also didn't give him a clear breakdown of the bill and delayed the refund of his deposit even after the insurance company approved his claim.

“ Testimony

My father (above 60 years) was unwell and started to cough continuously. Everything was closed over the weekend, so we took him to the hospital on Monday. The local doctor initially said he had typhoid. Later, he said it was pneumonia.

On 19th October 2020, we took him to the OPD of a corporate hospital where he was tested for COVID-19. Even though the test results would come a day later, his CT scan score was 17 and we were informed that his condition was critical and he needed to be admitted in a hospital.

Forced to pay heavy deposit, despite having cashless Mediclaim

After an entire day of calling up different hospitals, we finally managed to find him a bed in another prominent corporate hospital at 9 pm in the night. Even though my father had Mediclaim, a cashless health insurance policy worth Rs 3,00,000, we were asked to make an advance deposit of Rs 2,00,000 to begin his treatment. We assured the management that we had private insurance but they didn't budge from their stance. They would not admit my father without an advance deposit.

I contacted the insurance company and told their executive that we were being asked to pay a deposit. **The executive told us that we didn't need to pay a deposit as we had cashless facility as per my father's insurance policy. But the management insisted that it was their policy to take a Rs 2,00,000 deposit from everyone, irrespective of whether they had insurance or not. They kept on pestering us - Why were we refusing to pay the deposit? What proof could we give of our ability to settle the bill? Give us a statement in writing that you will settle the bill. When would we be able to settle the bill?** - It really felt like mental torture. On one side, we were being told that my father's condition was critical; on the other side, the admin said they wouldn't admit him if we didn't pay a deposit. Time was running out. We were not sure if we would find a bed somewhere else in this situation. Left with no recourse, I emptied my bank account and borrowed the rest to pay the deposit amount.

Poor quality of care in branded corporate hospitals

We were not able to visit my father during the time he was admitted. All communication with him was through video calls. The hygiene and sanitation in the hospital was also not up to expected standards. When it rained, the roof used to leak. The sweeper had to be called ten times before he showed up. The wards had no resident doctors, only nurses. The doctors used to come only once a day at 11 am in the morning for rounds with nurses taking orders over the phone for the rest of the day. The senior nurses used to depute junior nurses to keep a watch on the patients instead of supervising their work. When my father needed an Intravenous (IV) drip, the junior nurse botched the insertion of the needle and wasted two hours, but no senior nurse showed up. His hand was completely swollen due to her multiple attempts at IV catheter insertion.

I blame the management and administration, not the doctors. If we are spending so much money, then it is our right to expect quality care and attention. Why would you choose a private hospital otherwise? Here, they made my father sleep on a wooden bench at one time.

Endless arguments about overbilling and lack of transparency in billing

When my father was shifted from the ICU to the general ward, the bill till then had come to Rs 2,14,000. Just after two days, I was again given a revised bill-this time of Rs 3,19,000!! I asked the management to give me a breakdown of the expenses. When they returned Rs 64,000, I asked them for explanation of the bill particulars. On receiving no reply, I even took it to a corporation doctor who then clarified my doubts. It turned out that they had applied bedside charges. My father had no diabetes or hypertension, it just felt like the hospital was using COVID-19 as an excuse to loot the common man.

When my cashless claim was finally approved, I approached the management and asked them to return the money I had paid upfront as deposit. Most of it was money I had borrowed from relatives and friends which I had to return but the accounts person was unbelievably rude and dismissive with me. The people from the billing department also spoke very aggressively -“why did you bring your patient here if you can't afford the treatment or the deposit?” one of them said to me. After making umpteen requests, I had to threaten legal action, before they refunded the Rs 2,00,000 deposit to me.

When I told the resident doctors of my arguments with the billing staff, they shrugged and remarked, hospitals are all about business, they are heartless. They never told us that there is a MJPJAY scheme for free COVID-19 treatment. Nowhere we were informed that rates in private hospitals were capped by government. Room charges were some Rs 27,000 for a week. I paid Rs 35,000 extra for medicines and disposables, out of which Rs 10,400 were for two vials of Remdesivir, which they gave to him, even before his test results had come in.

Is COVID-19 being leveraged by hospitals to make money?

Actually, even today, I am confused if my father was COVID-19 positive or not. My mother, sister, her children and I were all tested for COVID-19 in the government COVID-19 testing centre. We all tested negative. I wonder if my father test came positive because his sample was taken in a private hospital.

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16 Cash and connections for COVID-19 care

Case synopsis

When 65 year old Dadasaheb Chauhan started to feel breathless in September 2020, doctors performed a CT scan and suspected COVID-19, advising immediate admission in a hospital with ICU facilities. Frantic enquiries revealed there were no oxygen beds available in any government COVID Care Centre in the village, the nearest towns and even Kolhapur. Based on the DHO (District Health Officer) dashboard data, the family drove to a private hospital with 13 available beds, only to be flatly told on their arrival that there were no available beds. It took the intervention of some political connections followed by the mandatory advance deposit to get a bed there after seven hours. Mr Chauhan's family also proactively followed up with the hospital management about the MJPJAY scheme since no information was forthcoming from them. Despite all efforts, Dadasaheb passed away after a week. The hospital refused to release his body before dues of Rs 1,41,000 were settled, claiming that the publicly funded health insurance scheme (MJPJAY) would not cover the amount entirely. It again took political intervention for the hospital to negotiate the bill amount to Rs 40,000 and release the body after 14 hours for final rites.

“ Testimony

It was in September 2020 that my 65 year old father Dadasaheb Chauhan started to feel weak and tired. Then he started to feel breathless. A local doctor from our village examined him and advised a HRCT scan of the lungs. The CT score from the scan was 20 out of 25. The doctor explained to us that the high score meant that my father could possibly be suffering from COVID-19 and needed to be admitted in a hospital with oxygen and ventilator facilities at the earliest.

Overwhelmed and completely occupied government COVID-19 Care Centres

On 18th September 2020, we took him to the government COVID-19 testing centre in Sangli district to get tested for COVID-19. We also enquired in the government COVID-19 Care Centres in Sangli and Meeraj if an oxygen bed was available there. We were informed there were none available and referred to the government CCC in the next district. There wasn't a bed available there too. All government facilities were completely occupied. There were long waiting lists for admission. We realised we had no option but to look in private hospitals for a bed.

Dashboard figures of available beds didn't match reality. Finally, political connections helped us get a bed

We referred to the District Health Officers dashboard for availability of beds in several hospitals. The first two private hospitals that we approached denied us admission, saying all beds had already been allotted. The dashboard showed us that there were 13 empty beds in a big private hospital in Sangli city so we drove there directly in the ambulance in the afternoon. But when we got there, the management at that hospital told us that there were no beds available and gave no explanation as to why the dashboard was showing 13 available beds. We waited outside the hospital for six and a half hours with my father in the ambulance as we made calls to influential people in our network who could help us to get a bed in the hospital.

At 6.30 in the evening, we finally managed to get admission due to the intervention of some political connections who spoke directly to the hospital owners. We also paid Rs 15,000 as advance deposit, though they had asked us to pay Rs 25,000.

No publicity about MPJAY scheme in the hospital

My father was admitted as a COVID-19 suspect and given oxygen in the isolation ward. His COVID-19 test came positive the next day. By this time, we had found out that the government MJPJAY scheme covered treatment costs of COVID-19 even in private hospitals. This was a huge relief to us. It was only after we enquired about the MJPJAY scheme with the hospital management, that they acknowledged that it was applicable to us. Then they took my father's *Aadhar* and *Ration* cards to enroll his name in the scheme.

For the first three days, he was in the isolation room. We could talk to him on the phone. Afterwards when he was moved to the ICU, we lost all contact with him as phones were not allowed. He was given Remdesivir injections, which we had to buy from different pharmacies outside.

Despite all efforts, his condition deteriorated. The doctors asked to be prepared for the worst as his vitals were very poor. Finally on the 28th of September, very early in the morning, we got the call we were dreading. He had passed away.

Pay the bill or we won't release the body

The hospital bill was Rs 1,41,000. We were told that the **MJPJAY scheme would cover only a very small part of this bill as per the regulations and we would have to pay for the rest. We were also informed that unless we did not settle the bill, the**

hospital would not release the body for final rites!! We were not prepared to pay this amount since our understanding was that the MJPJAY scheme would cover the bulk of the cost of treatment.

Hospitals respond only when you bring in big names to talk on your behalf

Finally, we had to talk to some political connections to intervene in the matter. They negotiated with the hospital on our behalf. We paid Rs 40,000 and finally, the hospital released the dead body some 14 hours later, around 8.30 in the night. The hospital bill has mentioned the amount Rs 39,800 as received from the patient and also that the case was covered by the MJPJAY scheme. But till the end, we did not get any explanations from the management as to why we had to pay the extra amount.

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17 Government scheme failed, leaving us in debt



Case synopsis

Nishikant Raut, a 60 year old farmer from Pune district fell ill with a cold in October 2020. When the local doctor's treatment did not result in recovery, Nishikant went to the COVID-19 Care Centre in his village. However, as his breathlessness and oxygen levels worsened, the doctors advised him to immediately move to a hospital with ICU facilities. He chose to get admitted in a private hospital in his village where he was put on the ventilator and was in the ICU for 12 days. The hospital and pharmacy bills came up to Rs 3,00,000, a sum that he managed to pay only by using all their savings and borrowing from friends and relatives. Nishikant did enquire if they could avail of subsidised treatment under the MJPJAY scheme, but were informed that the scheme was temporary and no longer covered costs of COVID-19 treatment. Nishikant suffers from long term COVID-19 sequelae and requires constant medical attention which he can no longer afford because he has so many debts to pay back.

“ Testimony

I am 60 years old and live with my family in a small village in Bhor block from Pune district. In October 2020, I developed a cold which became quite severe. So, my family took me to a local doctor's clinic for consultation. The doctor had tested COVID-19 positive, so his wife and the nurse were actually examining patients. They asked me to do some blood tests.

Local treatment didn't help

The tests showed that I was suffering from typhoid and they gave me medicines, injections through saline over the next five days. But my chest congestion and cough had increased. I had an infection of the lungs, something like pneumonia which was gradually getting worse. We had already spent some ten thousand rupees by then but we could not see any improvement in my health. The doctor said that he had done everything that was possible at his level. He advised me to get admitted to a hospital for further treatment. He left the choice of the hospital to us.

Lack of ICU facilities in government COVID-19 Care Centre forced us to turn to private hospital

So, we went to the government hospital. On 27th October, 2020 I was admitted there in the COVID-19 Care Centre. My oxygen saturation had gone down so much that even after being on supplemental oxygen for two hours, my breathlessness persisted. **The doctors there said I needed ICU facilities and a ventilator, which were not available there. They gave my family three choices - to take me to Sassoon hospital or Aundh Chest hospital in Pune which was almost three hours away, or to a private hospital here in Bhor.**

COVID-19 positive in the ICU but where was the money for treatment to come from?

My family did not waste any time. It was not possible to transfer me anywhere in our car as I needed oxygen. My son called up 108 - emergency number for ambulance. I was taken in the emergency ambulance to the private hospital in Bhor and admitted there late in the night. I was immediately tested for COVID-19 on admission and the report came positive the next day. My entire family was tested for COVID-19 as well, but their reports all came negative.

I was in the hospital ICU for a total of 12 days. For the first four to five days, I was on the ventilator, later I was only on oxygen. I was given some injections which my wife had to buy from outside. We could not see our family members as no one was allowed to come inside. I was discharged directly from the ICU.

Hefty hospital and pharmacy bills - We were forced to borrow from friends and family

The pharmacy bill alone came to Rs 1,90,000. The bill amounts were staggering. We are small-hold farmers, we don't even have our own land which we could sell. My only son had just joined the army but his insurance coverage had yet to kick in. He was not even around as he had just left for his first posting.

My wife used to pay money to the hospital every morning and was handed more bills to pay, more medicines to buy in the evening. My family was rushing around everywhere, trying to raise the money to pay to the hospital. My son's friends helped us a lot and even lent us money. We still owe them quite a sum.

MJPJAY scheme no longer valid for COVID treatment - our last hope died

We did ask the hospital to enrol us in the MJPJAY scheme but we were informed that the scheme had expired, that it was no longer covering COVID-19 treatment costs. We submitted all the necessary documents, but were not able to avail of the Scheme benefits. I even asked if it was possible to be transferred to another hospital where the scheme was still applicable but they told us that it would be the same anywhere else as well.

The daily PPE bill was Rs 1,200 per day and came to Rs 14,400. The hospital stay costed Rs 1,80,000 with the ICU and oxygen costing some Rs 7,500 every day. Every two days, we paid some Rs 10,000 to 15,000 to the hospital. On the last day, we paid the balance amount of Rs 65,000 before I was discharged.

We had to settle entire bill in cash - the spectre of debt and loans now haunts us

We pleaded with the hospital management and the doctor to give us some concession, some discount but they only gave us a discount of Rs 8,000. We had to pay the hospital and pharmacy bill in full.

I stayed in isolation at home over the next one and a half months because my daughter in law was pregnant. I still have breathing difficulties and feel very breathless when I walk. I have to get tested frequently so yes, medical expenditure is still happening even though we are struggling financially.

I do not understand why the scheme benefits were withdrawn at a time when so many people needed help with medical expenses. We would have greatly benefited from it. Instead, we are straddled with debt now and wondering how to pay back the money we borrowed.

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18 No schemes for critical patients

Case synopsis

Leelatai is an ASHA worker in a village in Kolhapur district whose 75 year-old mother-in-law had been feeling unwell for a few days in September 2020. Seeing her low oxygen saturation levels, they transferred her to the closest government COVID-19 Care Centre where her oxygen levels did not improve even after being given supplemental oxygen. The family took the decision to move her in an ambulance to a private hospital in the closest city and spent the entire day moving from hospital to hospital, searching for available ventilator beds till they found one at the end of the day. The hospital was reluctant to admit such a critical case but Leelatai and her husband pleaded with the hospital management to admit her till they consented. Her mother-in-law was in the hospital for 17 days without any contact with her family. Leelatai had submitted all documents for MJPJAY entitlements on admission as this hospital was empanelled with the state for MJPJAY, but to no avail, they had to pay the bill by themselves. The family could only pay Rs 1,00,000 out of the Rs 3,00,000 they owed the hospital by borrowing the money from various relatives and pledging to pay the rest in instalments. The hospital did not give them the medical records of their patient.

“ Testimony

My mother-in-law is 75 years old and lives with us in our village in Kolhapur district. She had been feeling unwell for a few days when one morning, she started to feel giddy and fainted in front of us. I work in our village as an ASHA worker and had a pulse oximeter, so we checked her oxygen saturation level. It was very low. We were very alarmed and decided to admit her and test for COVID-19. Realising that her condition was serious, we immediately called 108 for an ambulance, which reached our home in 30 minutes. We transferred her to the government COVID-19 Centre in the neighbouring village, where they gave her oxygen, but her oxygen levels didn't improve even after that. We were informed that her condition was critical and there was no guarantee that she would

survive. She needed investigations and a ventilator, both of which were not available at the COVID Centre. We were advised to shift her immediately to the government hospital in the closest city. So again, we arranged for an ambulance which had oxygen and took her there for a CT scan of the lungs. It costed us Rs 6000. In the meantime, we were thinking over the best course of action to follow.

No government schemes apply in emergency admission in private hospitals

We decided that we would take her to a private hospital for better care as government hospitals were very crowded. We went around from hospital to hospital in the ambulance, enquiring for availability of beds with ventilators, but it was almost next to impossible. Finally, at the end of the day, we were able to find a ventilator bed in a multispecialty private hospital. We saw that the hospital was approved for subsidised treatment through the government scheme. The management took my mother's *Aadhar Card* on our arrival and left us waiting outside in the premises for some 30 to 45 minutes. We were fortunate that we had oxygen in the ambulance, otherwise my mother-in-law would not have survived so long in that state.

Then after checking her condition, the staff refused to admit such a 'high risk critical' case, stressing on her low oxygen levels and no guarantee of recovery. We had to plead with them a hundred times to at least take her inside the hospital and do whatever they could before they agreed to admit her.

With no access to information about what was happening

At the time of admission, I enquired about eligibility and documents for treatment under the government scheme, but I received no reply and no information from them. It was finally 1.30 in the night when my mother was admitted. **No one was allowed to accompany her inside the hospital nor could she bring anything with her. She remained in the same clothes for the next 17 days.** We received daily updates about her condition from the staff on phone. We had no idea what she was feeling like, what food was she getting, what treatment was being given to her. All medicines and injections were supplied within the hospital.

With no help to apply for schemes, we incurred debt to even partly pay for hospital expenses

The hospital bill came to Rs 5,60,000. **They asked us to pay Rs 3,00,000 but how could we pay so much money all of a sudden? We are small hold farmers. All work and markets had come to a standstill during the lockdown. We were not able to sell any produce. In desperation, we called up our relatives and friends and borrowed what we could to pay them Rs 1,00,000.** We pledged in writing to pay the pending amount in monthly instalments and managed to get our patient discharged. There was no mention of any subsidised treatment under any scheme. We had to foot the entire expenses by ourselves.

Discharged without any medical records

However, other than just the discharge summary, we were not given any hospital records of medical treatment, and reports of lab and other investigations. We didn't get a detailed breakdown of the bill either. The medical file is still with the hospital. We observed that they kept a close watch on the medical files and didn't leave them out of sight or unattended. In fact, the management did not give hospital files to any patient on discharge.

First comes the package and then the patient

Being an *ASHA* worker, I am aware that there were many schemes announced by the government to help people with their medical expenses during the pandemic but I found that we were helpless when it came to emergency hospitalisation. Neither did the hospital staff cooperate with us, when we requested assistance with the scheme. I feel costs in private hospitals should be regulated and transparent so that common people are protected from looting. Everyone was being charged different rates for the same services. They used to talk about different packages when patients were being admitted. We have a Rs 3,00,000 package, pay the money first and then admit your patient. This is so wrong. What are those who don't have this kind of money, supposed to do?

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19 Is treatment only for those who can afford to pay hospital 'packages'?

