

# Patients' voices during the Pandemic

Stories and analysis of rights violations and overcharging by private hospitals



Published by SATHI

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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: <a href="https://sathicehat.org">https://sathicehat.org</a>

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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 21<sup>st</sup> 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 13<sup>th</sup>, 2021.

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

The compendium includes twenty-three testimonies that vividly illustrate what people experienced while seeking healthcare from private hospitals during the pandemic. These stories show the scale and magnitude of overcharging, how private hospitals ignored state rate capping orders, and how hastily created grievance redressal systems crumbled. Most of these testimonies were documented between October and December 2020, and they reveal how patients' rights were violated and overcharging took place while accessing private healthcare services in urban and rural parts of Maharashtra.

This compendium highlights the urgent need to address overcharging as a policy issue, although it is not an exhaustive documentation of patient testimonies. It debunks the myth that overcharging is primarily limited to metropolitan cities and shows that it is a generalised phenomenon. Due to overwhelming outrage, the government of Maharashtra was forced to issue a rate capping order on COVID-19 treatment to safeguard patients from overcharging in private hospitals. However, the government's repeated reassurances did not materialise to their full extent as the systems for grievance redressal were fraught with insufficiencies.

At a macro level, these cases provide a grassroots perspective to challenge national and global euphoria about harnessing the private health sector in achieving public health goals such as Universal Healthcare and the Sustainable Development Goals. It highlights the urgent need to put in place a robust people-centric regulatory system for India's private health sector at the national and state level.

People spoke out about their grievances and wanted them to be visible and in the public

domain, resulting in the anonymised testimonies in this compendium. They are not about death, but rather about how private hospitals took advantage of people's desperation for overcharging and profiteering, and how grievance redressal systems failed. They spoke out because they are still hopeful that their grievances will be heard and resolved.

This compendium is an essential reference document for civil society networks, individuals, and academics who work on patients' rights and private sector regulation-related issues. It is a collective web of real stories that can urge the government to regulate the private health sector. As an immediate step, there should be a state-wide systematic inquiry into instances of overcharging and financial unaccountability in private hospitals, and people who have been overcharged should be compensated.

I would like to express my sincere gratitude to Ms Shreya Nimonkar, who graciously agreed to write the foreword for this compendium. Her story exemplifies how resolute individuals can still triumph over a powerful medical lobby with sheer determination and resilience, even in an extremely adversarial environment.

I also extend my deepest gratitude to all the respondents, patients, and their relatives, who courageously shared their traumatic experiences in private hospitals during the pandemic. Without their willingness to speak out, this compendium would not have been possible.

I would also like to acknowledge the invaluable contributions of my colleagues, Shakuntala Bhalerao, who anchored and coordinated data collection and liaised with patients, and Shweta Marathe, who conceptualized and coordinated the development of this compendium. I am also grateful to Dr Kanchan Pawar and Dr Abhijit More for conducting interviews and writing cases. Dr Abhay Shukla has outlined key steps necessary to protect patients' rights and enhance the accountability of the private health sector.

I would like to thank Shripad Kondhe, Ravi Desai, Santosh Jadhav, and Ms Vaishali Gaikwad for their support in coordinating the data collection. I also express my gratitude to the Programme Development Committee and the Institutional Ethics Committee for guiding and approving this documentation.

Overall, I am deeply grateful to everyone who contributed to this compendium, and I hope it will serve as a valuable resource for policymakers, healthcare professionals, and civil society organizations striving to ensure that private healthcare services are accessible, affordable, and accountable.

Dr Dhananjay Kakade,

Director,

SATHI, Pune

## and logy methodology



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## Introduction and methodology

#### Introduction

The COVID-19 pandemic has exposed the magnitude of the private sector accountability crisis in India once again. During the peak of the pandemic, numerous instances of overcharging and profiteering were reported from different parts of India, including the state of Maharashtra, which is the focus of this compendium. 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.

The pandemic has been a double whammy for patients, who were forced to choose 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, but the pandemic has demonstrated how far we are from achieving that goal.

Particularly striking was how the private health sector, more specifically corporate hospitals, used the COVID-19 pandemic as an opportunity to extract profits through non-transparent overcharging. Notably, overcharging continued unabated despite the Maharashtra Government's order to put a rate cap on COVID-19 treatment.

Positive policy steps by the government, such as instituting audits of private hospital bills that exceeded the rate ceiling and expanding the 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 a range of governance and coordination glitches.

In summary, the pandemic has highlighted the urgent need to address the private sector accountability crisis in India, and this compendium is an important step towards that goal. It is a call to action for policymakers, healthcare professionals, and civil society organisations to work together to ensure that private healthcare services are accessible, affordable, and accountable to all.

#### Why the compendium?

At the heart of this compendium are the patients - the protagonists of their own healthcare journeys. Within these twenty-three anonymised case stories, readers will find resonant accounts of patients' experiences accessing private healthcare during the pandemic. While not exhaustive, this compendium offers a revealing glimpse into the patterns of overcharging, non-transparency, and, in some cases, complete apathy that patients have encountered.

Despite the abundance of academic papers and research briefs on the marketisation, commercialisation, privatisation, and corporatisation of healthcare, there remains a dearth of patient narratives focusing on their perceptions and experiences of interfacing with the private healthcare sector. As we documented patients' experiences for this compendium, we realised how desperately people want to share their stories and build a collective web of shared narratives.

This compendium presents an opportunity to strengthen patients and ordinary people as important constituencies and key stakeholders in shaping the regulatory landscape for the private health sector. In many ways, it is a unique contribution to amplifying the demand for patients' rights and better regulation of the private health sector. We hope it will encourage other organisations to document and analyse instances of overcharging, and further build the momentum towards greater accountability and transparency in private healthcare.

#### What is in the compendium?

The concise case stories presented in this document illustrate the various ways in which private hospitals have violated patients' rights with impunity. Some notable and illustrative patterns of overcharging, non-transparency, and illegal practices include:

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

Lastly, the compendium concludes with a critical section on the way forward. While sharing people's experiences is essential, those experiences should shape advocacy strategies and crystallise new ideas for better regulation of the private health sector. Therefore, the way forward section offers much-needed insights into what has not worked in regulation until now and what needs to be changed and reconceptualised.

#### Methodology

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

#### Data collection

The documentation aimed to capture the experiences of patients or their families residing in Maharashtra who had faced denial or violation of their patient's rights while seeking COVID-19 or non-COVID care during the pandemic and were willing to share their stories voluntarily. The research team identified potential respondents through referrals from health activists and allied health networks, especially those who had worked with people from vulnerable or marginalised backgrounds in both urban and rural areas of Maharashtra. The cases included in the documentation were from the first wave of COVID-19, spanning from March 2020 to December 2020, and were from various districts such as Pune, Yavatmal, Kolhapur, Nashik, among others.

In-depth interviews were conducted over the phone with patients or immediate family members, and the research team interviewed a total of 30 respondents from November 2020 to January 2021. Respondents were informed about the purpose of the interview and its anticipated outcomes beforehand to manage their expectations. Informed consent was taken, and the respondents were assured of privacy, confidentiality, and anonymity from the stage of participation in the documentation to its final dissemination. The interviewers reassured the respondents that personal information such as names of treating doctors, hospitals, places, and other identifying information would be strictly confidential and removed or disguised in the final narration, based on the respondents' preference.

Interviews followed an interview guide covering patient's experiences in the hospital, billing issues, impact of hospitalisation, and denial of patients' rights on their health. All interviews were conducted in Marathi and were audio recorded with the prior consent of the respondents. Audio-recorded interviews were first anonymised and transcribed for further analysis. Proxy names were used in the stories to protect the identity of the respondents..

#### Profile of respondents

We included a total of 30 respondents in the study, and 23 distinct cases are featured in this compendium. Of these cases, seven involved women while the remaining cases involved men. The respondents' ages ranged from 24 to 85 years. The majority of the total respondents had tested positive for COVID-19 and had experiences during the

period of July 2020 to December 2020. With a few exceptions, most respondents belonged to a lower-middle-class background. Two respondents were admitted to large charitable hospitals, three to large private-corporate hospitals, nine to medium-sized private hospitals, and the remaining nine to small private hospitals. Patients' hospital stays ranged from 2 to 25 days, and the total bill amounts varied from Rs 75,000 to 14,00,000. Ten patients had bills exceeding Rs 3,00,000, and two patients had bills above Rs 14,00,000. Among the total respondents, there were 11 deaths. Only five respondents had made a complaint, and all had filed their complaints with district-level authorities. (For more details, please see annexure A)



Victims of non-responsive private hospital My struggle to avait 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 disappointmen with grievance redressal forum No COVID-19 scheme benefits, no beds in government hospitals COVID-19, chaos

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#### Victims of non-responsive private hospital

#### Case synopsis

Manali Kuchekar's ordeal exemplifies the experiences of thousands of people in Maharashtra who were compelled to pay exorbitant advance deposits and dues for COVID-19 treatment in private hospitals. These hospitals, despite being empanelled with MJPJAY, did little to facilitate the entitlements to scheme beneficiaries and flouted state directives on price capping for COVID-19 treatment. Following her husband's demise, Manali also faced patient's rights violations such as the hospital's refusal to release the body of the deceased until dues were paid, denial of a proper bill, and medical records of the deceased.



### **CC** Testimony

My forty eight year old husband, Suryakant Kuchekar (name changed to protect identity), worked as a teacher in a primary school in a village near Kolhapur. In early September 2020, all of us began to feel unwell with symptoms such as fever and body ache. Although we all recovered in a few days, my husband's fever persisted. He visited a nearby MBBS doctor and took medicines for a few days, but his condition did not improve. On September 11<sup>th</sup>, his fever suddenly spiked, and I took him to the government COVID-19 Care Centre in our village, where he was given oxygen and intravenous fluids. Initially, he felt better after receiving treatment.

Although he gave his sample for COVID-19 testing on the same day, he had still not received the test report by September 13th. Late that night, he began to complain of breathlessness and a cough. The following morning, we decided to take him to Kolhapur, where a HRCT scan revealed COVID-19 changes in his lungs. We desperately searched for a hospital with available beds for admission, but all our efforts were in vain. Finally, in the late evening, we were able to admit him to a private multispecialty hospital after 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 a ventilator. After a few days, he was given non-invasive ventilation.

#### Empanelment in government scheme but benefits are denied to patients

We later discovered that the hospital was empanelled with the government MJPJAY scheme for COVID-19 care. However, when my family and I enquired about the scheme, the hospital did not provide us with any information or make any effort to facilitate the process of entitlement. Instead, they insisted on an advance payment 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 apply for this scheme during such chaos and tension.

As Suryakant's condition continued to deteriorate, he passed away on October 8<sup>th</sup>, 2020, 25 days after his admission. **The hospital administrator informed us verbally that the total bill had come up to Rs 14,21,000, but did not provide us with a detailed bill in writing.** We were also told that we would not be given my husband's dead body until the complete dues were settled.

Shocked at the hospital's stance, I sought help from relatives and friends. We held multiple 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 lengthy negotiations and a payment of Rs 2,00,000, the hospital released my husband's body after 11 hours at 6 pm. The hospital only issued a death certificate that stated the cause of death as Acute Respiratory Failure in case of Bilateral Pneumonia with COVID-19 with Septicemic Shock. **Despite our repeated requests, the hospital refused to hand over other documents, such as the patient's medical records, test reports, detailed death summary, and hospital bill.** We ended up paying Rs 5,90,800 in total, in addition to paying for all the investigations and medicines.

It is worth noting that the hospital did not inform beneficiaries about the MJPJAY scheme and refused to provide free treatment to eligible beneficiaries like my husband. The hospital also flouted all regulations by charging exorbitant amounts for treatment, ignoring the price capping measures for private hospitals announced by the government.

#### No transparency in billing

After several attempts over the three months, the hospital eventually provided us with my husband's medical records and an itemized bill for Rs 9,42,057. The bill contained a breakdown of Rs 72,202 for lab tests, Rs 20,000 for X-rays, and Rs 5,64,155 for medicines. I immediately noticed that we were charged Rs 14,21,000 on 8th October but were given a bill for an amount much lower than that. When I questioned the hospital about the Rs 4,80,000 discrepancy, they were unable to provide an explanation. This lack of transparency in billing was extremely frustrating and added to the already difficult situation.

#### Serious indebtedness

As a widow with two young children, I had to borrow money from relatives to pay off the hospital bill after our savings were exhausted. It's a difficult and stressful situation as I not only have to support myself and my children, but also find a way to pay back the money that I owe to different family members. I strongly believe that the government should take more proactive measures to ensure that schemes like MJPJAY are effectively implemented in private hospitals. Family members should not have to navigate through complicated processes and deal with apathetic hospital staff during a health crisis.





#### Case synopsis

The Maharashtra state government promised free treatment for 996 procedures to all residents under the MJPJAY insurance scheme. However, despite the government's assurance, many eligible beneficiaries struggled to avail scheme's benefits in reality. Pramod's mother tested positive for COVID-19, and he managed to admit her to a charitable trust hospital in Pune as government hospitals were fully occupied. The very next day, he submitted all necessary documents to avail of the MJPJAY scheme's free treatment benefits. To his dismay, the management denied his claim, stating that his mother had tested negative for COVID-19 after her admission. Despite providing an ICMRapproved COVID-19 positive test report and receiving COVID-19 treatment in the hospital's COVID-19 Care Unit, the management refused to budge and demanded an immediate payment of Rs 1,00,000 for the hospital expenses. Pramod found himself tangled in red tape and frustrating arguments with the management as he pleaded his case with various government representatives. He persisted, and finally, the hospital approved his claim. However, he still had to pay Rs 20,000 to the hospital for the first two days of her treatment and an additional Rs 70,000 for medicines. This incident highlights the difficulties that eligible beneficiaries face while trying to avail the MJPJAY scheme's benefits. Despite the government's promise, the implementation process can be challenging and frustrating, leading to delays and confusion. The government must take measures to ensure that eligible beneficiaries can avail scheme's benefits without any obstacles or unnecessary delays.