Case synopsis

When Vitthalrao Deshmane fell ill with what seemed like the flu in August 2020, his local doctor initially prescribed him treatment. When his condition worsened, the doctor advised his family to move him to a better hospital. His son took him to the nearest city of Kolhapur in an ambulance where they were turned away from several hospitals, who refused to admit him because his condition was critical. Finally, one private hospital agreed to admit him, provided the family was willing to pay the package cost of Rs 3,50,000. With options running out and the family getting desperate, Vitthalrao's son consented to pay the quoted package cost and admitted him there. The family were unable to visit Vitthalrao in hospital; they just received periodic updates about his condition from the doctors. It was only on the day before his death that the family found out about the MJPJAY scheme and approached the management to process their claim. They paid the hospital around a Rs 1,00,000 in cash for five days stay, unsure if they paid the package price or subsidised MJPJAY prices. Like many other people who went through a harrowing time in seeking medical care during the epidemic, the Deshmane family reflected on the sheer helplessness they felt while driving from hospital to the next, looking for one available bed with their sick father in the ambulance, and their anger with the money-minded approach of the many hospitals they were turned away from.

“ Testimony

A simple cold turned into severe pneumonia

My father felt unwell and had a fever, cold and some cough - so we took him to a local doctor in our village, who advised him to get an X-ray. The X-ray showed signs of pneumonia in the lungs. The doctor said it was just the beginning and that he would recover within two days of taking medication. But his condition didn't improve even after

four days; on the contrary, it got worse. Then the doctor threw his hands up, saying he could do no more and we should take our father to the nearest city (Kolhapur) for a CT scan and further treatment as soon as possible.

The hunt for one hospital bed

We then hired a private ambulance and took him to Kolhapur, where we first did the CT scan which cost Rs 6000. We drove around, going from hospital to hospital, enquiring if admission was possible. In some hospitals, we were flatly turned away; in some places, they just checked my father's oxygen levels and CT scan, before informing us that there were no beds for such a serious case. We felt helpless – nobody bothered to actually examine my father, he lay in the ambulance the entire time.

Finally, in one private hospital, the doctor checked my father's oxygen level and other vitals. We were told there was a bed available for him and that the 'package' would cost Rs 3,50,000. They were very clear - they would only admit him if we could afford to pay the package charges. We had no option but to agree to their conditions. Time was running out and we wanted to start treatment as soon as possible. We agreed to the package and admitted my father there.

Actually, there were government schemes in the COVID-19 situation there but no one told us about them. It was only on the last day that I discovered that there were schemes for subsidised treatment which we could have applied for.

We could not see our father once he was admitted. We used to call the doctor daily for updates. Initially, we were told that his condition was serious and we should prepare ourselves for the worst. But we hoped that he would pull through. My father did talk to us on the phone for the first three days. After that, his condition worsened and he was no longer able to speak. We did not hear his voice again. We had no idea what was happening with him inside.

We then received a call from the hospital, informing us that his condition was critical and we were then allowed to see him. **One day before he passed away, we found out that there was a government scheme for subsidised treatment costs in private hospitals. When we enquired with the management, then they conceded that there was indeed such a scheme and asked for our Ration Card and Aadhar Card. We pleaded with them to facilitate the scheme so we could avail of subsidised charges.**

Altogether, we paid Rs 78,000 for his hospital bill and Rs 25,000 for the pharmacy bill.

I lost my father but the memory of going from hospital to hospital looking for a bed for him while he lay in the ambulance will forever stay with me. What if we had not been able to afford the package rates? Does that mean that we don't deserve treatment? The government must ensure that treatment in private hospitals is fixed at affordable rates and patients should not be looted at a time of desperation and urgency.

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20 I was never
COVID-19
positive but
treated for
COVID-19

Case synopsis

Chandu, a taxi driver from Nashik, fell ill with a cold after being drenched in the rains, for which he consulted a local doctor in August 2020. When he didn't feel better, he went to a private hospital that did an X-ray and a CT scan. The doctor there advised him to get admitted immediately in a particular hospital and assured him that he would receive quality and affordable treatment there. Accordingly, Chandu got admitted in that private hospital and was tested for COVID-19 on admission. During his five day stay there, he enquired every day about his COVID-19 test report and was fobbed off with various excuses. He received a negative test report on the day of his discharge and realised that he was treated as a COVID-19 patient even when he had tested negative. The hospital refused to give him an itemised bill for the Rs 1,25,000 they had charged him even after repeated requests. When he finally got the bill, he was shocked to see that he was charged for all five days of ICU stay, though he had stayed in a general room and had not availed of any ICU services. The management did not acknowledge his complaint of fake charges. Unsure of grievance redressal processes, he had to settle the hospital bill in cash by borrowing the sum from his family and friends.

“ Testimony

My name is Chandu and I am 48 years old. I am a taxi driver from Nashik. I got drenched in the rains one day and fell ill later with a cold and fever. I then consulted a local doctor and took his treatment. However, after a couple of days, my cough worsened; So, I went to another hospital nearby. They took an X-ray which showed no signs of infection. So they advised me to get a CT scan of the lungs.

They directed me to a hospital with false promises

After the CT scan, they advised me to get admitted immediately and referred me to another hospital, saying that the cost of treatment would be less there; I would be able to afford it. Listening to them, I was scared; my condition appeared to be serious.

Accordingly, I went to that hospital and got admitted. I gave my swab for COVID-19 testing there. Unfortunately, my father who was not keeping well passed away the next day. My family did not inform me about my father's demise since they didn't want to upset me while I was already tense. Nobody was allowed to be by my side or even visit me; we could only communicate through video calls.

Intentional delay in COVID-19 test report - hospital exploited my ignorance to treat me for something I didn't have

I was in the hospital for five days. Every day, I would enquire if my COVID-19 test result had come and the staff would say no. On the day of my discharge, I got a COVID-19 Negative report! When I asked the doctor why was I being treated for COVID-19, if my report was negative, they replied that I had tested negative because of all the treatment I had received. **But I realised that I was tested for COVID-19 only once on the day of my admission and never after that. That was the report I was given on the fifth day. I didn't have COVID-19 but was treated for it nevertheless. The hospital, pharmacy and pathology lab all colluded to cheat and loot innocent people.**

Inflated billing, made up charges for services I never used

The bill for my five days of treatment in that hospital came to Rs 1,25,000. They delayed in giving me a proper itemised bill even though I asked them numerous times. When I finally got one, I was shocked! I was never given oxygen or put on the ventilator – yet I was charged for both oxygen and ventilator use. I was charged for five days of ICU charges – even though I stayed in a normal room with five other people. There were no machines in the room nor were any machines or monitors attached to me at any point of time. But according to them, the corporation had certified it to be an ICU facility. They had also prescribed a long list of medicines; I had to plead with the pharmacy and tell them I could not afford so many medicines; then they reduced some six to seven thousand worth of medicines from the list. **So, were the medicines necessary or not, in the first place? How is the common man to know which medicines are essential or not for this new disease?** There is no option but to trust the doctor and accept his treatment.

Have incurred debt to pay hospital bill, now have to repay the debts

Occupied with my father's demise and under pressure to start working again, I was unsure how to go about to file a complaint or follow up with the authorities regarding this fraud hospital. I paid the bill in cash.

I am just a taxi driver; I had to borrow from friends and family members to settle the hospital bill, now I am working to pay off this debt.

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21 Exorbitant COVID care, failed health insurance

Case synopsis

Dnyaneshwar, a 43-year-old man from Nashik tested positive for COVID-19 in August 2020 and decided to get admitted in a private hospital where his friend was being treated for COVID-19 as well. He was explicitly informed by hospital management that he should get admitted only if he could afford the treatment there. Even though he had very mild COVID-19 symptoms with normal oxygen levels, Dnyaneshwar was put on oxygen and given over six Remdesivir injections to which he had a severe reaction and developed a rash all over his body, that still has not healed. Despite being dissatisfied with the quality of service provided and the inexplicable insistence on a battery of daily investigations, Dnyaneshwar stayed in the hospital for two weeks and ended up paying Rs 1,76,000 to the hospital. His Mediclaim was rejected as the hospital denied having treated him for COVID-19. He is still trying to work out the confusion between the insurance company and the hospital, hoping to have his hospital bill reimbursed.

“ Testimony

I am 43 years old and live with my family in Nashik. I fell ill in the beginning of August 2020. I had body ache, giddiness and felt weak. So, I decided to get tested for COVID-19 in the corporation testing centre on the 7th August. Just as I feared, my report came positive the next day. Just as I was wondering what to do, I learnt that my friend had also tested positive and had gotten admitted in a private hospital nearby. So, I also decided to get admitted there.

Irrational Treatment and Unexpected complications

Based on my blood tests, the hospital doctors said my white cell count had decreased and I was given medicines. **I was able to breathe perfectly fine on my own; however, I was still given oxygen every day. They did not explain why I was being**

given oxygen when my oxygen levels were normal. Though my blood cell count improved, I was not feeling better.

I was in the hospital from 8th August to 17th August. I was given six injections of Remdesivir. I had a severe reaction to the injections - I developed a rash all over my body which left dark black marks everywhere. The doctor told me that the marks would fade in a week's time, but I still have them four months later. The hospital has refused to accept any responsibility to treat this complication of their treatment. I have had to manage the treatment for this complication on my own and have spent almost Rs 5,000 in consultations and treatment for these marks. They still persist to this day.

Poor quality of services affected my health further

The hospital amenities were not good. Especially the food that was served to us there was not at all nutritious. **It was unappetising and the quantity was also very less. Many of us just went hungry and therefore felt weaker. I was so hungry that I woke up one night at 2 am and had some dates.** The next day, my blood sugar level increased.

“Get admitted only if you can afford the treatment”

Even though we were in the general ward and had mild COVID-19 symptoms, we were being given a lot of different medicines - tablets and all kinds of injections through IV. We were being tested daily. There were blood tests, there were X-rays, CT scans - The total bill for 14 days came up to Rs 1,76,000! In fact, we had to pay Rs 25,000 as advance deposit on admission. The management was very upfront - they told us that the daily cost of treatment would come up to Rs 15,000 and the bill would come to around Rs 1,50,000 to Rs 2,00,000. We should only get admitted if we can afford the treatment. It seemed that irrespective of the severity of the disease, the starting package was Rs 1,50,000 onwards.

Mediclaim was rejected on wrong grounds

I had Mediclaim with coverage up to Rs 5,00,000 with a private insurance company. I thought I would be able to claim my treatment costs. But when I submitted the claim, I was informed that there were no medical records of a patient of my name in the hospital and the hospital had outrightly denied having treated me for COVID-19!! I was shocked to read that my claim was therefore rejected. When I went to the hospital to check with the claims processing department, they denied having issued such a report to the concerned insurance company. I am still trying to figure out the confusion between this hospital and the insurance company, in the meantime - I had to pay for the entire bill out of my pocket and now I am running around trying to have it reimbursed. ”

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22 Mediclaim - License to loot patients

Case synopsis

Sunil (24 years) and his mother both tested positive for COVID-19 in August 2020 and were admitted in a private hospital in Nashik which only accepted patients with medical insurance. Sunil had no symptoms and hence was not given any supplemental oxygen or IV fluids. Sunil's mother was given six Remdesivir injections, out of which the first two were purchased in another patient's name. Both mother and son felt that the quality of service in the hospital was poor and were hesitant in approaching the main doctor who was always accompanied by a bouncer-like person. Sunil highlighted the irrational and inflated billing of their treatment, pointing out that he was billed for oxygen, IV fluids and injections and even mineral water bottles none of which he had received during his stay. They also did not receive any lab reports and had to request an indifferent administration for a detailed bill repeatedly. They paid Rs 42,000 out of pocket as the insurance company refused to reimburse them for certain particulars.

“ Testimony

I live in Nashik with my mother. My mother tested positive for COVID-19 on the 7th of August 2020, and we admitted her the next day itself into a private hospital. She was discharged ten days later. I also tested positive along with her and was admitted in the same hospital, even though I was not experiencing any symptoms, out of an abundance of caution. I was discharged five days later, when I tested negative.

We were charged for treatment and amenities we were never given

During my stay, I was never given any supplemental oxygen, since I never felt breathless. I was never given any IV fluids or injections, just tablets. Imagine our great surprise, when I found that I was being billed for both oxygen and injections. There were daily charges for mineral water bottles, which we never got either.

Poor quality of service and lack of supervision

The hospital staff was not as attentive as it should have been. We had to call them repeatedly before someone showed up to enquire if we needed something. **The resident doctor did not come to examine us even once during our stay and indeed, we had the impression that the nurses were running the show in the hospital.** The food never came on time and everything served for breakfast, lunch and dinner was inevitably served cold.

Irrational treatment

We did not understand why our blood sugar levels were being checked daily when neither of us was suffering from diabetes or even had any history of Diabetes. In my mother's case, she was given Remdesivir injections even before the results of her swab test came in. Actually, Remdesivir injections are supposed to be bought in the name of the patients who have tested positive, but since her report had not yet come, the first two injections were bought in the name of another patient who was positive. Since they were not bought in my mother's name, we could not claim the costs through insurance. Altogether, my mother received six injections.

We didn't even dare to approach the doctor

We could never talk to the doctor because he used to be accompanied by a bouncer during his rounds. When we went to see him in his cabin, the bouncer used to come and wait right outside the door. It felt very intimidating.

No access to reports, no explanations for the bills

We had paid Rs 17,600 for lab investigations and other tests, but we did not get any reports. We wanted to make a complaint but it was just me and my mother. I had no support and felt too weak to argue with the management.

After the discharge, we asked for a detailed breakdown of the bill, which seemed inflated and had items that we hadn't even been given. We were charged Rs 2500 daily for PPE!!

The admin responded to our queries by rebuking us saying... Why can't you just let it go? Only you are cribbing about the bill, others have just settled their dues.

Our bills came up to Rs 2,35,000 (my mother's bill was Rs 1,60,000 and my bill was Rs 75,000). Our Mediclaim only covered expenses of Rs 1,91,000, refusing to pay Rs 42,000 which were billed extra for oxygen etc. This particular hospital had refused to admit us unless we had Mediclaim. Despite complying with all their conditions, the management hassled us for the bill settlement after the discharge.

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23 The price of my father's hospital stay was our ancestral land

Case synopsis

Govind Achekar, a 62 year old farmer from a small village in Kolhapur fell ill in November 2020. When treatment at the local doctor could not help him recover, his family took him to Kolhapur city in an ambulance where they made the rounds of some hospitals which refused to admit him as his condition was deemed critical. He was finally admitted in a private multi-specialty hospital in the ICU and treated for a viral infection, due to which he was given plasma therapy and dialysis. The family was never informed about the exact cause of his illness, nor were they allowed to see him, as hospital premises were sealed due to COVID-19. When a bed sore he developed during his 16 day long stay in the ICU did not heal even after a week, the family had to ask for Govind's discharge after 26 days, as they ran out of money. They were forced to sell their farm to settle the hospital bill of Rs 6,00,000 in cash, as the management had told them that Govind's illness was not covered under any MJPJAY category and they did not know whom to approach for assistance with the scheme.

“ Testimony

My father Govind Acharekar was 62 years old. He was a farmer and had a pension of Rs 1,700 a month from his job at the sugar factory. We live in a village close to Kolhapur.

In November 2020, my father had some pain and bloating in his stomach so we took him to the local doctor's clinic for admission. He then got a cold and fever, so we took him to a specialist doctor. He prescribed some medicines and assured us that my father would feel well in four days. If he didn't recover, he would then admit my father and give him IV fluids and antibiotics. As he didn't feel better, we took him again to the doctor on the 29th and 30th of November. After some blood tests, the doctor told us that my father's oxygen level and platelet count had gone down quite a bit and advised us to take our father to Kolhapur. My father became increasingly anxious as people came to meet him on hearing the news. We hired an ambulance and took him to Kolhapur. He even had a minor convulsion, for which he was given emergency first aid treatment by a hospital.

In Kolhapur, we were turned away by a couple of hospitals who said they would not accept critical cases. We then found a private multi-specialty hospital which had

available beds. My father was admitted there on the 1st of December. His oxygen levels were very low by then. My father stayed there for a total of almost 26 days. On admission, he was immediately tested for COVID-19, blood and urine along with a CT scan.

My father was in a coma for the first two to three days. The doctors were unable to diagnose what was wrong with him. On the fifth day, they told us it was a viral infection of the blood and he needed plasma therapy and dialysis as his kidneys were failing. We used to just get notes from the hospital staff, asking us to get a list of medicines from the in-house medical store. We just used to buy the medicines and give them to the ICU nurse on the second floor.

We had no idea what investigations were being conducted, since we were not allowed to come inside the hospital premises - we were just paying the bill. We were taken inside the ICU just once for a minute or so to see him. Otherwise, they just used to tell us every day that your patient is conscious, able to open his eyes and move all four limbs. We were informed that my father was not responding to plasma therapy. But he held on and slowly his condition stabilised.

On the 16th day, when he was transferred from the ICU to the general ward, we found that he had developed a huge bed sore on his back. The doctor told us it was normal to develop such a sore as he had been lying in bed in the ICU for 15 days and that it would heal in a few days after dressing and treatment. But the bed sore didn't heal even after a week; it was a four inch wide and deep wound that caused him so much agony. A doctor used to come and dress it daily but we could see that it would take much longer than a few days.

One illness and hospital admission robbed us of our land - our only source of income.

We are not that well to do and it was with a sense of helplessness that we informed the doctors that we could not afford his hospital stay any more. If the bed sore took a month or longer to heal, where would we bring the money from to keep him in the hospital that long? Even the general ward costed Rs 4500 a day. We reluctantly requested for a discharge on the 26th of December.

The hospital authorities did not share any information about the government MJPJAY scheme throughout his hospitalisation. **Since we were MJPJAY beneficiaries, we enquired with the hospital if my father's condition would be covered under the scheme. The hospital said no, it was a viral illness and it did not fit into any of the MJPJAY categories. They made it clear that we would have to foot the bill ourselves. We did not know how to pursue the matter further.**

The bills were very hefty. The hospital bill came to Rs 3,12,500, the pharmacy bill was Rs 1,57,00 and the investigations came to Rs 1,25,000. **We sold the little bit of ancestral land that we possessed to pay the bills; that too at a great loss. People saw an opportunity and exploited our predicament because we were vulnerable. That land was our only source of income.** We only sold it because of financial difficulties. I only wish my father had recovered sooner - we would not have found ourselves in this situation.