## **CC** Testimony

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

#### "Make your own arrangements, there are no beds available"

My mother's COVID-19 symptoms were worsening, and her oxygen levels were between 70% to 80%. Worried, I realized that I had to take her to a hospital before her condition turned critical. I decided to take her to one of the largest charitable trust hospitals in the city, hoping they would have space for her. After a lot of pleading, the hospital agreed to treat her temporarily in the casualty ward, while I frantically looked for alternative arrangements.

I immediately rushed to the divisional corporation office for assistance, hoping that they would help me get a bed in a government hospital. However, the Medical Officer there told me that all government hospitals were overwhelmed, with people even paying for their own oxygen, and advised me to make my own arrangements. It was a helpless situation, and I didn't know what to do.

#### "Pay the advance deposit if you want to admit your mother"

After managing to admit my mother in the COVID-19 isolation facility of the Trust hospital, I was relieved to know that I could avail of free or subsidised COVID-19 treatment under the MJPJAY and/or *Sheheri Garib Yojana*. But when I submitted all necessary documentation the next day, I was asked to update the ration card, and had to rush to the ration card office for the same.

The management then shocked me by informing 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. They demanded an immediate deposit of Rs 1,00,000, as that was the cost incurred for her treatment till then. This left me confused and frustrated, as she was being treated as a COVID-19 patient and was even shifted to the COVID Critical Unit (CCU). I was also told to procure seven Remdesivir injections for her, which took me days of running from one pharmacy to another.

To get some clarity, I discussed my mother's case with medical experts and the head of the CCU in the hospital. They informed me that even though my mother had tested negative, she was suffering from post COVID-19 complications and her treatment was based on her symptoms and condition rather than the test results. I urged the doctors to convey their observations to the hospital management, who refused to accept that my mother had COVID-19. The entire situation was frustrating and demoralizing, and I felt helpless in the midst of red tape and denial by the hospital management for MJPJAY eligibility on flimsy grounds.

#### "Negotiating with indifferent hospital management"

I was at loggerheads with the hospital management which refused to accept my explanations and kept asking me to pay up. I was so frustrated with their stance that I threatened to share my experiences with the press and 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 a team of MJPJAY officials approved my application during a scrutiny of pending applications. 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 came to Rs 1,12,000. To my shock, I was informed that I had to pay Rs 35,000!

#### "Exhausted, I finally paid the hospital"

I found out that the hospital management had approved my MJPJAY application from the 23<sup>rd</sup> of July onwards and had charged me for the first two days. Despite my explaining that I had submitted all the required documents within 12 hours of my mother's admission, they insisted on billing me for those two days. We went back and forth for several days, but I eventually gave in and paid the hospital Rs 20,000 as they would not stop harassing me. Though I was aware of the hospital's irregularities, I was exhausted from the arguments of the past 18 days and did not have the energy for another prolonged debate.

The total hospital bill came to Rs 1,12,000. Even after the MJPJAY subsidy, I still had to pay an additional Rs 20,000 to the hospital and around Rs 60,000 to 70,000 for medicines, of which Rs 40,000 was for Remdesivir alone. I used up all my savings and had to borrow the rest from my friends. I am still paying back those loans.

#### "Hospital management was just intent on fleecing patients"

As I walked through the hospital wards, I couldn't help but notice the dedication and sincerity of the security guards, nurses, and doctors working tirelessly to care for the patients. They were risking their own health to provide medical aid to those in need. However, the hospital management was a different story altogether. They seemed ruthless and only interested in extracting as much money as possible from the patients. They were indifferent to the suffering and helplessness of the patients and their families. It was disheartening to see such behavior in such a crucial time when people were in dire need of compassion and empathy.

#### "Unlocking Government Schemes: Bridging the Gap between Hospitals and Patient Assistance"

The whole process of applying for the MJPJAY scheme was incredibly stressful for me. All I wanted was to receive the government benefits that were promised to citizens during the pandemic. I did not expect the hospital to pay for my mother's treatment, but I did expect that the process would be facilitated for eligible beneficiaries by all hospitals. Unfortunately, the on-ground implementation was very poor, and the hospital management did not seem to care about the schemes. They were only interested in profiteering and billing patients as much as they could.

To add to my frustration, my bill for three days included a charge of Rs 12,000 for PPE. When I pointed out that the state health minister had said that PPE kits should be

provided for free, the administration told us that they had not received any such government resolution and had to bill the patients for it.

Although I was lucky to have access to a support system and be advised and supported by health rights activists and doctor friends, I still found the process incredibly challenging. I can only imagine how much more difficult it would have been for someone who had no access to legal guidance, contacts, or generous friends to lend money. I witnessed many people crying in front of the hospital management, pleading for help and begging for some time 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 was able to persist because I was aware of my rights, but many others would have given up. It's important that the government takes steps to ensure that such schemes are implemented effectively and that all eligible beneficiaries can access them without any hassle.

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

#### Case synopsis

Sandesh, age forty years, was experiencing symptoms of COVID-19 in August 2020. Despite testing negative, his chest X-rays and CT scan of the lungs confirmed COVID-19 changes. Government hospitals required a positive test for admission, so he was admitted to the ICU of a government-approved private COVID-19 Care Centre in a nearby village. Even when Sandesh was on a ventilator and struggling to breathe, he was anxious about the cost of his treatment and whether he could afford it. Though he was charged at governmentcapped rates, the hospital bill for his 22-day stay was approximately Rs 3,00,000 due to additional costs of PPE, investigations, and medicines. As the hospital he was admitted to was not empanelled for MJPJAY entitlements during his stay there, he could not claim any benefits. Like thousands of other patients, Sandesh paid his hospital bill in cash using his savings and personal loans from relatives. Due to a lack of audit facilities in small rural villages in Maharashtra, people hesitated to complain about overcharging for COVID-19 treatment at local hospitals, as they did not want to be in the bad books of the doctors there.



## **CC** Testimony

As an employee of a cooperative society that provides microloans to farmers, I have been working throughout the pandemic with all necessary precautions. However, in August 2020, there was a slip-up in our office. A colleague who had COVID-19-like symptoms did not disclose them to the management and continued to come to work. After he became really unwell, he got tested and turned out to be positive. Naturally, we were all concerned about possible exposure after finding out that he was infected.

A week after this incident, sometime in mid-August 2020, I started feeling unwell and developed a mild cough and fever. Although I took medication and rested, it seemed like I had recovered from both. We even had a five-day Ganpati Pooja (festival) at home. But after a few days, I again developed a high fever and cough. A doctor friend advised me to

get tested and an X-ray. Although the test came back negative, the X-ray showed typical signs of COVID-19 infection. I was feeling worse and was struggling to breathe. My oxygen levels were steadily decreasing, and I knew I had to be admitted. Therefore, I went to a private hospital in a nearby village that had been approved as a COVID-19 Care Centre by the government. Since I knew the doctor, I felt I would be safe there.

When the doctor examined me, he confirmed that even though my test was negative, I had all the symptoms of COVID-19 and that the infection had reached my lungs. He advised me to get admitted immediately as starting with the treatment quickly was necessary. It was the 29<sup>th</sup> of August 2020, and I was admitted right away into the ICU.