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Analytical reflections



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Analytical reflections

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The collage of patients' cases in this compendium represents the traumatic experiences of several patients, who sought healthcare from private hospitals during first wave of the COVID-19 pandemic. Though these stories belong to certain rural, peri-urban and urban parts of Maharashtra state, they appear to be ubiquitous to patients seeking care from the private sector across the country. Barring some honourable exceptions, these experiences are relatable to the majority of private healthcare establishments in India during the COVID-19 pandemic. These are indeed powerful testimonies concerning private hospitals, related to instances of overcharging, violating government regulations, denial of free care under state supported health insurance schemes, and violation of basic patients' rights such as not giving medical reports, proper bill, detaining the dead body of patients to extract charges etc. These stories reflect the vulnerability and helplessness of a large segment of people to access healthcare in the emergency situation of the COVID-19 pandemic. Moreover, they illustrate how people had to struggle for health care, how people had to resort to private sector due to shortage of resources with public hospitals, their piteous efforts to raise money for paying hefty bills of private hospitals, and their suffering with catastrophic loss of their near ones as well as of money. It also exposes how private hospitals capitalise on this situation, and continue profiteering with impunity based on irrational treatment and rampant overcharging of patients. At deeper level, it demonstrates the character of ruthless privatisation that operates in health care and ultimately highlights the failure of regulation of private sector during the crisis.

Commercialised private sector blatantly defying state regulatory measures

The pandemic has brutally exposed the consequences of highly commercialised and weakly regulated private healthcare, and innumerable patients have faced the brunt of this combination of private sector impunity and state impotence. In the wake of widespread overcharging of patients, various state governments issued orders to fix prices during the COVID-19 pandemic making use of provisions under the Epidemics

Diseases Act, 1897 and the Disaster Management Act, 2005. Given the backdrop of neglect of private health sector regulation since few decades, it is notable that around fifteen Indian state governments' have proactively intervened to fix the rates of treatment in the private healthcare sector¹. Maharashtra was in the forefront for taking these welcome steps. However, as evident from these stories, in the absence of an overarching regulatory framework in place, the private sector often did not comply with these impromptu measures, and frequently continued financial extortion of patients. State orders were strongly opposed by medical lobbies in some states². Some members of the Private healthcare lobby challenged the Maharashtra State's order of fixing the prices for non-COVID-19 treatment in the High Court. Consequently, the Court quashed the state order, opining that the state has no legislative competence to regulate prices for non-COVID-19 treatments³. Consequently, patients continued to be disenfranchised to seek affordable healthcare during the pandemic.

Hospitals did not inform respondents about government measures regarding rate capping, rather they used tactics to circumvent the government regulations. In fact, it would be interesting to know how many private hospitals actually followed these measures categorically and billed patients accordingly. State measures notwithstanding, most patients were required to pay hefty deposits. Some patients were mercilessly denied admission and were threatened with discontinuing care if they did not pay their bills. The majority of respondents paid a deposit before admission to a private hospital, ranging from Rs 50,000 to 2,00,000. Patients also reported to have been charged for PPE quite exorbitantly (for example Rs 2,500 per day). While high expenditure on medicines is not a new revelation, many patients complained that private hospitals did not inform them of separate charges for medicines, or the need to buy medicines from outside, incurring additional expenses.

The stories in this compendium bring attention to the serious violation of state regulatory measures during COVID-19, as well as violation of patients' rights leading to financial exploitation and social hardship for families. This is emblematic of specific characteristics of private sector, including its relentless profit seeking behaviour, and continued reluctance of the state government to regulate the private healthcare sector. In normal times, private healthcare sector accounts for around 70% of healthcare utilisation in India. During the COVID-19 pandemic too, private sector inevitably played a dominant role. It is estimated that it has provided 76.4% of total hospitalisation care

¹ Bhuyan, A. (2020, Sep 23). Covid-19 impact: Private hospitals running losses, despite 'high' prices. *The business standard*. https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233_1.html

² Sundaram, R. (2020, July 8) Private hospitals in Tamil Nadu oppose insurance council's unrealistic covid treatment rates. *Times of India*. http://timesofindia.indiatimes.com/articleshow/76846218.cms?utm_source=contentofinterest&utm_medium=text&utm_campaign=cppst

³ In the high court of judicature at Bombay Nagpur Bench, Nagpur Writ Petition No.1936 of 2020.

during the pandemic period⁴. Having said that, the numerous incidents of overcharging, inadequate quality of care, irrational treatment, denial of care, etc. in the private sector not only in Maharashtra but across various Indian states have become a matter of grave concern.

Financial exploitation of patients and harrowing indebtedness

Exorbitant charging by private hospitals forced nearly all of these documented cases into indebtedness. Some raised money by borrowing it from friends, relatives, some had to sell off domestic animals, some were forced to sell their farms which were vital for livelihood, and became landless. Some had to exhaust their entire provident fund and lost lifelong financial security. Although out-of-pocket payments and subsequent push into debt for private hospital expenses are not new phenomena, this was perhaps more widespread and catastrophic than ever before during the COVID-19 pandemic. Some patients had first approached public hospitals or government COVID-19 centres, but since the beds or necessary treatment was not available there, they were forced to seek care from private hospitals. Even though families knew that treatment in private hospitals would be expensive, saving the lives of their loved ones was their highest priority. Some families are bearing the double burden of losing life of their family member, and being saddled with heavy debts due to hospitalisation expenses. Average costs of healthcare in India have tripled from 2005 to 2015, due to unregulated private healthcare costs⁵. This estimate comes from the 'normal' times. Given the prevalence of hefty charging and indebtedness caused during COVID-19 pandemic, the cost of healthcare is likely to have further increased. It will be relevant to assess what is the situation now and calculate people who have been pushed into poverty in the context of COVID-19.

Lack of transparency and insensitive behaviour by staff

Besides bearing the brunt of catastrophic medical expenditure, patients and relatives were plagued with other issues such as non-transparency in treatment practices, doctors' minimal or no communication with them, dereliction in quality of care, and instances of rude behaviour of staff. Some patients were charged falsely for expenses not even incurred by them. Some were not given detailed bills, while some were issued a handwritten bill on a plain piece of paper. Two respondents were given a handwritten bill for a major amount of above Rs 9,00,000! Given this situation, some patients had to struggle even for getting the proper and full bill, despite which some have still not received it. Defying the state orders to not withhold dead body of patients for any reason, some private hospitals indulged in this grossly illegal practice. Some respondents mentioned that during the entire treatment process, doctors interacted with them only to convey the bill amounts! Such experiences will have serious ramifications on doctor-patient relationship and the trust on doctors as well as on the private health care sector.

⁴ Public private partnership towards universal healthcare in India (2020). National law school of India University Bengaluru https://ahpi.in/pdf/PPP-UniversalHealthCare-in-India_ver-27Oct2020.pdf

⁵ Sundararaman, T. (2015). Falling Sick, Paying the Price. *Economic & Political Weekly*. Vol. 50, Issue No. 33.

Uphill struggle to avail entitlements of Publicly Funded Health Insurance Schemes

Availing the entitlements under MJPJAY Health insurance scheme was a nightmare for many patients. Although, the Maharashtra state government expanded coverage of MJPJAY to all residents of the state⁶, many eligible patients faced an uphill struggle to avail of scheme benefits in reality. Most private hospitals did not inform patients about this scheme. MJPJAY scheme empanelled private hospitals have refused enrolling patients under the scheme, giving excuses like – 'patient is not eligible', 'required procedures are not covered under the scheme', 'documents are incomplete', 'hospital's quota for enrolling patients under the scheme is over' and so on. Some instances of double charging by private hospitals were also noted, wherein hospitals draw funds from the official agency through the scheme, and charge the patients as well. Despite the hype around government-run health insurance programs, in reality their implementation seems severely flawed.

Violation of patients' rights and lack of effective grievance redressal

Linked with the arbitrary behaviour by many private hospitals, violation of various patients' rights⁷ was also observed to be quite prevalent during the COVID-19 pandemic. Most respondents were never informed details about the line of treatment for their patient, relevant schemes, or state's order on rate capping for COVID-19 treatment. Similarly, many cases were never issued medical reports, diagnostic test reports, or discharge summaries after medical discharge. While consent for medical procedure was largely obtained from relatives, in most instances the signature on consent form was taken in hurry without explaining to them relevant details in laypersons language. As mentioned earlier, in some cases, discharge or handing over the body of deceased patient was withheld unless the entire bills were paid, which is not only an infringement of patients' rights, but also a reflection of inhuman treatment at private hospitals.

The following patient rights were frequently violated-

- Right to information
- Right to records and reports
- Right to emergency medical care
- Right to informed consent
- Right to safety and quality as per standards
- Right to transparency in rates and care

⁶ Economic times (2020, May 2). Maharashtra to provide free health care to all under MJPJAY. Economic times. <https://health.economictimes.indiatimes.com/news/policy/maharashtra-to-provide-free-health-care-to-all-under-mjpjay/75501973>

⁷ National Human Rights Commission of India. Patient rights Charter. <https://nhrc.nic.in/document/charter-patient-rights>

- Right to be discharged, right to receive the body of a deceased person from the hospitals
- Right to be heard and seek redressal
- Right to human dignity

In the light of large number of complaints of overcharging by private hospitals, Maharashtra state government had formed committees for grievance redressal in some cities. However, some respondents felt totally exhausted with their hospital experiences, and therefore were not in a position to pursue another fight to obtain justice from complaint redressal forums. A few respondents either approached the local corporator or municipal corporation's grievance redressal committee, but except for one respondent, none received a positive outcome. Along with the necessity to generate awareness on patients' rights, while displaying and adhering to these rights, it is also essential to ensure a patient friendly grievance redressal mechanism that is effective and properly functioning.

Altogether, the COVID-19 pandemic offers us critical lessons and opportunities to strengthen the health system and to re-imagine private sector engagement in a wider framework of public health obligation and social accountability. We theorise and discuss possible ways forward towards regulating and socialising private healthcare in the subsequent section.

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After market
disaster,
what is the
way forward?

Section IV



Socially accountable regulation of Private healthcare: Now or never? Towards socially re-embedding healthcare
Developing socially grounded, interventionist regulation
Key components of the regulatory process
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Strengthening public regulatory capacity
Public in-sourcing of private providers, to strengthen publicly organised health services
Multi-stakeholder governance platforms with promotion of social accountability
Regulation of private health sector should be integrated with public health system strengthening and movement towards Universal Health Care

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After market
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a. Socially accountable regulation of Private healthcare: Now or never?

Each of these stories from the COVID epidemic drives home the harsh reality of unregulated private healthcare in India, as experienced by many ordinary patients. These are true stories, which cannot be dismissed or minimised. Such incidents were not rare exceptions, they were the part of the norm, especially during the peak of the first and second waves. This scenario of private healthcare in India during COVID can perhaps best be summarised by the term 'Market Disaster'. While Indian political leaders and policy makers under successive neoliberal regimes trumpeted their mantra - 'leave healthcare to the market', ordinary patients and people reaped the bitter harvest of Market failure, with 50-60 million Indians being pushed below the poverty line every year due to unaffordable healthcare expenses. And when COVID hit, this ongoing market failure was precipitated into market disaster, with vulnerability of families desperately seeking a hospital bed being exploited to the hilt by many private hospitals with exorbitant advances and whopping bills, often paid under severe emotional and financial duress. The glorious Market God which had been blindly worshipped by neoliberal privatisers, during COVID was revealed to be a demon which refused to be controlled by last minute, ad-hoc regulatory measures.

During the last few decades under the stern dictates of 'Market Fundamentalism' with deliberate lack of regulation promoting unfettered profit maximisation in Healthcare, Society had been pushed into the background. The needs of Market Economy prevailed over the needs of Society for affordable, rational, responsive healthcare which should have been met through robust public health services, complemented by regulated and accountable private providers. However with COVID, since the God of Market Economy failed so spectacularly and obviously, policy makers were forced to remember Society, at least temporarily. State Governments which had blatantly stonewalled persistent demands for regulation from civil society, finally bowed to the dictates of the COVID-19 virus and endorsed at least short-term regulation of rates for COVID treatment in private hospitals, though these piecemeal measures had inadequate results as revealed by this study.

In effect the toxic policy brew of under-resourced, under-staffed public health services, and completely unregulated and unaccountable private healthcare, which had been concocted by a generation of neoliberal policy makers, boiled out of the cauldron during the heat of the COVID epidemic. It became obvious even to hardcore privatisation-oriented state governments that if private hospitals were not regulated in some form now, thousands of patients might start dying without treatment outside the gates of hospitals, and rising public discontent could threaten the survival of ruling politicians. However this makeshift regulation was cobbled together overnight with outdated and inadequate legal instruments like NDMA and Epidemic Diseases Act. These patchwork regulatory efforts were stymied by the private healthcare lobby at both legal and operational levels. At the legal level, the private sector lobby was quick to challenge the validity of these legal instruments, as evidenced by their petition to Nagpur bench of Mumbai High court, which ruled that Maharashtra government had no legal mandate to regulate rates for non-COVID services during the epidemic. And at the ground level, as revealed by each of these case studies, many private providers used their entire bag of tricks to evade, dilute and circumvent the regulations. There were honourable exceptions such as certain genuinely not-for-profit hospitals and some smaller providers, who responded to people's desperate need for care without always prioritising profits. But these islands of hope were overshadowed in the sea of profiteering, which was witnessed during the COVID epidemic.

We would all agree that no society should ever witness again what has been experienced during the COVID epidemic by patients in Maharashtra and many other states of India. Under no circumstances should Healthcare be left to the unregulated market anymore. Here the main plank of change must naturally be major expansion and reorientation of public health services, ensuring that these become effective, adequate and responsive to people's needs. Further in context of this study, we will deal with policy actions that must be taken in complementary manner regarding the massive private healthcare sector – the powerful genie which has been let free from the bottle of regulation until now.

b. 'Market efficiency' does not mean social effectiveness

Before coming to what might work, let us first review **what will not work, mainly because it has not worked until now**. *Firstly, after the COVID epidemic private healthcare must definitely not be allowed to return to 'Business as usual'*. After tens of thousands of families have been devastated due to unwarranted catastrophic expenditures, we cannot buy the 'few Black sheep' argument anymore. Profiteering is not the exception, it is the widespread rule – and this situation will continue until standard rates are legally ensured. Nor can we remain gullible enough to swallow the claim that 'doctors will self-regulate themselves' since that has never happened, and will never happen in India at least.

Secondly, the bombastic claims that Ayushman Bharat – PMJAY and related Health insurance schemes will solve all the healthcare problems of the poor, have proven to be a poor joke during COVID-19. As evidenced by the cases in this study, despite Maharashtra State government expanding the scope of MPJAY to cover the entire population, very few COVID patients effectively benefited from this scheme. Expecting otherwise completely unregulated and unaccountable private providers to magically start behaving rationally and sensitively towards patients and to give up profiteering, just because they are included in a particular scheme is indulging in wishful thinking.

Experience until now shows that providing public funds to unregulated private providers in the absence of a range of larger regulatory policy changes, is likely to further fuel profiteering, rather than containing it.

Thirdly we need to debunk and dismiss Niti Aayog's recent prescriptions for accelerated privatisation and corporatisation of healthcare, which are linked with their eager invitations to multinational capital, inviting it to further invest in Indian healthcare. These prescriptions have been dealt with elsewhere¹ so we will not describe these in detail. However, suffice it to say that advocating for further privatisation of healthcare to solve the problems created by a highly privatised healthcare system, is like trying to extinguish a fire by pouring petrol on it!

Finally, we should note that schemata for purely bureaucratic regulation which ignore the imperative for active social accountability and participation, and the key role of civil society actors in the regulatory process, are not likely to work. Similarly approaches which neglect the specific conditions of smaller, rural and not for profit providers will not achieve the desired objectives in the complex setting of highly differentiated healthcare provisioning in India. Such efforts of continuing 'more of the same' are likely to perpetuate the existing regulatory stalemate, or might result in a pro-corporate regulatory framework which relegates people to the sidelines, while further marginalising smaller and not-for-profit providers, whereby the cure could become worse than the disease.

c. Towards socially re-embedding healthcare

Writing in the aftermath of the Great depression, the economist Karl Polanyi² wrote about how Capitalism had converted Land and Labour into 'fictitious commodities'. These complex, multi-dimensional entities had always been deeply embedded in nature and society, but Capitalism wrenched them from their social roots, converting them into commodities and thrusting them entirely into the clutches of market mechanisms, leading to massive distortions and negative impacts for society. On the same lines, we can talk of **Healthcare as a 'contentious commodity'**³ since there is a deep and inherent tension in any framework which treats healthcare as a commodity. While training of healthcare providers and setting up of healthcare institutions are socially supported on the grounds that they should fulfill social objectives, their product i.e. healthcare services are supposed to be distributed purely on market lines, going only to those who can pay the market-driven maximised price.

We would recognise that historically in any society including India, Healthcare providers and institutions are deeply social embedded. Social ties and trust between healers and patients, relationships of patients with their doctors and health workers, the ritual status of doctors, and the socially recognised vulnerabilities and roles of patients, these are all

¹ Marathe, S. (2021). Lessons from COVID 19: strengthening the public health system in India or accelerating privatisation. BMJ blog series. <https://blogs.bmj.com/bmjgh/2021/09/04/lessons-from-covid-19-strengthening-the-public-health-system-in-india-or-accelerating-privatisation/>

² Polanyi, K. (1944), *The Great Transformation*, Beacon Press, Boston

³ Mackintosh, M. (2006). Commercialization, inequality and the limits to transition in health care: a Polanyian framework for policy analysis. *Journal of International Development*. 18(3):393-406

shaped through a complex web of social relationships. In any modern society, the availability of equitable, accessible and good quality healthcare to all its members should form the main rationale of the healthcare system; *this social rationale must be the primary foundation on which any healthcare system is designed and shaped*. It is on this basis that society and the state provide huge direct and indirect subsidies for medical education, as well as for setting up medical establishments. However over last few decades with growing commercialisation of healthcare, previously socially embedded individual and private (including not-for-profit) providers have become more and more hijacked by market forces. This has led to massive, widening inequities in access to care, as well as various distortions related to rationality and quality of care. *This process takes its extreme form with corporatisation of health care, whereby the healthcare enterprise becomes completely socially disembedded and detached from any social anchoring and becomes exclusively dictated by finance capital driven by aggressive profit maximisation, at huge cost to patients, health workers and society.*

It's time to re-socialise healthcare. In his classic work 'The Great Transformation'⁴, Polanyi also describes the 'Double movement' which takes place under Capitalism. The 'first movement' consists of push by various sections of capital to enlarge the scope of markets, greatly expanding commodification. This inevitably results in various socially damaging impacts, and is then followed by the 'second movement' for social protection, consisting of counter-initiatives by a wide range of social actors to protect social life from the destructive influences of commodification and unfettered market dynamics.

Whether we endorse Polanyi's specific framework or not, we might agree today that given people's catastrophic experiences during the COVID epidemic, **the time has come to now definitively launch a comprehensive countermovement on Health care.** Healthcare which has been a 'contentious commodity' must now become less and less of a commodity, and ultimately should become a universally accessible social good. In the Indian context, this would require two complementary arms of action. The first and most important is major strengthening and expansion of public health services, while ensuring their accessibility, quality and responsiveness for all sections of society, especially the deprived and marginalised. The second is regulation and progressive socialisation of private healthcare. As part of 'Building back better' beyond COVID, both of these policy actions would need to be integrated as part of the movement towards a system of Public-centred Universal Health Care (not to be confused with insurance based 'Coverage').

d. Developing socially grounded, interventionist regulation

In India most current private healthcare regulatory acts at state level are confined to 'registration and elementary infrastructural standards'. Due to continued resistance from the private sector lobby, such acts are limited to just registering private healthcare establishments, while attempting to lay down some baseline standards regarding physical and human power requirements. Given the current stalemate regarding implementation of the Central CEA (2010), despite certain important provisions contained in the Rules (2012), this national regulation is also yet to be effectively implemented on the ground in the states which have adopted the act, being blocked at

⁴ Polanyi, K. (1944), *The Great Transformation*, Beacon Press, Boston

stage of provisional registration. Such '**minimalistic' regulations might at best 'streamline' the market** by ensuring some infrastructural standards (likely to benefit corporate and larger for-profit providers who want to capture larger market share) but **have proven to be completely ineffective in correcting market failures**. Hence until now patients in India have received no protection from existing regulations regarding widespread overcharging, irrational care and violations of patients' rights in private hospitals.

At the same time, **while envisioning regulation we cannot remain 'agnostic' about the state of the rapidly changing healthcare market. We need to pay keen attention to growing corporatisation of healthcare in various forms** (which is linked with aggressive penetration by finance capital), and declining financial viability of smaller and not-for-profit providers. As any leader of a genuinely not-for-profit healthcare establishment will attest, in the current situation it is practically impossible to properly sustain such hospitals without some form of social or external financial subsidisation. With the pressure of continually unfolding technological upgradations, the rising financial expectations of specialist doctors (who are often the product of expensive private medical education) and spiralling costs of real estate in larger cities, it is often increasingly difficult for individual doctors to set up new small / medium hospitals and run these even on a 'break-even' basis. Hence growing financialisation (which often appears in the form of the 'EMI demon') and corporatisation of healthcare tends to 'infect' the practices of even hitherto 'charitable', medium and smaller providers⁵, pushing them into irrational and exploitative practices, as well as becoming enmeshed in the net of 'commissions and cuts' to maintain their financial viability and market share.

In this scenario, '**minimalist regulation' or 'legalistic regulation' are of no value to correct market failures**, these cannot reshape the market to counter monopolistic tendencies which inevitably arise from unfettered markets in any sector, neither can these reorient the health sector to meet social goals in effective manner. To break through the current regulatory stalemate, we need to imagine '**interventionist regulation' which has explicit objectives of countering market failures, reshaping the market towards furthering various social goals, and progressively removing healthcare from vagaries and distortions of the market**, towards making it a social good. This kind of regulation would have as its core objective, expansion of 'public logic' and rolling back of 'profiteering logic' in the health sector. Expansion of public logic would entail enlarging and strengthening public health services, as well as ensuring adequately staffed and resourced, effective public regulatory machinery at various levels to implement legislation for regulation of private healthcare providers.

Interventionist regulation would involve bringing the social back into regulation, since laws will be necessary but not sufficient; they must be accompanied by social accountability mechanisms and participatory governance. People and patients will need to be recognised as major stakeholders in the entire regulatory endeavour. Structures, processes and culture of social accountability and regulation of healthcare would need to be developed in integrated manner, since legal provisions alone have proved to be of limited value.

⁵ SATHI (2021). Growing Corporatisation of Private Healthcare in India and its Implications. Policy brief. Pune, September 2021.

The process of regulation must simultaneously bring social goals of affordable, rational, accountable healthcare centre-stage, while also countering corporatisation and commercialisation of healthcare. Corporate and large for-profit providers may be taxed at higher levels, while measures like regulation of rates would differentially impact them more, curbing their profiteering practices. There is also need to reorient more socially embedded providers such as not-for-profit, smaller and rural providers towards public health goals through supportive intervention by the state. Evolving such regulation would require a powerful public process to reclaim the healthcare sector and bring it increasingly under social control using laws and regulations, social accountability mechanisms, and strategic public funding, which would be used as complementary levers.

e. Key components of the regulatory process⁶

It is obvious that developing socially grounded, interventionist regulation will be an extended process, not a one-time change. This would be an unfolding, learning process regarding which we can only sketch the broad contours now, since many aspects will emerge as policy actions are implemented in a complex and contested context. Here we will deal with a set of recommendations related to Maharashtra state, which would however be relevant for most other states as well as for national regulatory processes.

i. Legal regulation: Enactment and effective implementation of appropriate Clinical Establishments Act (CEA)

Especially keeping in view lessons from the COVID 19 pandemic, central features of such Maharashtra CEA should include transparency in charges while moving towards standardisation of rates in private hospitals, observance of standard treatment protocols, protection of patients' rights and checking malpractices.

The government should undertake comprehensive analysis about costing of healthcare to generate evidence-based data, which would demystify healthcare costs. This analysis can be used to formulate viable pricing options that are cost-effective and assure optimal quality of care and health outcomes in hospitals, and are acceptable to large sections of the private healthcare sector.

However, the government would also need to adopt innovative approaches and affirmative action plans to improve compliance and overcome deeply entrenched resistance to regulation in the private sector. This may include building the capacity of private providers to meet standards such as ensuring transparency of rates, followed by capping of rates in private health facilities while fostering a culture of accountability, transparency and good governance in the healthcare sector. There is also need to address certain genuine regulatory issues faced by the private healthcare sector, such as their demands for a single window mechanism for registration and grievance redressal, and flexibility in infrastructural and human resource standards, particularly in rural and remote areas.

⁶ This section is based on summarization and adaptation of the sub-section 'Directions for government action on regulation of private healthcare' in Section III of the working paper – Shukla, A., Pawar, K., & More A. (2021). Analysing regulation of private healthcare in India. Oxfam, India. <https://www.oxfamindia.org/knowledgehub/workingpaper/analysing-regulation-private-healthcare-india>

In particular, the regulatory process must adopt a differential approach to different kinds of private providers, taking into consideration the genuine issues faced by individual practitioners, smaller clinical establishments and not-for-profit providers while meeting infrastructure standards, and their ability to meet the costs of regulatory compliance.

ii. Universal implementation and social awareness regarding Patient Rights Charter

The NHRC Patient Rights Charter (Annexure B) should be included in standards of the Clinical Establishment Act, and must be made legally mandatory in all clinical establishments. This should be accompanied by ensuring very wide publicity to the Charter in Marathi and other locally spoken languages, with involvement of mass media as well as variety of civil society organisations. The State government should also respond to patients' rights groups who have pointed out the inefficiencies and biased nature of current grievance redressal mechanisms (such as Medical Councils) for victims of medical negligence and malpractice. There is need to establish an accessible Patient grievance redressal mechanism which is objective, prompt and people friendly.

iii. Strengthening public regulatory capacity

Moving beyond neoliberal prescriptions for 'minimum government', it is necessary to ensure the legal formation of adequately staffed, full time public regulatory authorities functioning at state and district / city levels, which will regulate the standards, rationality, quality and costs concerning healthcare in all private hospitals and health facilities. Legal regulatory provisions must specify allotment of sufficient human resources to operate regulatory agencies like State Health councils and District Registering Authorities, along with additional staff for inspections and grievance redressal. This would make it feasible for them to enact, monitor and enforce regulatory provisions in the CEA in an efficient, independent and transparent manner.

iv. Public in-sourcing of private providers, to strengthen publicly organised health services

Especially keeping in view the COVID experience, State government should progressively in-source private healthcare providers by bringing under public direction a large proportion of beds in all private hospitals above a specified minimum size. This publicly funded measure could replace the problematic MPJAY scheme (associated with PMJAY), which has proved to be grossly inadequate for dealing with the challenge of the COVID-19 epidemic.⁷ The cost of maintaining engaged beds would be properly and promptly reimbursed by the public system to the concerned private providers. These would be utilised as an extension of the public health system, to provide tax funded and free healthcare to a progressively increasing proportion of the population.

⁷ Torgalkar, V (2020, Oct 10). Less than 4% COVID-19 patients benefit from Maharashtra's free private treatment schemes. Newsclick. <https://www.newsclick.in/Less-4%25-COVID-19-Patients-Benefit-Maharashtra-Free-Private-Treatment-Scheme-Pune-Data-Shows>

v. Multi-stakeholder governance platforms with promotion of social accountability

'Social regulation' refers to action-oriented approaches designed to reinvent and democratise regulation, with greater participation and accountability of the regulatory process to users and the public. Patient's Rights can be used as a fulcrum for social mobilisation related to regulation and demanding substantial representation of civil society, citizens, especially from marginalised communities in the regulatory framework.⁸

The State government must create spaces for civic engagement in healthcare governance, by ensuring multi-stakeholder bodies at district, city and state levels. These should be converted into truly inclusive platforms for diverse stakeholders including government health officials, healthcare providers, representatives of frontline doctors, nurses and health staff from public and private hospitals, civil society organisations, health rights and patients' groups and consumer forums. These councils should also include a gender and inclusivity component, which addresses gendered and socially marginalised vulnerabilities in healthcare. The experiences and lessons from participatory Health councils in Brazil⁹ and Health Assemblies in Thailand¹⁰ can provide useful inputs in creating spaces for meaningful engagement of people with policy making processes. Based on the principle of participatory governance of health systems, such platforms would help to monitor delivery of quality healthcare services, could represent and address healthcare concerns of the most vulnerable and marginalised communities, can facilitate social accountability of public and private healthcare providers while preventing corruption and mismanagement, and would help to address genuine concerns of healthcare providers and rights of healthcare staff.

*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**¹¹.*

⁸ Working paper. South Asia level Learning Exchange Workshop on Patient's Rights, Thematic Hub. 2018. https://www.copasah.net/uploads/1/2/6/4/12642634/working_paper-pvt_sector.pdf

⁹ Mayka, L. (2019). Brazil's Health Councils: Successful Institution Building through Sweeping Reform. In Building Participatory Institutions in Latin America: Reform Coalitions and Institutional Change (pp. 98-139). Cambridge: Cambridge University Press. doi:10.1017/9781108598927.004

¹⁰ Rajan, D., Mathurapote, N., Putthasri, W., et al. (2019). Institutionalising participatory health governance: lessons from nine years of the National Health Assembly model in Thailand. *BMJ Global Health*. 4:e001769.

¹¹ Shukla, A., More, A., and Marathe, S. (2018). Making Private Health Care Accountable: Mobilising Civil Society and Ethical Doctors in India in *IDS Bulletin* Vol. 49 No. 2 March 2018. <https://bulletin.ids.ac.uk/index.php/idsbo/article/view/2970>

It should be emphasised that the culture of accountability must include the regulators themselves, so that regulation does not reinforce corruption and rent seeking from providers, but rather it is transparent and open to scrutiny by all stakeholders. This would ensure that public goals of regulation are maximally achieved, while distortions (such as evading standards through bribing of regulators) are minimised.

vi. Regulation of private health sector should be integrated with public health system strengthening and movement towards Universal Health Care

The processes of regulation and progressive socialisation of private healthcare will need to proceed in tandem. Public in-sourcing will be ineffective if not accompanied by ensuring standards of care, however ensuring regulatory standards will be facilitated if accompanied by use of public funds and authority to leverage care from private providers; *'Those who pay the piper, can call the tune'*.

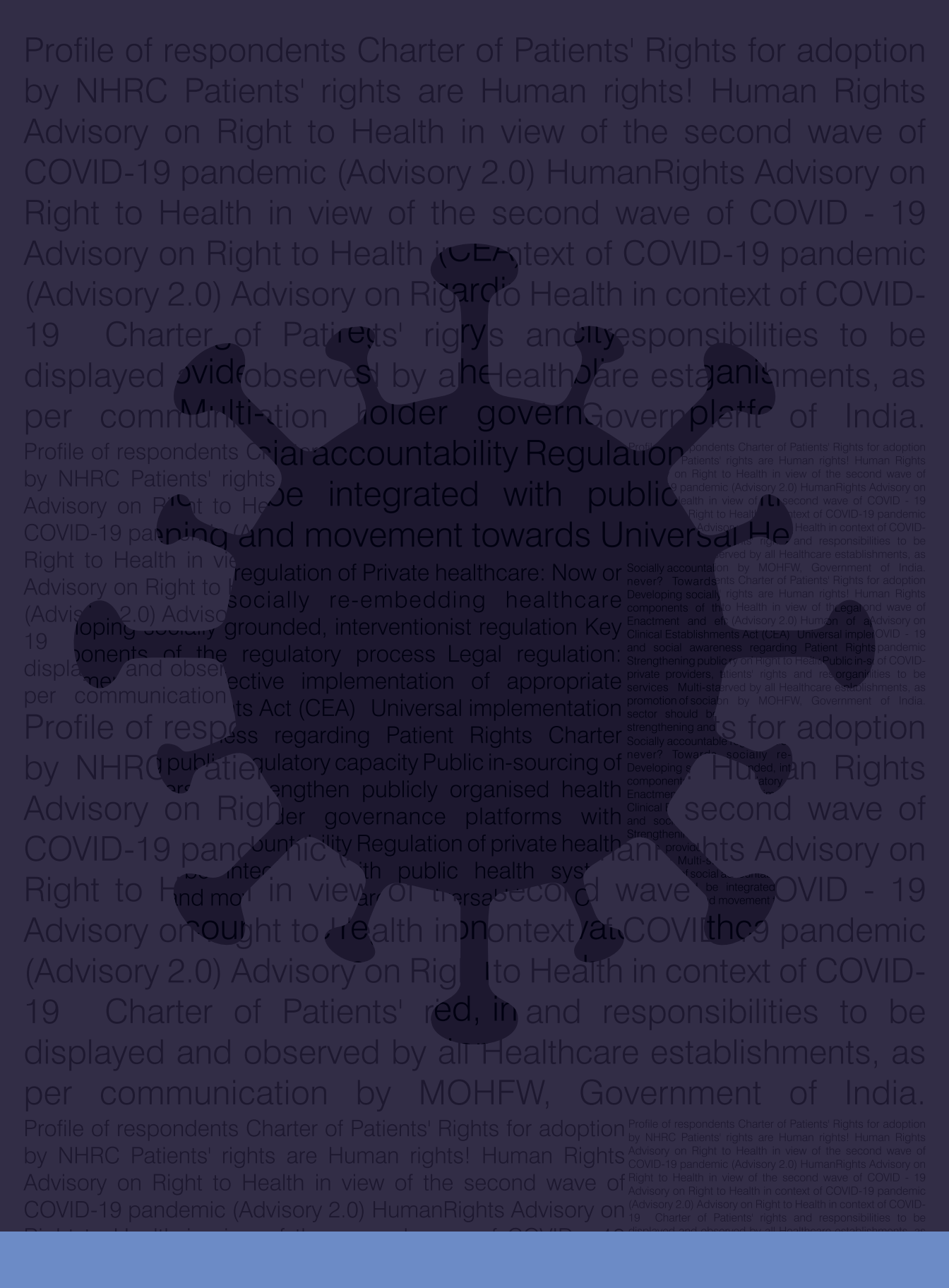
Maharashtra government will need to move towards developing a Public-centred system of Universal Health Care (not 'Coverage'), which will be significantly based on **expanded and strengthened public provisioning**, which in itself can prove to be a major check and counter-balance to arbitrary behaviour by private healthcare providers. Further, bringing private healthcare resources under public management through in-sourcing of private healthcare providers would be one of the 'building blocks' for UHC. Some steps in this direction could be **provision of free healthcare to all formal and informal sector workers** (including rural cultivators and workers, and self-employed), which would be based on strengthened public and insourced private providers. This could move much beyond and replace the current MPJAY scheme. Similarly tax funded, free healthcare services should be provided universally for maternal and child health. These actions would help to create a realistic and popularly supported foundation for Universal Health Care, which is publicly funded and organised, and is free of cost to ordinary people.

To conclude, there is now need to confront the 'culture of impunity' promoted by the commercialised private healthcare sector, replacing this by a new public-centred social compact. This must squarely and explicitly place the social imperative for universal, equitable, free or rate-regulated, rational healthcare above market driven profiteering in healthcare. Under this new social compact, interactions between public agencies and private providers will not be optional, allowing cherry picking and optional involvement as per current health insurance schemes, but rather will be binding and legally enforced with social backing. Rather than market driven profiteering ruling the roost, the terms will be set with public interests being firmly held paramount. This will need to be the way forward, if as a society we are to learn the glaring lessons emerging from market disaster during the COVID-19 epidemic; if we seek to prevent further such disasters which could devastate any of us, healthcare must become a social good accessible to all of us.