#### Constant Worry of Treatment Costs in Critical Times

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. My mind was constantly preoccupied with financial concerns; the CT scan had cost me Rs 8,000, and the ambulance charge was Rs 2,500. I hoped that my stay would not be too expensive since the hospital was a government-approved COVID centre.

During the first week of my stay, my condition was not stable, and I was put on a ventilator for three days while staying in the ICU for twelve days. I was given costly Remdesivir injections and provided with oxygen support daily. After my condition stabilised, I was shifted to the general ward, where I stayed for another ten days. Although I could speak, I was extremely weak, and getting up from the bed required considerable effort. But even in that state, I was constantly worried about how much the hospital stay cost me and how I would arrange the necessary funds.

Overall, I was satisfied with the treatment I received in the hospital, particularly since I was acquainted with the doctor. The medical staff provided excellent care during my stay. However, the hospital was extremely crowded, with approximately 60 patients undergoing treatment. The beds were placed within a few feet of each other, and hygiene and sanitation practices were inconsistent. Once in the general ward, I could communicate with my relatives and family via phone, but no one could visit me. I was particularly worried about my son, who had also tested positive and was in home quarantine.

#### I settled the entire bill in cash as I was told MPJAY is not applicable in my case

On the 18<sup>th</sup> of September, after 22 days in the hospital, I was finally discharged. However, the bill for my stay had amounted to a staggering Rs 3,00,000, even though I was charged at government-specified rates. The cost of PPE kits alone had come up to Rs 44,000 at a rate of Rs 2,200 per day! Furthermore, the medicines from the hospital pharmacy had cost an additional Rs 1,27,000, for which I got a 5% discount. The lab investigations had incurred an additional cost of Rs 25,000.

When I enquired about the MJPJAY scheme, I was informed that it was not approved for the hospital where I had stayed during my illness. Although the hospital received approval for MJPJAY a week after my discharge, it was of no use to me at that point. I had to pay the entire bill in cash, which I did by utilizing all my savings and borrowing the rest from my in-laws.

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

In our small town, there was no auditor present to scrutinize the bills. Although I managed to arrange for the funds required, I couldn't help but wonder about the plight of those who were less fortunate than me. For the poor, there is no alternative during such times, especially **when government hospitals are overburdened, and admission may be refused on technical grounds, such as a negative COVID-19 test result.** In such cases, people living in rural areas like us are forced to go to private hospitals and pay whatever charges are demanded.

We cannot even afford to argue or file a complaint against the hospital or doctor, as we might need their services in the future. Being in their bad books is not an option for us. The fear of being denied medical attention or receiving substandard treatment is always looming over our heads. It is a sad reality that the poor are often left with no choice but to succumb to the whims of those in power, despite the fact that they are already struggling to make ends meet.

#### Expectation of quality affordable treatment

If the government has approved private hospitals for COVID-19 treatment, then it should also ensure that subsidised treatment is available to everyone admitted there. Many of us who were hospitalized in such facilities assumed that the government recognition meant that the hospital stay would be free of cost or subsidised. Unfortunately, we were not prepared for the hefty bills that followed, and we had no choice but to take on debt to settle them.

It is frustrating to think that we had no say in the matter. We were simply trying to access the medical attention that we needed, and yet we were hit with unanticipated financial burdens. The government must take steps to ensure that private hospitals provide affordable treatment options for everyone, irrespective of their economic status. It is only then that the most vulnerable members of society will have access to the care that they deserve.

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Unending demands for money and unanswered questions till the end

#### Case synopsis

In October 2020, a local hospital admitted Altaf Javed, a 30-year-old shop owner from a small village near Kolhapur district, after he fell ill with COVID-19-like symptoms. However, his family was dissatisfied with the quality of care he received and his deteriorating condition. As a result, they shifted him to another private hospital in Kolhapur. Upon arrival, the hospital staff inquired about the family's ability to pay for the treatment upfront.

Desperate to provide the best possible care to Altaf, his family borrowed money from relatives to admit him to a hospital with ICU facilities, and they ended up spending more than Rs 1,50,000 in just two days. Sadly, Altaf's condition worsened, and he passed away on the third day, leaving his family devastated. Over the past three months, they have been struggling to repay the borrowed money by selling household assets.

Liyakat Javed, Altaf's brother, is one of the many individuals who were forced into debt due to out-of-pocket catastrophic medical expenses during the lockdown. The attitude of hospitals prioritizing money-making over patient care has left him and his family embittered.



## **C** Testimony

As a part of our joint family, my younger brother Altaf owned a small footwear shop, and I had a small store that repaired watches. On the 10<sup>th</sup> of October 2020, I took him to a local hospital in our village as he had been feeling unwell for a few days and had started coughing.

To our shock, the doctor informed us that his condition was severe and that he needed to be hospitalized immediately as he seemed to have COVID-19. Frightened and bewildered, we agreed to the doctor's suggestion, and he was admitted to the general ward. Before his admission, we were provided with a long list of medicines that amounted to nearly Rs 30,000. He was tested for COVID-19, given oxygen support, and several other blood tests and X-rays were conducted.

Two days later, the COVID-19 test came back negative, yet he was still being treated for the virus. During the three days that he was there, we noticed that the hospital staff labelled all patients as COVID-19 positive, irrespective of their actual condition. The medical staff paid little attention to the patients, and my brother had to request the nurse to stop the IV drip when it ran out. The doctors or staff only interacted with us or other relatives when asking for more money. I felt that the hospital's priority was money first, and the patient's life later. We ended up paying Rs 40,000 to the hospital, including the cost of the medicines.

It was disheartening to see how private hospitals viewed COVID-19 as an opportunity to profit. Their greed for money was evident in their careless treatment of the patients. I was appalled by the fact that despite the negative test result, my brother was still being treated for a disease that he did not have, simply because it would bring in more money.

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

On the third day of my brother's hospitalization, he insisted to take him to another hospital as his condition had deteriorated, and he was feeling breathless due to insufficient oxygen. After agreeing to his request, we asked for his discharge from the previous hospital as he was being given an excessive amount of medication. We then took him to a small hospital run by a madrasa in the neighbouring village, hoping for better care without unnecessary medication. However, to our disappointment, the hospital lacked even the most basic facilities, such as oxygen. After a day and a half, we decided to shift him to a good hospital in Kolhapur that had a proper ICU.

We took him to a medium-sized private multispecialty hospital in Kolhapur, which was just a ten-minute drive from our village. However, we had to pay an exorbitant amount of Rs 3000 for the ambulance service to transport him to the hospital.

#### "Can you afford treatment here? Should you wish to admit your patient pay a deposit first"

Upon reaching the hospital, we informed them about my brother's grave condition and his need for urgent medical attention. However, we were told bluntly that we should not have even come to the hospital if we did not have the funds to pay for hospital services. Hospital quoted a minimum package of Rs 1,00,000 for three days and demanded an advance deposit of Rs 50,000 for his ICU admission. Additionally, hospital provided us with a list of medicines costing Rs 56,000, and asked it to purchase from the hospital medical store. With no other options available, we had no choice but to agree to their exorbitant terms to admit my brother. Our only concern was to have him admitted as soon as possible, and we did not want to delay his treatment due to financial issues.

#### "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 around 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 all night. We prayed that he would recover.

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

The following morning, the hospital demanded another Rs 50,000, which we could not afford. At that point, my father suggested taking Altaf home since we could not pay for his treatment. However, when we requested his discharge, the hospital informed us that we still had to pay the outstanding dues of Rs 20,000, or they would not discharge my brother.

Once again, we had to scramble and seek help from relatives who graciously came to our aid during this crisis. With their assistance, we paid Rs 20,000 for the outstanding dues and an additional Rs 15,000 for the medicines. During this time, we had no communication with Altaf and were unaware of his condition. The only time the staff approached us was to demand more money. We had no idea what was happening, but we put our faith in God and the doctors.

Sadly, on the morning of 16<sup>th</sup> October, we received a phone call from the hospital informing us of my brother's passing. His body was handed over to us at around 3 pm that afternoon, wrapped in plastic.

#### "The hospital didn't give us Altaf's medical records even after his death"

Ironically, we never received a confirmed COVID-19 report for my brother Altaf—he passed away before we received the test results. Furthermore, we were never provided with any of his hospital records or files, leaving us in the dark about his medical treatment. The hospital bill for just two days of treatment amounted to an astounding Rs 1,68,000.

## In the following three months, we were forced to repay our debts by selling all of Altaf's footwear stock at a loss, totalling around Rs 1,75,000.

At the time, we were not aware of the government insurance scheme that offered subsidised treatment in private hospitals. However, even if we had known about the scheme, it would have been too late for my brother as he had already passed away. The hospital never informed us about this option, and we were too dejected and crushed by his sudden demise to follow up with the hospital.

I want to share our struggle in providing Altaf with good medical care and the way we were treated in all hospitals. It felt as though hospitals were solely focused on making money during the lockdown, and we were unable to ask any questions because of the COVID-19 situation. Unfortunately, my family does not have any documents or files from the hospital as my mother threw them away in a bout of grief and anger.

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## 5 Desperate and futile struggle against COVID-19 and hospital

#### Case synopsis

As a first-person account, here is the story of Prakash, who was a father of three. In July 2020, he developed COVID-19-like symptoms and was quarantined for three days in the government COVID-19 Care Centre in our village. When his test report returned positive, his condition worsened, and we decided to move him to a private multispecialty hospital in the nearest city. On paying an advance deposit of Rs 50,000, he was admitted immediately to the ICU. Due to the hospital's strict COVID-19 protocols, we were not allowed to enter the hospital premises, and we lost all contact with Prakash.

Despite procuring Remdesivir and even plasma, his condition did not stabilise, and with many members of our family having tested positive, Prakash's aged father passed away due to COVID-19-related complications on 11<sup>th</sup> August. Prakash himself passed away a day after. We were left shattered and wanted to take his body home for the last rites, but the hospital refused to release it until we settled the pending dues of Rs 1,15,000.

We had to borrow money from friends and relatives to pay off what we could. However, the hospital refused to give us Prakash's medical records and an itemised bill until we settled the entire amount. Despite being empanelled under the publicly funded health insurance scheme (MJPJAY) scheme, the hospital did not provide us with any information about our eligibility nor did it comply with the government-capped rates for private hospitals. It felt like they were only focused on making money during the pandemic and did not care about the patients and their families.

#### Testimony

We are a joint family residing in a small village in Kolhapur district. My elder brother, Prakash, was a labour contractor for the Maharashtra Industrial Development Corporation and had diabetes and hypertension. In July 2020, he started feeling unwell, complaining of body ache, cold, and a dry cough. We took him to a local doctor who prescribed medication and advised him to rest at home. However, his condition worsened after three days, and he developed a high fever.

On July 27<sup>th</sup>, we took him to a specialist who suggested that Prakash get tested for COVID-19 immediately. We visited a government COVID Centre for the test, but they told us he would have to be admitted for institutional quarantine for two days. So, we went to Kolhapur the same evening and got his HRCT scan done, which showed low scores (17/40). The doctor advised us to get him admitted and start treatment immediately.

On the 30<sup>th</sup> of July, Prakash went for his COVID-19 test at the COVID-19 Care Centre in Kagal, where he stayed in the quarantine centre until his test returned positive on the 2<sup>nd</sup> of August. His condition had already deteriorated, and he complained of breathlessness. That night, we shifted him from the government COVID-19 Care Centre to a private multispecialty hospital in Kolhapur at 11 pm. We had to pay an advance deposit of Rs 50,000 to the hospital before his admission.

#### "No communication about the brother's condition, the only communication was to pay more money"

The hospital admitted Prakash immediately into the ICU and put him on the ventilator. For the next three days, we were not permitted to enter the hospital. We, along with other patients' relatives, waited outside the hospital gate, with no direct contact with Prakash. The hospital staff informed us that the doctor would update us about his condition twice a day. However, every evening, a nurse would call us to the watchman's cabin and demand more money, which she noted on a card.

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

On 3<sup>rd</sup> 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 procured three doses the next day. On 5<sup>th</sup> 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 the 7<sup>th</sup> August. Thankfully, the doctor informed us that his condition had stabilised that evening. 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 needed. On the morning of the 9<sup>th</sup> and 10<sup>th</sup> of August, Prakash's condition fluctuated between stable and critical. All we could do was pray for him to recover.

#### Crises on all fronts beset us

While Prakash was in the hospital, my 65-year-old father had also been admitted to the government COVID Centre in our taluka place as his condition had worsened. On the 11<sup>th</sup> of August, we received a call at 5 am informing us that our father had passed away due to

COVID-19-related complications. As we were organizing the last rites for my father in our village, we received another call from the hospital in Kolhapur on the morning of the  $12^{th}$ , informing us that Prakash had passed away as well. It was a huge shock to our family as both elders passed away within 24 hours of each other.

#### "Hefty bill, and then Prakash's dead body held back over nonpayment of dues"

We rented an ambulance to collect Prakash's body from the hospital in Kolhapur. However, before the hospital could hand over the body, we had to settle the pending dues. Initially, the staff on the phone had quoted a pending amount of Rs 85,000, but upon reaching the hospital, we were presented with a bill for Rs 1,15,000. The total hospital bill for Prakash had come to Rs 2,95,000, and on top of that, there was a pharmacy bill of Rs 89,000. After negotiations with the hospital, we paid Rs 1,00,000 in cash to take Prakash's body to our village, where we cremated him alongside our father. We had to borrow all the money from our relatives and friends to pay the hospital bills in cash. It was a difficult time for us, and the financial burden only added to our grief.

#### "Long arguments with hospital to access Prakash's medical records for insurance purposes "

During that stressful and chaotic time, we were not able to receive help from anyone, as we were all COVID-19 positive and had to stay away. Despite our repeated requests, the hospital did not provide us with a proper itemized bill or Prakash's medical records. We explained that we needed these documents to claim insurance, but the hospital management kept asking for the balance of Rs 45,000 either by cash or RTGS.

They kept making excuses for several days until we became impatient and created a scene at the hospital, threatening to involve the media. The following day, the hospital finally handed over photocopied case papers and the bill, which we needed for insurance claims.