Annexures





Profile of respondents Charter of Patients' Rights for adoption by NHRC Patients' rights are Human rights! Human Rights Advisory on Right to Health in view of the second wave of COVID-19 pandemic (Advisory 2.0) HumanRights Advisory on Right to Health in view of the second wave of COVID - 19 Advisory on Right to Health in context of COVID-19 pandemic (Advisory 2.0) Advisory on Right to Health in context of COVID-19 Charter of Patients' rights and responsibilities to be displayed and observed by all Healthcare establishments, as per communication by MOHFW, Government of India.

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Annexure A - Profile of respondents

Code	Story title	Age of patient (Years)	Sex of patient	Geographic location of patient	Occupation of patient	Types of health institution accessed for treatment	Date of the incidence	Co-morbidities	Health-care intervention	Total bill (in Rs)	Deposit taken by hospital (in Rs)	Number of days of hospitalisation	Health outcome	Redressal mechanisms approached, if any
1.	Victims of non-responsive private hospital	48	M	Kolhapur	Teacher	Rural hospital and big private hospital	Sep 2020	No	COVID -19	Rs 14,21,000	Rs 1,50,000	25 days	Death	NO
2.	My struggle to avail the publicly funded health insurance scheme (MJPJAY)	65	F	Pune city	Housewife	Big charitable trust hospital	July 2020	Diabetes, BP	COVID -19	Rs 1,12,000 plus Rs 20,000 advance, Rs 20,000 for days when scheme not approved, Rs 70,000 medicine	Rs 25,000	15 days	Recovered	MJPJAY district coordinator, Deputy collector, the local corporator and other political leaders
3.	In our country, only wealth can help bring health back	40	M	Bhor, Pune	Service in co-op society	Private hospital- approved as COVID center	Aug 2020	No	COVID -19	Rs 3,00,000 (stay-Rs 1,65,000, PPE- Rs 44,000 at 2200 Rs/day, medicine- Rs 1,27,000, lab- Rs 25,000)	Not mentioned	22 days	Recovered	
4.	Unending demands for money and unanswered questions till the end	30	M	Kolhapur	Small shoe shop owner	3 small-med private hospitals	Oct 2020	No	COVID -19	Rs 1,50,000	Rs 50,000	2 days	Death	
5.	Desperate and futile struggle against COVID-19 and hospital	38	M	Kolhapur	Labour contractor	Govt covid care then to small private hospital	July 2020	No	COVID -19	Rs 2,95,000 plus medicines Rs 89,000	Rs 50,000	9 days	Death	
6.	Inflated charges and incomplete information	72	F	Yavatmal	Senior citizen	Small private hospital	Aug 2020	Yes	COVID -19	Rs 1,48,000	Rs 80,000	5 days	Death	NO

Code	Story title	Age of patient (Years)	Sex of patient	Geographic location of patient	Occupation of patient	Types of health institution accessed for treatment	Date of the incidence	Co-morbidities	Health-care intervention	Total bill (in Rs)	Deposit taken by hospital (in Rs)	Number of days of hospitalisation	Health outcome	Redressal mechanisms approached, if any
7.	Health insurance coverage denied to eligible patient despite efforts	65	F	Pune -urban	Waste picker	Big Charitable trust hospital, Private Medical college hospital	Dec 2020	plus other medical condition	COVID -19	Rs 1,13,000	Rs 35,000	15 days	Recovered	Complaint letter submitted to MJPJAY district Committee
8.	Did my mother really die of COVID-19?	67	F	Yavatmal	Not working, senior citizen	Govt and small hospital	Sep 2020	Asthma	Asthma, pneumonia	Rs 73,000 (inclu. Rs 16,000 of ambulance, Rs 1,500 of gloves) plus medicines- Rs 1,30,000	Rs 1,00,000	4 days	Death	NO
9.	Exorbitant yet negligent hospital and disappointment with grievance redressal forum	85	F	Pune urban	Retired	Big corporate hospital	July 2020	NO	COVID-19	Rs 2,80,000	Rs 50,000	15 days	Recovered	Complaint submitted to Redressal Grievance Cell of Pune Municipality
10.	No COVID-19 scheme benefits, no beds in government hospitals	65	F	Pune, Nasarapur	Small ladies shoppie	Small private hospital	July 2020	NO	COVID-19	Rs 1,27,000 plus medicines Rs 80,000	Rs 50,000	12 days	Recovered	NO
11.	COVID-19, cha.os and fake reports	55	M	Bhor, Pune	Watchman	Small private hospital and then govt COVID center	Sep 2020	Severe Anaemia, Piles	COVID-19 positive	Total Rs 1,04,000	Not mentioned	10 days	Death	NO
12.	We were cheated by a corporate hospital	60	M	CIDCO, Belapur	Doctor	Corporate hospital		Yes	COVID-19	Rs 1,40,000	Rs 2,50,000	25 days	Death	Complaint submitted to Mumbai Municipality Grievance Cell
13.	Debt and disease go hand in hand in my village	52	M	Bhor, Pune	Farmer	PHC then small private hospital	August 2020	NO	COVID-19	Total- Rs 3,00,000 Hospital bill- Rs 1,89,000, for medicines- Rs 1,18,000	Rs 50,000	18days	Recovered	NO
14.	Advance cash deposits first	30	M	Kolhapur- Rural	Mobile repairer	Two medium sized Private hospital	Sep 2020	NO	COVID-19	Rs 3,25,000 plus Rs 63,000	Rs 20,000	10 days	Death	NO

Code	Story title	Age of patient (Years)	Sex of patient	Geographic location of patient	Occupation of patient	Types of health institution accessed for treatment	Date of the incidence	Co-morbidities	Health-care intervention	Total bill (in Rs)	Deposit taken by hospital (in Rs)	Number of days of hospitalisation	Health outcome	Redressal mechanisms approached, if any
15.	Advance deposits were compulsory despite cashless mediclaim	Above 60	M	Nashik-Rural	Service	Big Corporate hospital	Oct 2020	Initial diagnosis was pneumonia	COVID-19	Rs 3,19,000 (Refunded Rs 2,00,000 after passing insurance)	Rs 20,000	7 days	Recovered	NO
16.	Cash and connections for COVID-19 care	65	M	Sangali	Senior citizen	Medical college private hospital	Sep 2020	NO	COVID-19	Rs 1,41,000	Rs 25,000	10 days	Death	NO
17.	Government scheme failed, leaving us in debt	60	M	Bhor, Pune	Senior citizen	Medium private hospital	Oct 2020	NO	COVID-19	Rs 1,90,000 inclu. medicines of Rs 90,000	Info not available	12 days	Recovered	NO
18.	No schemes for critical patients	75	F	Kolhapur	Farmer	Govt COVID center then medium private hospital	Sep 2020	NO	COVID-19	Rs 5,60,000	Info not available	17 days	Recovered	NO
19.	Is treatment only for those who can afford to pay hospital 'packages'?	Missing	M	Kolhapur	Info not available	Medium private hospital	Aug 2020	NO	Pneumonia	Rs 1,03,000, inclu. medicines- Rs 25,000	Info not available	10 days	Death	NO
20.	I was never COVID-19 positive but treated for COVID-19	48	M	Nashik	Taxi driver	Medium private hospital	Aug 2020	NO	COVID-19	Rs 1,25,000	Info not available	5 days	Recovered	NO
21.	Exorbitant COVID care, failed health insurance	43	M	Nashik	Info not available	Medium private hospital	Aug 2020	NO	COVID-19	Rs 1,76,000	Rs 25,000	9 days	Recovered	NO
22.	Mediclaim-Licence to loot patients	24	M	Nashik	Info not available	Medium private hospital	Aug 2020	NO	COVID-19	Rs 75,000	Info not available	5 days	Recovered	NO
23.	The price of my father's hospital stay was our ancestral land	62	M	Kolhapur	Worker in factory	Medium private hospital	Nov 2020	NO	COVID-19 plus other complications- COMA, blood viral infection plasma therapy	Rs 3,25,000 inclu. diagnostic tests- Rs 1,57,000	Info not available	27days		NO



Patients'
rights
are
Human
rights!

Charter of Patients' Rights for adoption by NHRC

Preamble

The Universal Declaration of Human Rights (1948) emphasizes the fundamental dignity and equality of all human beings. Based on this concept, the notion of Patient Rights has been developed across the globe in the last few decades. There is a growing consensus at international level that all patients must enjoy certain basic rights. In other words, the patient is entitled to certain amount of protection to be ensured by physicians, healthcare providers and the State, which have been codified in various societies and countries in the form of Charters of Patient's Rights. In India, there are various legal provisions related to Patient's Rights which are scattered across different legal documents e.g. The Constitution of India, Article 21, Indian Medical Council (Professional Conduct, Etiquette and Ethics) Regulations 2002; The Consumer Protection Act 1986; Drugs and Cosmetic Act 1940, Clinical Establishment Act 2010 and rules and standards framed therein; various judgments given by Hon'ble Supreme Court of India and decisions of the National Consumer Disputes Redressal Commission.

This Charter of Patient's Rights adopted by the National Human Rights Commission¹ draws upon all relevant provisions, inspired by international charters and guided by national level provisions, with the objective of consolidating these into a single document, thereby making them publicly known in a coherent manner. There is an expectation that this document will act as a guidance document for the Union Government and State Governments to formulate concrete mechanisms so that Patient's Rights are given adequate protection and operational mechanisms are set up to make these rights functional and enforceable by law. This is especially important and an urgent need at the present juncture because India does not have a dedicated regulator like other countries and the existing regulations in the interest of patients, governing the healthcare delivery system is on the anvil, some States have adopted the national Clinical Establishments Act 2010, certain other States have enacted their own State level legislations like the Nursing Homes Act to regulate hospitals, while a few other States are in the process of adopting / developing such regulation. The Charter of Patient's Rights has been drafted with the hope that it shall be incorporated by policy makers in all existing and emerging regulatory legislations concerning the health care sector. This charter would also enable various kinds

¹ National Human Rights Commission of India. Patient rights Charter. <https://nhrc.nic.in/document/charter-patient-rights>

of health care providers to actively engage with this framework of patients' rights to ensure their observance, while also benefiting from the formal codification of patients responsibilities.

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

NHRC believes that this Charter of Patients' Rights will be an enabling document to ensure the protection and promotion of Human rights of those who are among some of the most vulnerable sections of society – ordinary patients and citizens seeking health care across India.

No.	Rights of patients	Description of rights and associated duty bearers	Reference
1	Right to information	<p>Every patient has a right to adequate relevant information about the nature, cause of illness, provisional / confirmed diagnosis, proposed investigations and management, and possible complications To be explained at their level of understanding in language known to them.</p> <p>The treating physician has a duty to ensure that this information is provided in simple and intelligible language to the patient to be communicated either personally by the physician, or by means of his / her qualified assistants.</p> <p>Every patient and his/her designated caretaker have the right to factual information regarding the expected cost of treatment based on evidence. The hospital management has a duty to communicate this information in writing to the patient and his/her designated caretaker. They should also be informed about any additional cost to be incurred due to change in the physical condition of the patient or line of treatment in writing. On completion of treatment, the patient has the right to receive an itemized bill, to receive an explanation for the bill(s) regardless of the source of payment or the mode of payment, and receive payment receipt(s) for any payment made.</p> <p>Patients and their caretakers also have a right to know the identity and professional status of various care providers who are providing service to him / her and to know which Doctor / Consultant is primarily responsible for his / her care. The hospital management has a duty to provide this information routinely to all patients and their caregivers in writing with an acknowledgment.</p>	<p>1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010</p> <p>2) MCI Code of Ethics</p> <p>3) Patients Charter by National Accreditation Board for Hospitals (NABH)</p> <p>4) The Consumer Protection Act, 1986</p>
2	Right to records and reports	<p>Every patient or his caregiver has the right to access originals / copies of case papers, indoor patient records, investigation reports (during period of admission, preferably within 24 hours and after discharge, within 72 hours). This may be made available wherever applicable after paying appropriate fees for photocopying or allowed to be photocopied by patients at their cost.</p>	<p>1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
		<p>The relatives / caregivers of the patient have a right to get discharge summary or in case of death, death summary along with original copies of investigations. The hospital management has a duty to provide these records and reports and to instruct the responsible hospital staff to ensure provision of the same are strictly followed without fail.</p>	<p>as per Clinical Establishment Act 2010</p> <p>2) MCI Code of Ethics section 1.3.2</p> <p>3) Central Information Commission judgment, Nisha Priya Bhatia Vs. Institute of HB&AS, GNCTD, 2014</p> <p>4) The Consumer Protection Act, 1986</p>
3	<p>Right to Emergency Medical Care</p>	<p>As per Supreme Court, all hospitals both in the government and in the private sector are duty bound to provide basic Emergency Medical Care, and injured persons have a right to get Emergency Medical Care. Such care must be initiated without demanding payment / advance and basic care should be provided to the patient irrespective of paying capacity.</p> <p>It is the duty of the hospital management to ensure provision of such emergency care through its doctors and staff, rendered promptly without compromising on the quality and safety of the patients.</p>	<p>1) Supreme court judgment Parmanand Katara v. Union of India (1989)</p> <p>2) Judgment of National Consumer Disputes Redressal Commission Pravat Kumar Mukherjee v. Ruby General Hospital & Others (2005)</p> <p>3) MCI Code of Ethics sections 2.1 and 2.4</p> <p>4) Article 21 of the Constitution 'Right to Life'</p>
4.	<p>Right to informed consent</p>	<p>Every patient has a right that informed consent must be sought prior to any potentially hazardous test/treatment (e.g. invasive investigation / surgery / chemotherapy) which carries certain risks.</p> <p>It is the duty of the hospital management to ensure that all concerned doctors are properly instructed to seek informed consent, that an appropriate policy is adopted</p>	<p>1) MCI Code of Ethics section 7.16</p> <p>2) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
		<p>and that consent forms with protocol for seeking informed consent are provided for patients in an obligatory manner.</p> <p>It is the duty of the primary treating doctor administering the potentially hazardous test / treatment to explain to the patient and caregivers the main risks that are involved in the procedure, and after giving this information, the doctor may proceed only if consent has been given in writing by the patient / caregiver or in the manner explained under Drugs and Cosmetic Act Rules 2016 on informed consent.</p>	<p>Council set up as per Clinical Establishment Act 2010</p> <p>3) The Consumer Protection Act, 1986</p> <p>4) Drugs and Cosmetic Act 1940, Rules 2016 on Informed Consent</p>
5	Right to confidentiality, human dignity and privacy	<p>All patients have a right to privacy, and doctors have a duty to hold information about their health condition and treatment plan in strict confidentiality, unless it is essential in specific circumstances to communicate such information in the interest of protecting other or due to public health considerations.</p> <p>Female patients have the right to presence of another female person during physical examination by a male practitioner. It is the duty of the hospital management to ensure presence of such female attendants in case of female patients. The hospital management has a duty to ensure that its staff upholds the human dignity of every patient in all situations. All data concerning the patient should be kept under secured safe custody and insulated from data theft and leakage.</p>	<p>1) MCI Code of Ethics sections 2.2, 7.14 and 7.17.</p> <p>2) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010</p>
6	Right to second opinion	<p>Every patient has the right to seek second opinion from an appropriate clinician of patients' / caregivers' choice. The hospital management has a duty to respect the patient's right to second opinion, and should provide to the patients caregivers all necessary records and information required for seeking such opinion without any extra cost or delay.</p> <p>The hospital management has a duty to ensure that any decision to seek such second opinion by the patient / caregivers must not adversely influence the quality of care being provided by the treating hospital as long as the patient is under care of that hospital. Any kind discriminatory practice adopted by the hospital or the service providers will be deemed as Human Rights' violation.</p>	<p>1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010.</p> <p>2) The Consumer Protection Act, 1986</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
7	Right to transparency in rates, and care according to prescribed rates wherever relevant	<p>Every patient and their caregivers have a right to information on the rates to be charged by the hospital for each type of service provided and facilities available on a prominent display board and a brochure. They have a right to receive an itemized detailed bill at the time of payment. It would be the duty of the Hospital / Clinical Establishment to display key rates at a conspicuous place in local as well as English language, and to make available the detailed schedule of rates in a booklet form to all patients / caregivers.</p> <p>Every patient has a right to obtain essential medicines as per India Pharmacopeia, devices and implants at rates fixed by the National Pharmaceutical Pricing Authority (NPPA) and other relevant authorities. Every patient has a right to receive health care services within the range of rates for procedures and services prescribed by Central and State Governments from time to time, wherever relevant. However, no patient can be denied choice in terms of medicines, devices and standard treatment guidelines based on the affordability of the patients' right to choice.</p> <p>Every hospital and clinical establishment has a duty to ensure that essential medicines under NLEM as per Government of India and World Health Organisation, devices, implants and services are provided to patients at rates that are not higher than the prescribed rates or the maximum retail price marked on the packaging.</p>	<p>1) MCI Code of Ethics section 1.8 regarding Payment of Professional Services</p> <p>2) Section 9(i) and 9(ii) of Clinical establishments (Central Government) Rules 2012</p> <p>3) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010</p> <p>4) Various Drug price control orders</p> <p>5) The Consumer Protection Act, 1986</p> <p>6) Drugs Price Control Order (DPCO) section 3 of the Essential Commodities Act, 1955</p>
8	Right to non-discrimination	<p>Every patient has the right to receive treatment without any discrimination based on his or her illnesses or conditions, including HIV status or other health condition, religion, caste, ethnicity, gender, age, sexual orientation, linguistic or geographical /social origins.</p> <p>The hospital management has a duty to ensure that no form of discriminatory behaviour or treatment takes place with any person under the hospital's care. The hospital management must regularly orient and instruct all its doctors and staff regarding the same.</p>	<p>1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
9.	Right to safety and quality care according to standards	<p>Patients have a right to safety and security in the hospital premises. They have a right to be provided with care in an environment having requisite cleanliness, infection control measures, safe drinking water as per BIS/FSSAI Standards and sanitation facilities. The hospital management has a duty to ensure safety of all patients in its premises including clean premises and provision for infection control. Patients have a right to receive quality health care according to currently accepted standards, norms and standard guidelines as per National Accreditation Board for Hospitals (NABH) or similar. They have a right to be attended to, treated and cared for with due skill, and in a professional manner in complete consonance with the principles of medical ethics. Patients and caretakers have a right to seek redressal in case of perceived medical negligence or damaged caused due to deliberate deficiency in service delivery.</p> <p>The hospital management and treating doctors have a duty to provide quality health care in accordance with current standards of care and standard treatment guidelines and to avoid medical negligence or deficiency in service delivery system in any form.</p>	<p>1) Clinical establishments (Central Government) Rules 2012</p> <p>2) The Consumer Protection Act, 1986</p>
10.	Right to choose alternative treatment options if available	<p>Patients and their caregivers have a right to choose between alternative treatment / management options, if these are available, after considering all aspects of the situation. This includes the option of the patient refusing care after considering all available options, with responsibility for consequences being borne by the patient and his/her caregivers. In case a patient leaves a healthcare facility against medical advice on his/her own responsibility, then notwithstanding the impact that this may have on the patient's further treatment and condition, this decision itself should not affect the observance of various rights mentioned in this charter.</p> <p>The hospital management has a duty to provide information about such options to the patient as well as to respect the informed choice of the patient and caregivers in a proper recorded manner with due acknowledgment from the patient or the caregivers on the communication and the mode.</p>	<p>1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010</p> <p>2) The Consumer Protection Act, 1986</p>
11.	Right to choose source for obtaining medicines or tests	<p>When any medicine is prescribed by a doctor or a hospital, the patients and their caregivers have the right to choose any registered pharmacy of their choice to purchase them. Similarly when a particular investigation is advised by a doctor or a hospital, the patient and his caregiver have a right to</p>	<p>1) Various judgments by the National Consumer</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
		<p>obtain this investigation from any registered diagnostic centre/laboratory having qualified personnel and accredited by National Accreditation Board for Laboratories (NABL).</p> <p>It is the duty of every treating physician / hospital management to inform the patient and his caregivers that they are free to access prescribed medicines / investigations from the pharmacy / diagnostic centre of their choice. The decision by the patient / caregiver to access pharmacy / diagnostic centre of their choice must not in any ways adversely influence the care being provided by the treating physician or hospital.</p>	<p>Dispute Redressal Commission</p> <p>2) The Consumer Protection Act, 1986</p>
12.	Right to proper referral and transfer, which is free from perverse commercial influences	<p>A patient has the right to continuity of care, and the right to be duly registered at the first healthcare facility where treatment has been sought, as well as at any subsequent facilities where care is sought. When being transferred from one healthcare facility to another, the patient / caregiver must receive a complete explanation of the justification for the transfer, the alternative options for a transfer and it must be confirmed that the transfer is acceptable to the receiving facility. The patient and caregivers have the right to be informed by the hospital about any continuing healthcare requirements following discharge from the hospital. The hospital management has a duty to ensure proper referral and transfer of patients regarding such a shift in care.</p> <p>In regard to all referrals of patients, including referrals to other hospitals, specialists, laboratories or imaging services, the decision regarding facility to which referral is made must be guided entirely by the best interest of the patient. The referral process must not be influenced by any commercial consideration such as kickbacks, commissions, incentives, or other perverse business practices.</p>	<p>1) Medical Council of India code of ethics section 3.6</p> <p>2) World Health Organisation – Referral Notes</p> <p>3) Various IPHS documents</p>
13.	Right to protection for patients involved in clinical trials	<p>Every person / patient who is approached to participate in a clinical trial has a right to due protection in this context. All clinical trials must be conducted in compliance with the protocols and Good Clinical Practice Guidelines issued by Central Drugs Standard Control Organisation, Directorate General of Health Services, Govt. of India as well as all applicable statutory provisions of Amended Drugs and Cosmetics Act, 1940 and Rules, 1945, including observance of the following provisions related to patients rights:</p> <p>a) Participation of patients in clinical trials must always be based on informed consent, given after provision of all</p>	<p>1) Protocols and Good Clinical Practice Guidelines issued by Central Drugs Standard Control Organisation, Directorate</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
		<p>relevant information. The patient must be given a copy of the signed informed consent form, which provides him / her with a record containing basic information about the trial and also becomes documentary evidence to prove their participation in the trial.</p> <p>b) A participant's right to agree or decline consent to take part in a clinical trial must be respected and her/his refusal should not affect routine care.</p> <p>c) The patient should also be informed in writing about the name of the drug / intervention that is undergoing trial along with dates, dose and duration of administration.</p> <p>d) At all times, the privacy of a trial participant must be maintained and any information gathered from the participant must be kept strictly confidential.</p> <p>e) Trial participants who suffer any adverse impact during their participation in a trial are entitled to free medical management of adverse events, irrespective of relatedness to the clinical trial, which should be given for as long as required or till such time as it is established that the injury is not related to the clinical trial. In addition, financial or other assistance must be given to compensate them for any impairment or disability. In case of death, their dependents have the right to compensation.</p> <p>f) Ancillary care may be provided to clinical trial participants for non-study/trial related illnesses arising during the period of the trial. This could be in the form of medical care or reference to facilities, as may be appropriate.</p> <p>g) Institutional mechanisms must be established to allow for insurance coverage of trial related or unrelated illnesses (ancillary care) and award of compensation wherever deemed necessary by the concerned Ethics Committee.</p> <p>h) After the trial, participants should be assured of access to the best treatment methods that may have been proven by the study.</p> <p>Any doctor or hospital who is involved in a clinical trial has a duty to ensure that all these guidelines are followed in case of any persons / patients involved in such a trial.</p>	<p>General of Health Services, Govt. of India</p> <p>2) Amended Drugs and Cosmetics Act, 1940 and Rules, 1945 especially schedule Y</p> <p>3) National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, Indian Council of Medical Research, New Delhi, 2017</p> <p>4) World Medical Assembly Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects available at www.wma.net/en/30publications/10policies/b3/17c.pdf</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
14.	Right to protection of participants involved in biomedical and health research	<p>Every patient who is taking part in biomedical research shall be referred to as research participant and every research participant has a right to due protection in this context. Any research involving such participants should follow the National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 laid down by Indian council for Medical Research and should be carried out with prior approval of the Ethics Committee.</p> <p>Documented informed consent of the research participants should be taken. Additional safeguards should be taken in research involving vulnerable population. Right to dignity, right to privacy and confidentiality of individuals and communities should be protected.</p> <p>Research participants who suffer any direct physical, psychological, social, legal or economic harm as a result of their participation are entitled, after due assessment, to financial or other assistance to compensate them equitably for any temporary or permanent impairment or disability.</p> <p>The benefits accruing from research should be made accessible to individuals, communities and populations whenever relevant.</p> <p>Any doctor or hospital who is involved in biomedical and health research involving patients has a duty to ensure that all these guidelines are followed in case of any persons / patients involved in such research.</p>	<p>1) National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, Indian Council of Medical Research, New Delhi, 2017</p> <p>2) World Medical Assembly Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects available at www.wma.net/en/30publications/10policies/b3/17c.pdf</p> <p>3) Drugs & Cosmetic Act, Rules 2016 on Clinical Trails</p>
15.	Right to take discharge of patient, or receive body of deceased from hospital	<p>A patient has the right to take discharge and cannot be detained in a hospital, on procedural grounds such as dispute in payment of hospital charges. Similarly, caretakers have the right to the dead body of a patient who had been treated in a hospital and the dead body cannot be detailed on procedural grounds, including nonpayment/dispute regarding payment of hospital charges against wishes of the caretakers.</p> <p>The hospital management has a duty to observe these rights and not to indulge in wrongful confinement of any patient, or dead body of patient, treated in the hospital under any circumstances.</p>	<p>1) Prohibition of wrongful confinement under Sec. 340-342 of IPC. Statements of Mumbai High Court.</p> <p>2) Consumer Protection Act 1986</p>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
16.	Right to Patient Education	<p>Patients have the right to receive education about major facts relevant to his/her condition and healthy living practices, their rights and responsibilities, officially supported health insurance schemes relevant to the patient, relevant entitlements in case of charitable hospitals, and how to seek redressal of grievances in the language the patients understand or seek the education.</p> <p>The hospital management and treating physician have a duty to provide such education to each patient according to standard procedure in the language the patients understand and communicate in a simple and easy to understand manner.</p>	<ol style="list-style-type: none"> 1) The Consumer Protection Act, 1986 2) Standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010
17.	Right to be heard and seek redressal	<p>Every patient and their caregivers have the right to give feedback, make comments, or lodge complaints about the health care they are receiving or had received from a doctor or hospital. This includes the right to be given information and advice on how to give feedback, make comments, or make a complaint in a simple and user-friendly manner.</p> <p>Patients and caregivers have the right to seek redressal in case they are aggrieved, on account of infringement of any of the above mentioned rights in this charter. This may be done by lodging a complaint with an official designated for this purpose by the hospital / healthcare provider and further with an official mechanism constituted by the government such as Patients' rights Tribunal Forum or Clinical establishments regulatory authority as the case may be. All complaints must be registered by providing a registration number and there should be a robust tracking and tracing mechanism to ascertain the status of the complaint resolution.</p> <p>The patient and caregivers have the right to a fair and prompt redressal of their grievances. Further, they have the right to receive in writing the outcome of the complaint within 15 days from the date of the receipt of the complaint.</p> <p>Every hospital and clinical establishment has the duty to set up an internal redressal mechanism as well as to fully comply and cooperate with official redressal mechanisms including making available all relevant information and taking action in full accordance with orders of the redressal body as per the Patient's Right Charter or as per the applicable existing laws.</p>	<ol style="list-style-type: none"> 1) The Consumer Protection Act, 1986 2) NHS - Charter of Patient Rights and Responsibilities

Responsibilities of patients and caretakers

Along with promoting their rights, patients and caretakers should follow their responsibilities so that hospitals and doctors can perform their work satisfactorily.

- 1) Patients should provide all required health related information to their doctor, in response to the doctor's queries without concealing any relevant information, so that diagnosis and treatment can be facilitated.
- 2) Patients should cooperate with the doctor during examination, diagnostic tests and treatment, and should follow doctor's advice, while keeping in view their right to participate in decision making related to treatment.
- 3) Patients should follow all instructions regarding appointment time, cooperate with hospital staff and fellow patients, avoid creating disturbance to other patients, and maintain cleanliness in the hospital.
- 4) Patients should respect the dignity of the doctor and other hospital staff as human beings and as professionals. Whatever the grievance may be, patient / caregivers should not resort to violence in any form and damage or destroy any property of the hospital or the service provider.
- 5) The Patients should take responsibility for their actions based on choices made regarding treatment options, and in case they refuse treatment (not clear???)

Recommended mechanism for implementation of Charter of Patient's Rights and Grievance redressal mechanism

NHRC recommends to the Government of India, all State Governments and Administration of all the Union Territories that they should seriously consider the adoption of the charter and incorporate this Charter of Patients' Rights in the entire range of existing and emerging regulatory frameworks concerning the health care sector, under their jurisdiction.

Further NHRC recommends that all State Human Rights Commissions should adopt the Charter of Patients' Rights to be treated as a reference document in all cases related to human rights violations concerning patients and all users of health care services.

NHRC further recommends that all administrative and regulatory authorities completely or partially related with the healthcare sector, including but not limited to the following should incorporate and promote implementation of the Charter of Patient's Rights within their jurisdiction wherever applicable.

1. Ministry of Health and Family Welfare, Government of India
2. Public Health and Family Welfare Departments in all States and UTs
3. Medical Education Department of States and UTs, wherever they exist
4. Executive/Managing authorities of all publicly funded healthcare insurance schemes and Public-Private-Partnership arrangements in healthcare by Government of India, all State Governments and administrations in all UTs
5. National Council for Clinical Establishments
6. State Councils for Clinical Establishments, wherever applicable
7. Authorities established under State Nursing Home Acts or equivalent acts, wherever applicable

8. Medical Council of India / National Medical Commission or equivalent body
9. State Medical Councils in all States and UTs
10. Central Council of Indian Medicine
11. State Councils for Indian Medicine in all States and UTs
12. Any other healthcare related statutory councils established in all States and UTs
13. Central Consumer Protection Council, all State and District consumer protection councils
14. Registrar of Societies in all States and UTs, in the context of non-profit clinical establishments
15. Charity Commissioner in those States wherever applicable, in the context of non-profit clinical establishments
16. Department of Religious and Charitable Endowments in those States wherever applicable, in the context of non-profit clinical establishments
17. Registrar of Companies, in the context of for-profit hospitals run by companies and non-profit clinical establishments run by companies registered under Section 25
18. Central Drugs and Standard Control Organisation, Ministry of Health & Family Welfare, Government of India
19. Quality Council of India, New Delhi
20. Department of Consumer Affairs, Ministry of Consumer Affairs, Food & Public Distribution, Government of India

Once the Patients' Rights Charter has been adopted by the Govt. of India, State Governments and the Administration of the Union Territories, they may stipulate/ensure that all types of Clinical Establishments (both therapeutic and diagnostic) display this Charter prominently within their premises, orient all their staff and consultants regarding the Charter, and observe the Charter of Patients' Rights in letter and spirit irrespective of whether such clinical establishment is owned, controlled or managed by-

- i. the Government or a department of the Government;
- ii. a trust, whether public or private;
- iii. a corporation (including a society) registered under a Central, Provincial or State Act, whether or not owned by the Government;
- iv. a privately owned enterprise;
- v. a local authority

Further, NHRC recommends to the Government of India, all State Governments and administration of Union Territories to ensure the setting up of a grievance redressal mechanism for patients, as a component of their existing or emerging regulatory frameworks for clinical establishments, by making required modifications in rules, regulations and acts where required. Observance of patients' rights and setting up of grievance redressal mechanism for protection of these Rights should be made an integral component of the implementation of Clinical Establishment (Registration and Regulation) Act 2010 in those states who have adopted it, or as a component of state specific regulatory frameworks for clinical establishments in other states, which have equivalent state specific legislations, or are planning to enact state specific legislations to regulate clinical establishments.

NHRC recommends that Patients' rights grievance redressal mechanisms should have the following components-

1. Every clinical establishment should set up an internal grievance redressal mechanism. First, patients may file a complaint with an authorized representative who can be named 'Internal Grievance Redressal Officer' of the clinical establishment, either individually in person through an authorized representative or collectively through a consumer group or civil society organization. The clinical establishment's Internal Grievance Redressal Officer shall consider the complaint and try to find an appropriate solution, keeping in view the provisions of the Patients' Rights Charter and promptly acknowledge the receipt of the complaint within 24 hours by assigning a registration number for tracking and tracing the status of the complaint.
2. If a solution acceptable to the patient is not found at the level of the clinical establishment and the patient/representative is not satisfied, then he/she may approach the office of the district level registering authority set up under Clinical Establishment (Registration and Regulation) Act 2010 in those States who have adopted it, or equivalent district level authorities created under the State specific clinical establishments act or similar regulatory frameworks for clinical establishments in other states which have other State specific legislations. The district level registering authority shall verify the facts of the matter, and where there is clear violation of patient's rights as brought out facts, the registering authority may issue necessary executive orders to the clinical establishment for rectification. If there is any dispute over interpretation of Charter of Patient's Rights and provisions in the regulatory framework, the registering authority may clarify the procedure, rules, regulations and attempt to resolve the complaint through mediation between both parties within 30 days from the date of receipt of the appeal.
3. In case of any particular complaint, if even after completing the above mentioned procedure, the patient or his/her representative is not satisfied, then he/she can file appeal before the State Council of Clinical Establishments under Clinical Establishment (Registration and Regulation) Act 2010 in those states who have adopted the Act. Section 8(5)(e) empowers the 'State Council for Clinical Establishments' to hear appeals against the orders of the District Registering Authority set up under CEA 2010. 'State Council of Clinical Establishment' can set up a three or five member sub-committee / cell (with multi-stakeholder participation) which can be named as 'Healthcare Grievance Redressal Authority' for resolution of patient's grievances, and pass rectification orders or disciplinary orders or punitive orders which would be binding upon the clinical establishments within the framework of CEA within 30 days from the date of receipt of the appeal. The complaints procedure to be set up under the State Council of Clinical Establishments should explicitly state that it is not intended as a means of achieving monetary compensation.
4. Apart from the above mentioned grievance redressal mechanisms, patients/representatives would always be free to approach the State Medical Council to seek disciplinary action against unethical conduct of any specific doctor, and also free to approach Consumer Forums at various levels to seek financial compensation, or approach Civil/Criminal Courts keeping in view the nature of the complaint i.e., creation of a separate grievance redressal machinery to deal with violations of Patients' Rights Charter shall in no way either extinguish or affect adversely the existing legal remedies both civil and criminal available to patients and their caregivers under the existing legal framework.





Human Rights Advisory on Right to Health in view of the second wave of COVID-19 pandemic (Advisory 2.0)



राष्ट्रीय मानव अधिकार आयोग National Human Rights Commission

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May 4, 2021

Subject: Human Rights Advisory on Right to Health in view of the second wave of COVID-19 pandemic (Advisory 2.0)

The National Human Rights Commission (NHRC) is mandated by the Protection of Human Rights Act, 1993, to protect and promote the human rights of all the citizens in the country.

2. Keeping in view the prevailing situation in the country due to the second wave of the COVID-19 pandemic, and taking into consideration the ground reports relating to human rights violations (particularly denial of the right to access to healthcare & related issues), the Commission hereby issues another "Human Rights Advisory on Right to Health in view of the second wave of COVID-19(Advisory 2.0)"(copy enclosed), which may be read and implemented in conjunction with the earlier 'Human Rights Advisory on Right to Health in the context of COVID-19' issued by the Commission on 28.09.2020.

3. All the concerned authorities of the Union/ State Governments/ UTs are advised to implement the recommendations made in the said **Advisory 2.0** and need to submit the **action taken report (ATR)** within 4 weeks for information of the Commission.