#### No information about any schemes, lack of clarity regarding Prakash's condition

The hospital did not inform us about any government scheme, nor did they communicate that COVID-19 treatment rates in private hospitals were capped. We didn't care about any scheme at that moment; we just wanted our brother to recover. Although we were able to gather the money to pay for his treatment, we saw many people being turned away because they couldn't afford it.

Even after finding out that the hospital had charged us more, we didn't follow up with them. My mother had a heart attack due to the shock of losing her husband and son and had to be admitted for 15 days. We were just trying to cope with what had happened.

We feel that the hospital authorities and the doctor didn't bother to communicate with us at all. They didn't provide us with any information about my brother's real condition, and we wondered if they were concealing information from us to prolong his stay in the hospital. At the end of the day, his demise was all that mattered, and he couldn't make it despite our efforts.

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#### Inflated charges and incomplete information

#### Case synopsis

When 72-year-old Sumantai was admitted to the hospital for apparent heart trouble, the only private hospital that had available beds asked her son to pay an advance deposit. Despite repeated requests, the family did not receive the reports of the COVID-19 test she took upon admission. However, three days later, she was declared COVID-19 positive and given Inj. Remdesivir. Despite all efforts, Sumantai's condition deteriorated, and she passed away. Her family felt that the doctors did not manage her spiked sugar levels, which led to complications that caused her death.

After Sumantai's demise, the hospital did not hand over her medical records and reports, nor did they provide a proper bill. The family noticed that many charges in the bill appeared to be inflated, including a Rs 16,000 charge for a twokilometer ambulance ride to the crematorium. The family is still unsure whether Sumantai's death was due to COVID-19 since the hospital did not share any positive test reports with them.



## **CC** Testimony

#### Insistence on advance payment before admission

At that time, there was only one big private multispecialty hospital with available beds. When I approached them, they were initially unwilling to admit my loved one. They asked me to pay an advance deposit of Rs 80,000, but I only had Rs 40,000 in cash with me. I pleaded with them to accept the amount I had and assured them that I would pay the balance the next day. Only then did they agree to admit my loved one.

I kept my promise and paid the balance as soon as possible, the very next day. It was a stressful and anxious experience, but I was relieved that my loved one was finally admitted to the hospital.

#### COVID-19 report not shown to us

After my mother was admitted to the hospital, the doctor insisted that she undergo a CT scan. Apparently, every patient admitted to the hospital had to undergo this procedure. We were told that the CT scan should be done in the diagnostic lab attached to the hospital. The cost of the CT scan was Rs 8,500, which we paid.

Subsequently, the hospital did an RTPCR COVID test in their pathology lab, for which they charged us Rs 3,000. However, they did not provide me with a bill for the test. I repeatedly asked for the test result report, but every time I asked, they came up with one excuse or the other. They said that the sample was being sent to Nagpur, and the result would take time. However, I did not receive the test result report until the end. It was a frustrating experience, and I felt that the hospital was not being transparent about their procedures and billing.

#### Absence of separate COVID-19 patients' ward

My mother was admitted to the hospital on August 13th, and was put on oxygen. For the first two days, she felt better and was able to talk and even have her food by herself. However, there were suspect COVID-19 patients whose test reports were pending and non-COVID-19 patients 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 complained to the administration about the lack of quarantining of COVID-19 suspect patients. The administration called the police to deal with the complainant, and after that, we all kept quiet despite our misgivings.

Every day, my mother had to give blood and urine samples. When we enquired about the tests, we were told they were to screen for COVID-19 related complications. On the third day, we were informed that my mother had COVID-19, and she needed to be given Remdesivir injections. We were asked to procure six doses of this injection, costing Rs. 6,000 per dose. Unfortunately, the injections were not available anywhere in Yavatmal, so I ordered them from Akola. I also obtained a few doses from a friend whose relative had passed away the previous night.

They started giving my mother the Remdesivir injections on August 17<sup>th</sup>. The doses were supposed to be given every six hours, but after the fourth dose, her condition took a turn for the worse. When I visited her on the evening of August 18<sup>th</sup>, she was on oxygen, breathless, and unable to even talk. Later that night, the doctor called me into his cabin and informed me that my mother's condition was critical and he could not guarantee her recovery. He suggested that I shift her to Nagpur, but it was too late. My mother passed away that night.

My mother was also diabetic, but the hospital did not treat her high blood sugar levels. Her sugar level had shot up to 560, causing complications that led to her death. We were not kept informed about what she was being treated with. My mother had become so weak that she was unable to change her sari, and the hospital charged us Rs 1,500 for staff assistance to change her clothes. It was a difficult and distressing experience for our family.

#### We did not get medical record/proper bills/death certificate

The hospital did not allow me to touch or review my mother's medical file. They did not provide a death certificate or a proper bill. All they gave me was a stamped piece of paper with the total amount of the bill written on it. I received no explanations for any of my questions regarding the treatment my mother received. It was frustrating and disheartening not to have access to her medical records or a detailed breakdown of the charges billed to us.

### To carry my mother's dead body to a crematorium barely two kilometres away, ambulance changed us Rs 16,000!

The cremation ground was just two kilometers away from the hospital, and I was shocked to learn that the hospital charged me Rs 16,000 to transport my mother's body there in their ambulance. When the ambulance driver took my mother's body out of the ambulance, they gave me a form to sign. I was so overwhelmed by grief and shock at my mother's sudden demise that I didn't realize that they were overcharging me even after she had passed away. I couldn't understand how a two-kilometer ambulance ride could cost Rs 16,000.

In total, I paid Rs 1,48,000 to the hospital, excluding the extra amount I paid for my mother's medicines. The hospital did not mention any government schemes like MJPJAY, nor did they provide any information to patients about entitlements or eligibility for such schemes. It felt like everyone was being taken advantage of there, and the entire experience left me feeling helpless and exploited.

#### Negligent attitude and poor treatment

I believe that the doctors at the hospital failed to treat my mother properly for her blood sugar and heart issues, which ultimately contributed to her death. Her sugar levels remained high until the last day, which worsened her condition. The hospital did not maintain any security or segregation of COVID-19 suspect and COVID-19 patients, and the staff was irresponsible in their conduct, not wearing proper PPE. As a result, my mother contracted COVID-19.

Despite the doctor stating that my mother's death was due to COVID-19, I never received a positive test result from the hospital. I am still unsure if my mother really had COVID-19 or not. To make matters worse, I have yet to receive a death certificate from the hospital. The entire experience has been frustrating and disheartening for me and my family.

#### Patients' demand

My relatives and friends lent me money to help me pay the hospital bill, but it is unfair that poor people have to struggle to pay medical bills when their loved ones fall ill. Should they simply let their patients die? Private hospitals need to be held accountable for their actions. It is unfortunate that experiences like these, where hospitals extort money from us while our loved ones are suffering, often result in frustrated people losing their temper and resorting to violence, such as smashing hospitals. It is essential that the healthcare system is reformed to ensure that all individuals, regardless of their financial situation, have access to quality healthcare.