24/5/21
(Bimbadhar Pradhan)
Secretary General

Encl: Advisory 2.0

1. **The Secretary to the Govt of India**
M/o Health and Family Welfare
D/o Health and Family Welfare
Nirman Bhavan, C-Wing
New Delhi – 110001
2. **Chief Secretary (All States/ UTs)**



National Human Rights Commission

Human Rights Advisory on Right to Health in view of the second wave of COVID - 19 pandemic (Advisory 2.0)

Background

NHRC, being deeply concerned with severe impact on the human rights of the people due to the COVID-19 pandemic, issued a comprehensive set of human rights advisories in September and October 2020, including the ones related to Health and Mental Health, to protect and promote Right to Health as guaranteed by the Article 21 of the Constitution of India.

With the advent of the second wave of COVID-19, the situation has worsened and India is now facing a public health emergency of unprecedented proportion and severity. Critical gaps are apparent in the system related to patients' access to life-saving healthcare, including availability of critical care beds, oxygen supplies, essential medicines, emergency transport, and other facilities. Acute shortage of these resources is resulting in high mortality and putting a huge burden on the hospitals and healthcare professionals, beyond their capacity so much so that the healthcare infrastructure of the country appears to be on the verge of a breakdown.

As per the data of the Ministry of Health and Family Welfare, Gol, the total number of deaths from COVID-19 in India has now reached 2.12 lakhs claiming 4416 lives in 24 hours (as on 1st May, 2021). While the COVID vaccination programme is being rolled out, so far only about 2% of the population has been fully vaccinated, leaving a vast majority of the population vulnerable to infection.

The media reports giving information coming from ground zero, show serious concern about the COVID patients having to run from pillar to post in search of essential medicines, vaccines, oxygen, hospital beds, etc, for want of treatment, leading to death due to denial or delay in access to proper healthcare.

Keeping in view the abovementioned concerns and the urgency of redressal in the present context, NHRC hereby issues a second advisory on Right to Health in the context of COVID-19, to protect the human rights of the patients and public in general so as to enable them to effectively access the requisite healthcare.

This advisory should be read and implemented in conjunction with the NHRC Advisory on 'Right to Health in context of COVID-19' issued on 28.09.2020. While issuing this advisory, NHRC strongly upholds and reiterates the human rights principles of Universality, Equality, Non-discrimination, Transparency, Accountability and Protection of vulnerable sections, which underlie the operationalisation of Right to Health for all as a basic human right.

I. Immediate Actionable Recommendations

(i) Arrangements for Oxygen, Essential Medicines and Devices: The Centre and the State Governments/ UTs must coordinate for providing continuous, rapid and seamless logistics to meet the demand of oxygen, essential medicines and devices in all healthcare establishments in the country. Additionally, a single point of contact may be established for the same, especially for oxygen.

(ii) Responsibility to ensure access to care: Any COVID-19 patient who approaches any public health facility should receive the treatment free of cost. In case, the care appropriate to the severity of the condition is not available, it would be the obligation of the Health Department to organise his/ her transport to another hospital where appropriate care is available. In case of COVID patient approaching a private hospital where there is no vacant bed for admission, then the hospital must contact the Government Nodal Officer for providing necessary help/ support. Till the time proper arrangement is made, the private hospital may be directed by the Nodal Officer to provide available emergency healthcare support to the patient. Both help-desks and the COVID dashboards, given below, are essential tools to implement this approach.

(iii) Help Desks: Functional and effective Help-Desks should be set up in all public and private hospitals for preliminary check-up of all incoming patients to assess their need. If he is in need of urgent hospitalization and bed is not available, then the patient should be handheld to reach a clinical establishment where the needed resources are available. In no case the patient and his family members should be left to cater on their own.

(iv) Universally functional COVID dashboards: COVID-19 related websites/ dashboards displaying real time COVID bed availability, including general isolation beds, oxygen beds, ICU beds, and ventilator support beds, etc., may be set up, which should be regularly updated and maintained to cover all Districts and Cities in the country.

(v) Display of Information in Clinical Establishments: Each health facility or clinical establishment, whether public or private, treating COVID patients, must prominently display at the entry/ reception itself (in Local and English language) the Facility Specific Information regarding availability and rates of COVID testing, number of beds of each type and other provisions provided free and / or with regulated cost; and mobile number of the grievance redressal authority or other responsible person to contact in case of any grievance or need for further assistance.

(vi) Accessible healthcare at regulated, affordable rates in private hospitals: Private hospitals to be directed by the respective Government to provide care for COVID-19 patients at defined, affordable rates. The regulated rates should be made applicable to the maximum proportion of beds, at least two third of all available beds or as per local requirements.

(vii) Cap on prices: A cap on the prices of COVID treatment resources like essential medicines, oxygen cylinders, ambulance services, etc., should be operationalized, monitored and audited to prevent exploitation of patients. A Grievance Redressal Mechanism must be established by the Centre & State Governments/ UTs in this regard.

(viii) **Hoarding and black marketing:** Immediate cognizance of the cases of hoarding and black marketing of essential medicines, oxygen cylinders and other medical resources should be taken seriously and those found guilty must be brought to book. A complaint management system should be established in this regard and nobody should be harassed on grounds of making such a complaint.

(ix) **Production, transportation and distribution of essential resources:** Production and procurement of essential medicines, vaccines and oxygen should be ramped up to match the present and future demand. Speedy and seamless transportation of these resources to the health centres/ facilities must also be ensured along with its fair and need-based distribution.

(x) **Augmentation of healthcare workforce:** Strategies to augment healthcare workforce availability may be adopted including urgent filling up of existing vacancies, re-deploying staff from non- affected areas, engaging freshly graduated or post-graduate doctors after accelerated orientation in COVID care, engaging retirees who are capable of working especially for non-COVID services, and hiring / requisitioning private sector healthcare workforce capacity.

(xi) **Crematoriums/ Burial Grounds:** Management of crematoriums and burial grounds should be improved to reduce waiting time for cremations/ burials by adding more such facilities. Use of electric crematoriums should be promoted by the stakeholders. An App in this regard may be developed and made functional.

(xii) **Administrative verification of availability of beds:** Each State/ UT may conduct regular administrative verification of private health establishments who are treating COVID patients to verify the actual position, and to ensure that bed availability is being promptly updated on dashboard so that no patient is refused a bed.

(xiii) **Deceased Patients:** Body of a deceased COVID-19 patient should be treated with due respect to uphold its dignity and should be handed over to the family/ caretakers as soon as the death is declared, while ensuring that all COVID control protocols are followed. Hearse services should be provided by the hospital which must be treated as an essential service.

II. Containment

With a view to prevent further spread of the COVID-19, the Central/ State Governments/ UTs must ensure the following:

(i) **Public Information on COVID Protocols:** All COVID-related protocols, like physical distancing, wearing a mask properly at all times, sanitization, IEC activities, banning mass gathering, etc., must be widely and appropriately disseminated. To be effective, the messages and media chosen must be based on understanding of the social determinants and barriers to covid appropriate behaviour in different sections of the population.

(ii) **Practical Time Restrictions** for buying essential commodities from the market should be made to avoid crowding as suitable to the local requirements, and a feedback system for gathering public response on the arrangements made by the public administration should also be established.

(iii) **Restriction on public gathering:** Any public gathering having the potential of being a super spreader of the virus must be banned till the pandemic subsides.

(iv) Establishment of Consultative Counseling Programmes/ Feedback Platform:

Establishment of virtual/ tele consultative programmes along with a feedback mechanism needs to be setup to provide required support to the patients and their caregivers. For this purpose, human interface (without long waiting time) may be established to provide needed counseling to reduce the panic.

(v) Vaccination: There should be universal coverage and non-discriminatory pricing of COVID vaccines in all health facilities in the country, and if feasible, vaccination should be made free for everyone irrespective of private or public health establishment. Further,

- a) Number of vaccination centres should be increased to speed up the pace of vaccination wherein the social distancing norms and COVID protocols must be strictly followed.
- b) Production of vaccine and supply chain arrangement for vaccination centres should be reviewed and reworked to ensure availability of vaccines for all in time.
- c) The Public Health Outreach Program including vaccination should reach the people who are most vulnerable and at the most risk like destitute, homeless, prisoners, migrant workers, beggars, etc, and the arrangements for people not in possession of Aadhaar cards or other documents must be made.

(vi) Creating Awareness among patients: Necessary information must be shared with all the patients using the following methods:

- a) **Brochure for COVID-19 management:** A simple-worded information brochure having factual and clear information in an easy to understand local language related to COVID-19 and its management, should be made available to all, especially to COVID patients and their caregivers at the time of receiving their Covid positive test report.
- b) **Patient Guidance Protocol for Home Isolation:** COVID patients who are advised home isolation must be provided a 'Standard Patient Guidance Protocol for COVID-19' in the local language, with detailed practical information regarding home isolation care and practices for the patient and the caregiver.
- c) **Regular monitoring of patients in Home Isolation by field staff** through personal visits and/ or telephonic consultation to be conducted along with ensuring prompt transfer to hospitals when required.
- d) **24 X 7 Helpline:** All State Governments/ UTs may ensure the availability of authentic and widely publicised State level toll free 24x7 Helpline, where the appropriate conduct of the information provider must be ensured with prompt response and human interface. Social Media platforms, which are also the major platforms to disseminate information may be used to rapidly circulate essential and authentic information.

III. Clinical Management

(i) Provision of Free Test, Adequate Number of COVID Testing Facilities and Timely reports: The COVID-19 test in all Government laboratories and health facilities

should be done free of cost. Collection of samples from home and number of testing facilities may be increased to avoid long queues and to prevent the spread of the virus,

It must be ensured that people receive their COVID-19 test reports within a reasonable time, preferably within 24 hours of the sample collected by the testing laboratory. Adequate resources in the laboratories should be augmented, wherever required.

(ii) Planning / Logistics: Adequate provision of essential resources should be planned by the Government, taking into account the possibility of another wave in future. Planning must be done for increasing the number of beds, especially ICU beds and strict measures must be adopted throughout the year to maintain adequate stocks of resources, including RT-PCR testing requirements, essential medicines, vaccines, oxygen, ICU equipment etc., in all the clinical establishments.

(iii) Functioning of Health care services for Non-Covid Patients: All Government hospitals must integrate COVID care with continued adequate care for non-COVID conditions. Administrative cessation of all non-covid services for fear of infection spread should be discouraged. It is feasible and desirable to sustain essential non-covid services through better infection control measures, innovative organization of care and better public information. The successful approaches and techniques in sustaining non-covid services can be learnt from WHO and the best practices within the country and elsewhere.

(iv) Standard treatment guidelines: In order to avoid unnecessary use of COVID related medications and also to reduce panic, the standard treatment guidelines must be adhered to. Keeping in view the reports about irrational prescribing of expensive medicines which are of marginal or circumscribed value in reducing COVID mortality (Remdesivir, Tocilizumab, etc.), the algorithms issued by AIIMS - ICMR Task Force must be rigorously followed by all private and public hospitals. A proper and common list of eligible and available plasma donors should be maintained and regularly updated.

(v) Treatment for all Symptomatic Patients: All patients who are moderately or severely symptomatic or show suggestive chest X-ray / CT scan, where clinical assessment is indicative of COVID, must be treated as COVID-19 patients, even if the RT-PCR test report is awaited/delayed or is negative. Submission of ID or certification shall not be made a precondition for admission or treatment, if the patient has COVID symptoms and the attending doctor feels it a fit case for admission.

(vi) Ensuring adequate ambulance services at reasonable prices: Ambulance services to be improved and augmented in number to meet the patients' needs. A Grievance Redressal Mechanism must be established in this regard. Further, an App may be developed for this and made functional.

(vii) Auditing of bills and provision of an itemized bill: The Government(s) should deploy officials to audit adherence of private hospitals for ensuring regulation of rates for COVID patients. Bills of higher amount, say more than 1.5 lakhs, may be randomly checked/ audited, and all hospitals must provide a detailed itemised bill to the patients or their caregivers.

(viii) Availability of reagents and ancillaries for COVID tests: A regular and continuous

supply of these items must be ensured to all the laboratories to enable them to carry out various Covid related tests.

IV. Community Engagement and Responsiveness

(i) Mobilizing voluntary support and promoting community engagement: The States/UTs may engage in large scale mobilization of suitably trained volunteers at the district/ sub-district level, to supplement the staff in designated Covid Care Centres (CCCs) and community run isolation and quarantine centres, as well as for home visits, contact tracing and providing necessary support to patients in home isolation. The Civil Society Organizations may also be involved for this purpose. This may be done by expanding existing participatory committees such as Rogi Kalyan Samitis (RKS), and multi-stakeholder committees formed through Community Action for Health processes.

(ii) Display and observance of COVID Charter including Patients' Rights- Each health facility managing COVID patients, whether public or private, must prominently display at reception of the facility (in local language and English) the COVID Charter. This COVID Charter would include facility specific information defined in section I (v) of this advisory, along with the ***Set of Patients' rights and responsibilities*** which was communicated by the Secretary, MoH&FW, Govt of India, to all States / UTs vide D.O. No. Z.28015/09/2018-MH-11/MS dated 2nd June 2019, and was circulated along with NHRC Health Rights Advisory dated 28.9.2020. This list of patients' rights and responsibilities should also be displayed on the website of the Health Department of each State/ UT for public information.

All governments should ensure regular monitoring of display and implementation of such COVID Charter in all health facilities which are providing care to COVID patients.

(iii) Grievance redressal mechanism: The Union/ States/UTs should establish an effective and accessible health grievance redressal mechanism at various levels to deal with cases of violation of health rights as described in ***NHRC Advisory on Right to Health (dated 28 Sep. 2020), sections 11.1 to 11.4***. This may be linked with the toll-free helpline and operated in local language. The civil society organisations may also be involved in this.

(iv) Assisting homeless people: For patients wandering on streets in any critical health conditions and in need of assistance, the State Governments/ UTs/ Municipal Corporations may make arrangements for them to be taken to the appropriate clinical establishment. NGOs or volunteers may be involved to assist in this regard. Distribution of free food packets and implementation of Gareeb Kalyan Yojana should remain functional till the situation normalises.

(v) Reporting on COVID: Reporting on COVID cases or related deaths should be encouraged to portray the correct picture and magnitude of the problem in order to help the Government as well as other stakeholders to be prepared accordingly on the basis of correct information.

V. Measures Creating Enabling Conditions:

(i) Ensuring rights of healthcare workers and frontline staff: The NHRC Health Rights Advisory related to Healthcare Workers (Regular and Contractual) – sections 13.1 to 13.9 (issued on 28.9.2020) remain fully relevant and should be implemented in the present situation. Remaining gaps in vaccination coverage of Health Workers and Frontline Staff must be bridged rapidly, and necessary personal protective equipment must be ensured.

(ii) Insurance Coverage for Corona Warriors: The insurance coverage for 'Corona Warriors' needs to be extended in a seamless manner for all healthcare workers and other personnel such as Asha workers, Anganwadi workers, etc., involved in frontline work during the pandemic.

(iii) Implementing Best Practices: Best practices/ models which have been proved to be successful in containment of COVID-19 in some States may be followed.





Advisory on Right to Health in context of COVID-19



राष्ट्रीय मानव अधिकार आयोग National Human Rights Commission

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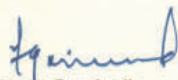
September 28, 2020

Subject: Human Rights Advisory on Right to Health in context of Covid-19

National Human Rights Commission (NHRC) is mandated by the Protection of Human Rights Act, 1993 to promote and protect the human rights of all in the country. Towards fulfilment of its mandate, the Commission is deeply concerned about the rights of the vulnerable and marginalised sections of the society which have been disproportionately impacted by the COVID-19 pandemic and the resultant lockdowns.

2. In order to assess the impact of the pandemic on realization of the rights of the people, especially the marginalised / vulnerable sections of the population, the NHRC constituted a Committee of Experts on Impact of Covid-19 Pandemic on Human Rights and Future Response including the representatives from the Civil Society Organizations, independent domain experts and the representatives from the concerned ministries/ departments.
3. On the basis of impact assessment done by the Committee of Experts and recommendations made by it, the Commission hereby issues an advisory on "Right to Health in context of Covid-19" as given in the annexure.
4. All the concerned authorities are requested to implement the recommendations made in the advisory and to submit the action taken report for information of the Commission.

Encl: As above


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National Human Rights Commission

Advisory on Right to Health in context of COVID-19

Background

The outbreak of COVID-19 in India has caused an unprecedented humanitarian crisis with a total of 4,465,863 cases and more than 9 lakh active cases as on 10th September, 2020 making India to have the second highest caseload of COVID-19 in the world. The continuing rise in the number of COVID-19 cases is putting enormous strain on the health system in the country. Even before the eruption of the COVID-19 epidemic, the public health infrastructure in many states is struggling to meet population healthcare requirements, and the diversion of this already overstretched system for meeting the COVID-19 crisis is impacting access to healthcare for patients with other severe ailments. Routine care for tuberculosis, HIV/AIDS, mental health disorders and other chronic ailments have been affected, along with reproductive and child health services including deliveries and immunization, due to restrictions imposed by the lockdown, and the engagement of frontline health workers in COVID-19 duties. Even the emergency trauma care has also been hit due to the disruption in transportation, and reduced availability of staff to handle emergencies.

In response to the above situation, the Central and the State Governments are taking special measures to provide much needed healthcare to people. They have insourced private hospitals temporarily to provide COVID-19 care free of charge to its citizens and capped the costs of treatment. The government has been proactive in taking measures for reducing the difficulties emerging due to the pandemic for people of the country. Measures concerning employment, healthcare, migration, economic stimulus, as well as measures to ease the lockdown gradually with proper guidelines for every aspect are being taken by the Central Government as well as the State governments.

However, patients may need guidance enabling them to obtain required care in public health facilities, and the guidelines and measures to be followed by the private healthcare sector is not always followed. There are repeated instances of patients facing problems in getting admission to designated COVID-19 facility, overcharging, denial of treatment, stigmatization, discrimination, patients not being provided formal reports etc.

All such issues faced by the residents of India, which include not only the patients, but healthcare providers, family of the patients and the society at large, indicates violation of human rights. The rationale of this advisory is to bridge the gap, complement and support the existing advisories and guidelines thereby empowering each individual and strengthening our healthcare system.

Given the need for systematic protection of health rights and patients' rights, and keeping in view the human rights imperative to ensure that all patients with COVID-19 are able to access required healthcare without financial or other barriers, NHRC is issuing the following advisories:

1. Advisory related to access to Healthcare

- 1.1 Access to free healthcare for COVID-19 patients in public health system and engaged facilities:** COVID-19 patients who approach public health facilities should receive treatment free of cost to the patient. This may be through available public health facilities, or engaged private health facilities empanelled by the government.
- 1.2 Access to healthcare for non-COVID patients:** Patients with conditions other than COVID-19 should continue to receive essential healthcare from public health facilities.
- 1.3 Access to testing for COVID-19:** COVID-19 testing should be provided free of cost to those approaching government laboratories or hospitals, based on referral by a medical practitioner, Concerning person who directly approach private laboratories for testing of COVID-19, maximum rates may be fixed.
- 1.4 Access to transport for patients:** Patients with COVID or non-COVID conditions may be provided ambulance services to reach hospitals timely.
- 1.5 Access to cashless payment for COVID-19 treatment:** There should be cashless facility for COVID-19 treatment in all hospitals, and insurance agencies should cover treatment of COVID-19 for all policyholders having hospitalization coverage.

2. Advisory related to observance of Patients' Rights Charter

- 2.1 Display of Patients' Rights Charter:** Patients' rights and responsibilities (given in annexure), issued by Ministry of Health and Family Welfare, Govt. of India, to the chief secretaries of all States/UTs vide D.O. No. Z.28015/09/2018-MH-II/MS dated 2nd June, 2019 which was based on NHRC Patients' Rights' Charter, should be prominently displayed (in state language and English) and observed in all public and private hospitals and health Patients' rights charter should be displayed on the website of each State health department.
- 2.2 Ensuring implementation of Patients' rights charter:** State governments may ensure monitoring of display and implementation of the charter, while operationalising grievance redressal mechanism for patients who may have complaints regarding its implementation.

3. Advisory related to right to information:

- 3.1 Providing Information to Patients:** All patients have the right to information, including daily updates, about the illness, investigations, treatment and possible complications. This information along with 'Standard Patient Guidance Protocol for COVID-19' should be shared with the patients and caregivers in a language that is understandable to them. Hospitals should ensure that relatives / caregivers of serious/ critical COVID patients are updated on the condition of the patients at least on a daily basis.

- 3.2 Availability of medical services:** Information regarding COVID facilities, regulated cost of treatment, availability of free or subsidised beds, services and detailed rates for various kinds of medical care in the hospital or quarantine centre may be displayed outside each facility, public or private, as well as on digital media. The information related to non-COVID services offered by all public and private facilities may be displayed along with timings for the same. Wherever certain public health facilities have been converted into dedicated COVID facilities, this information should be widely publicised, while informing the public regarding the alternative local health facilities which have been designated to provide non-COVID care.
- 3.3 Transparency of Rates:** An itemized bill must be given to every patient, including cost of medicines, professional fees, PPE, various investigations, treatment of co-morbidities, etc.
- 3.4 COVID Dashboards:** The COVID-19 related websites / dashboards / Apps of state governments and municipal corporations may be updated covering health provisions, programmes and entitlements, regarding isolation, quarantine and treatment centres in public and private sectors (district or locality wise) with the currently available number of ICU beds, oxygen beds and ventilator support beds available in each facilities.
- 3.5 Helpdesk (24x7):** All state governments may operate a 24x7 centralised call centre facility, linked with nodal person(s) designated in each district for helping the patients and their caregivers, and also for providing the information on availability of beds.
- 3.6 Integrated Disease Surveillance Programme (IDSP) dashboard:** The IDSP portal should be updated immediately, and information on various data points pertaining to major communicable diseases should be entered and updated on a regular basis. The current focus on tracking COVID-19 should in no way compromise surveillance of other major communicable diseases.
- 4. Advisory related to records and reports:**
- 4.1 Timeline for Report:** It may be ensured that people receive their COVID-19 test reports within a reasonable time, preferably within 24 hours of the sample being submitted to the laboratory.
- 4.2 Medical Records:** The right to access all medical records, discharge summary or death summary along with original copies of all investigations which have been performed during the hospital stay may be ensured
- 4.3 Online Reports:** Civic bodies and State governments may consider sharing COVID test results online in a confidential manner, whereby patients can check their status through confidential test. ID cards provided only to the patient. It may be done through a printed test report, email, or SMS message and it may be given only to the patient or designated caregiver.
- 4.4 Death Certificate:** All relevant records and death certificates related to the patient should also be duly and timely handed over.
- 5. Advisory related to emergency medical care:** No patient should be denied

emergency medical care for both COVID and non-COVID conditions. The state must ensure prompt and free initiation of the treatment process without demanding advance payment, provided to the patient irrespective of paying capacity. For non-COVID patients approaching a dedicated COVID hospital, system may be set up to ensure referral, transport and admission to the alternative local non-COVID facility, whenever required.

6. Advisory related to confidentiality, human dignity and privacy:

- 6.1 Respect and Dignity:** Human dignity of every patient in all situations must be maintained, with no stigmatizing or public labeling of COVID-19 patients. Use of force should be avoided while taking COVID-19 positive people to hospitals or quarantine facilities; this should be done through persuasion after providing appropriate information.
- 6.2 Deceased Patients:** Bodies of deceased COVID-19 patients should be treated with due respect and handed over to the family / caretakers as soon as possible after death has been declared, while ensuring that all infection control protocols are followed.
- 6.3 Confidentiality:** Information regarding the patient may need to be communicated to Health authorities in the interest of public health considerations, but besides this such information should not be revealed to others except the patient and designated caregivers.

7. Advisory related to non-discrimination:

- 7.1 Non- discrimination:** All patients and persons seeking healthcare have the right to be treated in a non-discriminatory manner, free from any prejudice related to caste, religion, ethnicity, gender, and sexual orientation, linguistic, geographical or social origins. Accordingly, no form of discriminatory behavior must take place concerning any COVID-19 patient under care of the hospital/COVID care center.
- 7.2 Unconditional treatment:** No person should be denied treatment in a public or private hospital due to the lack of a negative COVID-19 test result. COVID-19 test may be arranged by the hospital if considered necessary on clinical grounds.
- 7.3 Homeless Persons:** Policy must be made for testing and treatment of homeless / destitute persons. If a Photo ID of the person is not available, it may not be insisted upon.
- 7.4 Accessibility:** Access to healthcare for elderly persons, differently abled persons, sex workers, LGBTQI persons, various other vulnerable groups may be prioritized and ensured during the COVID situation without discrimination.

8. Advisory related to safety and quality care, according to standards:

- 8.1 Quality Health Assurance:** Right to receive quality health care according to currently accepted norms and guidelines may be ensured for COVID patients and suspects in health facilities and quarantine centres.
- 8.2 Availability of Drugs:** Essential drugs and therapeutics for various forms of COVID-19 care must be readily available in public health facilities as well as through outreach

measures where required. Essential therapeutics may be given free of cost, with priority to vulnerable and lower income sections and those covered by Government healthcare schemes for free care.

- 8.3. Treatment at Private Hospital:** Governments should ensure that the rates are regulated in private hospitals. Due measures may be taken to widely publicise these rates along with available facilities and there must be no hidden costs. Adequate quality of care may be ensured for COVID-19 patients who are treated in private hospitals free of cost or at regulated cost. Regular inspection by Government teams must be ensured to check if they adhere to the regulated rates and quality standards.
- 8.4 Safety and Support:** Right to safety and security including the female patients, minors, PWD and elderly persons, as well as right to access to support in the hospital and quarantine premises may be ensured.
- 8.5 Facilities at Quarantine Centers:** Various essential amenities should be ensured in all Covid Care Centers and institutional quarantine facilities including availability of clean and potable drinking water, adequate nutritious diet with regular meal times, hygienic living space, adequate number of clean bathrooms and toilets, regular change of bed linen, sanitation and disinfection of the premises, availability of recreation and reading material, facility for meeting relatives with proper safety and distancing, and access to personal support through phones etc. Appropriate facilities for women such as separate bathrooms and availability of sanitary napkins must be ensured, along with ensuring their safety. Daily medical check up, availability of medical staff, linkage to COVID Hospitals for referral, and availability of ambulance services may be ensured as per MOHFW guidelines.
- 8.6 Support to COVID positive persons in home isolation:** After ascertaining that management at home is appropriate, COVID positive persons in home isolation to be monitored by field staff through personal visits and / or telephonic consultation, while ensuring prompt access to transport and further treatment at health facilities when required.
- 8.7 Mental Health Assistance and Counseling:** Pre and Post testing counseling may be provided to patients affected with Covid-19 by a mental health professional to deal with various issues including fear, apprehensions, anxiety, etc, along with providing information regarding precautions to be followed, guidelines for seeking further care, and sources of additional support.
- 8.8 Promoting Community Based Assistance:** Participation of volunteers Civil Service Organizations should be encouraged with proper precautions ensured for them, to provide logistical help to the patients who do not have immediate attendants.
- 8.9 Advisory related to Post-COVID Follow-Up:** The 'Post COVID management protocol' issued by the Ministry of Health and Family Welfare should be widely publicised and also be added on Aarogya Setu application. The same may also be sent on mobile by automated text to the patients recovered from Covid-19, to guide and help the people for coping with the post- COVID impacts, if any.

9. Advisory related to Clinical trials and Experimental treatments:

- 9.1 Providing information and informed consent:** Trial participants should be provided adequate information prior to enrolment in a clinical trial or experimental treatment. Participants must be given consent form in advance before their joining the trial with explanation of the consent form, and should be offered choice of signing it. Obtaining of such informed consent in writing should be mandatory for onrolling all participants in the trial
- 9.2 Voluntary participation:** Trial participants should be made aware that their participation is voluntary, and that they can withdraw at any stage without prejudice or loss of future treatment.
- 9.3 Compensation:** Adequate compensation may be paid to all participants involved in trials of COVID-19 interventions who suffer serious adverse events (SAE) or suffer fatality.
- 9.4 Significance of Clinical Trials:** All clinical trials should be conducted only if they offer significant social value, and the products emerging from such trials should be made accessible to all without any discrimination.
- 9.5 Monitored emergency use of unregistered and experimental interventions (MEURI):** During use of such experimental medications aside from clinical trials) for treating COVID-19 by either public or private healthcare providers, doe protection of patients' right should be ensured. This includes obtaining informed consent from each patient, to be sought after providing the patient relevant information in writing, and by rigourously following ICMR guidelines concerning Monitored emergency use of unregistered and experimental interventions.

10. Advisory related to patient education:

- 10.1 Ensuring Awareness through mass media:** Effective mass communication should be done by State governments through various media, to disseminate information regarding COVID-19 to all sections of the population in order to spread awareness. Information on COVID health facilities, testing facilities, programmes and entitlements including information on free care or regulated rates for treatment in private sector hospitals, should be made widely available to the public.
- 10.2 Publicising Information in Health facilities:** Attractive and comprehensible messages conveyed through mass media or posters may be displayed in various health facilities and other public places.
- 10.3 Counseling:** All persons getting tested for COVID-19 have the right to counselling, both pre-test and post-test, in the language of their choice, either in person or over telephone, regarding the illness, precautions, care and treatment and relevant sources of further information and support.

11. Advisory related to being heard and seeking redressal

- 11.1 Grievance Redressal Mechanism:** All states may establish an effective and

accessible health grievance redressal mechanism including provision of Appellate authority, which is linked with a toll free and round the clock state level complain line (operated in languages commonly spoken in the state). This would enable people to lodge complaints and seek prompt and effective redressal regarding various issues like availability and quality of care, harassment, discrimination, overcharging, denial of treatment, admission or cashless facility, and other issues concerning COVID-19 or non-COVID treatment by both public and private hospitals.

11.2 Grievance Redressal Person at Health Institution: Every Covid Care Centre, quarantine centre, Covid Health Care Centre, and Dedicated Covid Hospital must have a designated grievance redressal person, whom patients and caregivers can approach to register their concerns and complaints, and also provide feedback about the treatment and care they have received at the facility.

11.3 Grievance redressal officer at District / City level: The Health department / Municipal Corporation may designate an official at district / city level to respond to complaints which have not been resolved at institution level. Multi-stakeholder grievance redressal oversight committees including civil society representatives may be set up at District / Municipal corporation level, which would regularly review status of processing complaints, and would recommend action on unresolved or common issues.

11.4 Sharing Directory: The name and phone number of the Grievance redressal officer, along with the contact number of the Grievance redressal oversight committee at district/city level may be prominently displayed at key locations in the health facility.

11.5 Complaint Database: A state level, live, publicly-accessible database may be maintained of all the complaints received with details of numbers resolved or pending.

12. Advisory related to Provisioning of Essential Healthcare Services:

12.1 Providing Healthcare Services: Adequate capacity and services for treating COVID-19 patients and provision of essential healthcare services for non-COVID patients in public hospitals may be ensured.

12.2 Utilization of Unused / Underused Facilities: Facilities that are unused for a long time for COVID-19 related services may actively be engaged to provide essential non-COVID healthcare services.

12.3 Augmentation of health workforce: Strategies to augment health workforce availability may be adopted including expedited filling up of existing vacancies, re-deploying staff from non-affected areas, engaging freshly graduated post-graduate doctors after accelerated orientation in COVID care, utilizing retirees who are capable of working especially for non-COVID services, and hiring / requisitioning private sector health workforce capacity.

12.4 Blood Transfusion Services: State governments must operationalise the national guidance related to blood transfusion services in light of COVID-19 issued by MOHFW, to ensure sufficient availability of blood for all patients requiring transfusions.

12.5 Improving testing facilities: Steps may be taken by State and Central Government to cover a larger number of populations by increasing the number of available testing

laboratories and expanding their capacity.

13. Advisory related to Healthcare Workers (Regular and Contractual):

- 13.1 Personal Protection Equipments (PPEs):** All categories of health workers involved in patient care, testing, family contact, home care, patient transport, waste disposal and cleaning at any level of healthcare, in hospital or ambulatory settings, may be provided adequate quantities of quality assured personal protection equipments (PPEs). These must apply to Covid19 designated healthcare facilities as well as non-Covid-19 healthcare locations, wherever health workers are at risk of viral exposure.
- 13.2 Free Medical Care:** All healthcare workers including rehabilitation professionals who are exposed to Covid19 virus may be given all possible medical care free of cost, considering it as an occupational health hazard by the government or the private healthcare institution where the health worker is employed, as the case may be. This facility may be extended to their family also if the health workers are the source of infection.
- 13.3 Defined and humane working hours:** All healthcare workers in both public and private sector, who are engaged in Covid19 related work may be assured of defined and humane working hours, predictably functioning reliever rosters and scheduled off-duty days.
- 13.4 On duty quarantine period:** Any healthcare worker who is exposed to the virus and is at a high risk of infection and advised to quarantine then such period may be treated as 'on duty' irrespective of regular or contractual employee.
- 13.5 Benefit to worker:** All healthcare workers, whether regular or contractual engaged in Covid19 related duties may be provided similar protection with respect to: grant of exposure or infection related quarantine or isolation period as leave on duty; testing and illness care with full financial cost coverage and protected accommodation or transport for persons working till late night or early morning.
- 13.6 Job Training:** All categories of healthcare workers must be regularly provided updated information and on the job training on Covid-19, to enable them to protect themselves and perform their jobs efficiently.
- 13.7 Accommodation and Transport:** Any healthcare worker having late duty hours ending in the night or early morning may be provided safe and clean on-site or near-site accommodation and/or safe transport by the employer.
- 13.8 Protection of healthcare workers:** Strict legal action against individuals, groups or organisations that provoke, perpetrate or prejudicially publicise stigma or violence against health workers engaged in providing Covid-19 related services may be taken.
- 13.9 Timely payment of salary:** Timely payment of salary/ wages, etc. may be ensured to all healthcare workers including ASHA workers. by all employers, Government or Private.

Annexure

Charter of Patients' rights and responsibilities to be displayed and observed by all Healthcare establishments, as per communication by MOHFW, Government of India.*

Patients' Rights: A Patient and his/her representative has the following rights with respect to the clinical establishment

- i. To adequate relevant information about the nature, cause of illness, proposed investigations and care, expected results of treatment, possible complications and expected costs.
- ii. To information on the Rates charged for each type of service provided and facilities available. Clinical establishment shall display the same at a conspicuous place in the local as well as in English language.
- iii. To access a copy of the case papers, patient records, investigation reports and detailed bill (itemized).
- iv. To informed consent prior to specific tests treatment (e.g. surgery, chemotherapy etc.).
- v. To seek second opinion from an appropriate clinician of patients' choice, with records and information being provided by the treating hospital.
- vi. To confidentiality, human dignity and privacy during treatment.
- vii. To have ensured presence of a female person, during physical examination of a female patient by a male practitioner.
- viii. To non-discrimination about treatment and behavior on the basis of HIV status.
- ix. To choose alternative treatment if options are available.
- x. Release of dead body of a patient cannot be denied for any reason by the hospitals.
- xi. It is recommended that patient seeking transfer to another hospital/discharge from a hospital will have the responsibility to 'settle the agreed upon payment'.
- xii. It may be specified in the charter that no discrimination in treatment based upon his or his illness or conditions, including HIV status or other health condition, religion ethnicity, gender (including transgender), age, sexual orientation, linguistic or geographical/social origins.
- xiii. Informed consent of patient should be taken before digitization of medical records.

Patients' Responsibilities:

- I. Provide all health related information.
- ii. Cooperate with doctors during examination, treatment.
- III. Follow all instructions.
- iv. Pay hospitals agreed fees on time.
- v. Respect dignity of doctors and other hospital staff.
- vi. Never resort to violence.



* **Source:** D.O. No. Z.28015/09/2018-MH-II/MS dated 2nd June, 2019 issued by the Secretary, Ministry of Health and Family Welfare, Govt. of India, to the Chief Secretaries of all States/ UTs which was based on NHRC Patients' Rights Charter.



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