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### Health insurance coverage denied to eligible patient despite efforts

### Case synopsis

Neelavati Jadhav, a waste picker from Pune, had to be admitted to a teaching hospital in Pune for an emergency operation during the lockdown.

Unfortunately, she also tested positive for COVID-19 prior to the operation. Despite being eligible for various subsidised treatment schemes, her family faced great difficulty in availing them, resulting in them paying the hospital bill in its entirety and incurring a huge debt in the process.



# **CC** Testimony

I am a waste picker and live in Pune with my family of six. My 65-year-old mother and I work as waste pickers and we worked throughout the lockdown as essential workers. However, in July 2020, my mother started experiencing acute pain in her lower abdomen after breakfast. We consulted a doctor in a nearby nursing home who recommended urgent ultrasonography. At another centre, we were informed that there was a growth/twist in her stomach that needed to be removed immediately. She required urgent admission and surgery.

Double whammy- distant and indifferent care at corporation hospital and private hospital's refusal to admit my mother without deposit!

We first went to a Corporation Hospital, where the treatment we received was shocking. PPE-clad doctors talked to us from a distance of 16-17 feet behind a barricade. They did not even examine my mother and only read her sonography report. They said she could not be admitted there for surgery and referred us to the District General Hospital. However, my mother refused to go there as she was terrified of the hospital.

We then decided to go to a large hospital associated with a private medical college. However, even getting an auto-rickshaw during the lockdown was a herculean challenge. When we finally reached the hospital, we were relieved that my mother was immediately taken to the casualty and examined by a doctor. The doctor informed us that she needed an emergency operation and gave us an initial estimate of Rs 35,000. We had no idea where we could raise that amount at such short notice. However, a corporator we knew intervened and contacted the hospital to ask them to admit my mother without the deposit. We were extremely thankful when my mother was finally admitted. There was still some humanity left in the world!

#### Struggle to access subsidised treatment schemes

However, even after my mother was admitted to the hospital, we faced another struggle-availing subsidised treatment under various schemes such as MJPJAY, Shaheri Garib Yojana (scheme for urban Poor), and the charitable trust hospital schemes. Despite following up with officials and providing all necessary documents, we faced great difficulty in availing these schemes. We ended up paying the hospital bill in its entirety, incurring a huge debt in the process. It was a difficult and distressing experience for our family, and we hope that the healthcare system can be reformed to ensure that everyone has access to quality healthcare, regardless of their financial situation.

We were told that she was being treated as a suspect COVID-19 patient until 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. Thereafter, we lost complete contact with her. We were not allowed to see 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 on 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 be 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 not to delay the operation. Nobody was updating us about what was happening, and 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 to 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 standing outside the hospital gates the whole day. We were not allowed to come inside or use hospital facilities like the toilet or canteen since we were relatives of a COVID-19 patient, even though we were paying for her treatment there. There were no shops open outside because of the lockdown, and 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 the organization 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* and *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.

#### **Debt Burden**

The hospital bill for my mother's operation totalled Rs 1,13,000, which the hospital reduced to Rs 1,07,000 after we requested a discount due to our circumstances. Additionally, we had already paid around Rs 15,000 to Rs 16,000 for all her medicines. To cover the remaining costs, we borrowed Rs 25,000 from relatives and received Rs 32,500 from a collection organized by my employer's society. I also took a personal loan of Rs 60,000 from a private money lender at a monthly interest rate of 10%, and I am currently paying an instalment of Rs 6,000 every month. During the 15 days that I was by my mother's side at the hospital, I lost my job that paid me Rs 16,000 a month. We are now struggling to manage our daily expenses and pay off the debt incurred due to this operation.

At the time of my mother's discharge on July 21<sup>st</sup>, we were waiting outside the main gate. However, the hospital staff dropped her off at another exit, and she had to walk all by herself for around 300 feet. Considering her weakened state after the operation, it would have been helpful if they provided her with a stretcher or allowed us to pick her up.

#### Hospital refused to give us reports at the time of discharge

The hospital did not provide us with my mother's medical file or test results upon her discharge. It took multiple attempts and written applications before we were finally given some of her reports. Our only hope is that if the government announces schemes like these, big hospitals should provide assistance to people like us to help them avail of the benefits. There should be a dedicated assistance desk for the poor and helpless in these situations. Hospital staff should communicate regularly with the families and keep them updated on their patients' conditions, particularly in current circumstances. I wouldn't wish an experience like the one we went through on my worst enemy.

### Testimony by social worker, who helped the family

#### Cumbersome process to avail scheme

Initially, we had tried to avail the MJPJAY scheme, but we later found out that we were not eligible for it. Hence, we tried to apply for other subsidised treatment schemes such as Sheheri Garib and Trust Hospital Scheme. For the Sheheri Garib Yojana, people are required to submit their documents at the corporation offices to obtain an eligibility card, which can be used at the hospital to get a subsidised quotation. However, due to the pandemic and lockdown, the corporation offices were closed, and hospitals were supposed to collect soft copies of the required documents and enrol the patients in the scheme. Even though we had submitted all the necessary documents, the hospital did not enrol us in any of the schemes.

We contacted the supervisor who assured us of help from the hospital authorities, but by then, we had lost all patience with the red tape and lack of cooperation from the hospital management and social workers. We ended up paying the hospital bill the next morning by borrowing money from friends and relatives without informing anyone.

After discharge, we continued to follow up with the district coordinator of the MJPJAY scheme and filed a complaint with the MJPJAY Maharashtra Committee. However, despite our efforts, the hospital replied that the procedure conducted on my mother was not covered by the MJPJAY Scheme. It was challenging to contact officials due to lockdown restrictions, and our efforts were all in vain.

It is disheartening to note that despite three subsidised treatment schemes being available, the deserving wastepicker family could not avail of any benefits. Our experience suggests that the hospital social workers in many major hospitals in Pune do not proactively assist people with scheme eligibility assessment and only collect documents after getting approval from the billing in-charge. It is crucial to have a dedicated assistance desk to help poor people like us who are completely helpless in such situations.

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### Did my mother really die of COVID-19?

### Case synopsis

Siddhesh had to admit his elderly mother to a government hospital in Yavatmal due to a severe asthma attack. Despite submitting a COVID-19 test sample during admission, the family never received any test results, not even a text message. Since family members were not allowed to enter the hospital premises, they were unaware of her treatment. As her condition worsened over the next few days, Siddhesh decided to move her to a private hospital, believing that she was not receiving adequate care in the government hospital. After making the mandatory advance deposit, she was treated as a COVID-19 patient with costly drugs and injections, despite no record of a COVID-19 test being conducted in her medical records. Unfortunately, Siddhesh's mother passed away on the third day after her condition suddenly worsened. Instead of providing the family with a proper itemized medical bill and complete medical records, the hospital issued a handwritten bill with arbitrarily inflated charges.



# **C** Testimony

On September 11th, 2020, I had to admit my 67-year-old mother to the government hospital in Yavatmal. My mother had a history of asthma and was hospitalized every year for a couple of days whenever her asthma worsened. However, during the lockdown, her asthma worsened and turned into pneumonia, causing her to experience breathlessness and a persistent cough. We took her to a multispecialty hospital where the doctor examined her and took an X-ray. The doctor informed us that they were not permitted to admit/treat patients for pneumonia during the pandemic and referred us to the government hospital. As a result, we ended up taking my mother to the government hospital.

### Uncertainty about COVID-19 test results

When my mother was admitted, she underwent a COVID-19 test. On September 12th, I received a message confirming that her test sample was submitted, but I did not receive any other updates thereafter. Since we received a message confirming the submission of the test sample, we expected to receive an SMS with her test results as well. However, we did not receive any communication about whether she was COVID-19 positive or negative throughout her stay at the hospital.

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

During the first two to three days of her hospitalization, my mother was only given tablets, which caused her difficulty while urinating. Despite being on oxygen, it was unclear what treatment she was receiving, as relatives were not permitted at her bedside due to pandemic restrictions. Even as her condition deteriorated, we were not allowed to stay with her for even a short time. Our only interaction with the hospital was between 11 am to 12 pm when we delivered lunch to the staff. We were completely in the dark about her treatment and care. As her condition worsened, it became apparent that she was not being properly treated. Only X-rays had been taken, and no further tests were conducted. We were extremely distressed and felt that our mother had been left alone and neglected in the government hospital.

#### Encountered with similar issues at another private hospitals

After confirming that there was a bed available for his mother in a private hospital, Siddhesh made the decision to move her there. The hospital asked for an advance payment of Rs 1,00,000 on admission, but after negotiation, Siddhesh paid Rs 50,000 to ensure that a bed was reserved for her before applying for the required NOC (No Objection Certificate) for her discharge from the civil surgeon and district health officer. After receiving the NOC, Siddhesh's mother was admitted to the private hospital at 8 pm on September 14<sup>th</sup>.

Initially, she was admitted to a common room with four beds, but the doctor who later examined her declared that her condition was serious and moved her immediately to the ICU. She was given injections for pneumonia, and the next evening on September 15th, she was administered an injection called SEBSIVAC (Tocilizumab) that cost Rs 40,545.

### No access to any reports of medical investigations

It is unclear whether my mother was tested for COVID-19 in the hospital or not, but we were charged for numerous blood and urine tests that we never saw the reports for. To this day, there is no report of her COVID-19 positive status in the file. Additionally, the CT scan reports are not included in the file we received. Although my mother was treated as a COVID-19 patient, we were unsure whether her condition was due to asthma complications or COVID-19 pneumonia.

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

After my mother received the injections, her condition deteriorated rapidly, despite feeling well before that. One of the injections was priced at Rs 6,000, which the doctor had initially asked for, but since it was not available, he said that she would have to be given the more expensive injection, which cost Rs 9,000. **Neither we nor the doctors** 

#### provided any explanation for these injections, despite our repeated requests.

However, I purchased both injections from the hospital pharmacy as we were willing to do anything to help my mother recover. Additionally, we had to purchase all of the medical supplies, including gloves, as the medical store was always crowded, and it took hours to purchase everything we needed.

#### Sudden deterioration in health

On the second day of her admission, September 16<sup>th</sup>, the doctor informed us that my mother's condition was critical. After she received the injections, her pulse rate dropped from 78 to 60-62. Since there were no sleeping arrangements at the hospital, I left my mother around midnight to go sleep at a friend's place. However, within an hour of leaving, the hospital called to inform me that my mother's condition had worsened. I rushed back to the hospital to find my mother seated on her bed in the ICU. Unfortunately, I also witnessed another patient passing away in front of her. My mother was understandably shaken, but stable and conscious. I stayed with her for about 40 minutes until everything seemed normal, and then left for my friend's place again. Before leaving, the hospital staff made me sign a letter stating that they would not be held responsible for any consequences due to my mother's critical condition. I reached home at 2:30 AM. However, the hospital called me again at 7 AM to inform me that my mother had passed away. What happened in those five hours is still a mystery to me.

#### Incomplete file with crucial reports missing

According to my mother's death certificate, she was COVID-19 positive. However, I did not receive any positive test report or document in the file provided by the hospital. Even when my mother was in the hospital, there was no such report as I was going through the file daily. This raises the question of how the doctors determined that her death was caused by COVID-19, and it continues to haunt me today.

### Inflated billing, we received "kachcha bill" (handwritten bill)

The hospital issued us an incomplete and unorganized bill on its letterhead, where they only listed the medicines and their costs, totaling Rs 73,800. To our surprise, they had charged us Rs 250 for diaper changes, which my mother did not require.

Furthermore, the hospital did not offer any facility or counter for the MJPJAY scheme. I had heard that if we submitted the hospital expenses for a COVID-19 related death to the Collectors office, they would be reimbursed. However, I was not in the right frame of mind to go through that process, so I paid the entire bill in cash.

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Exorbitant yet negligent hospital and disappointment with grievance redressal forum

### Case synopsis

When Vishal Karnik's elderly aunt was diagnosed with COVID-19 in July 2020, she was admitted to a Private COVID-19 Care Centre approved by the corporation. Since she was asymptomatic, her recovery was uneventful. However, when Vishal received a bill of Rs 2,80,000 for two weeks, he was shocked at the inflated charges, some for services that she didn't even need or use. Realizing that he was being overcharged, Vishal sought redress in various grievance redressal forums established by the city corporation for complaints related to COVID-19 treatment bills. He has been waiting for a final resolution from the Technical Committee for the last two months. Despite negotiations, the bill was still quite high at Rs 1,47,000. Vishal also pointed out several irregularities, and the hospital administration refused to give him clear explanations and all documentation related to his patient, as per his Patients' Rights. Of greater concern was the neglect during the COVID-19 Care Centre's transfer of his aunt after discharge. As a result of being caught in the rain, she fell severely ill and took a long time to recover from the incident.



## **CC** Testimony

My 85-year-old aunt resides in a nursing home that provides round-the-clock assistance to elderly individuals who need help with daily living activities. Unfortunately, one of the nursing staff tested positive for COVID-19 in July, and as a precaution, the management tested all the residents for COVID-19. My aunt also tested positive for COVID-19, which caused us to worry. Although she was asymptomatic and stable, we consulted our doctor, who advised admitting her to a COVID-19 Care Centre due to her advanced age.

After conducting some research, we chose a private hospital approved by the city corporation as a COVID-19 Care Facility. The hospital administrator informed us that it was an isolation facility and could treat asymptomatic patients. They provided oxygen to patients, but did not have critical ICU facilities such as ventilator-equipped beds. I agreed to this arrangement as I had made sure that my aunt would be immediately transferred to another hospital with ICU facilities if needed. When we inquired about the estimated costs, we were told that it would be Rs 7000 per day, including all charges. I found the costs to be steep, considering that the patient was completely asymptomatic, but this was during the lockdown, and our priority was to get her admitted as soon as possible.

She was admitted to the hospital in the last week of July, and her hospitalization for the next two weeks was uneventful, except for some minor issues that we resolved with the hospital's front desk. I spoke to the consultant doctor, who examined her once a day and reported that she was doing well.

#### Inflated and Irrational charges in hospital bill

Four days before her aunt's discharge, the hospital administrator informed the writer that the final bill would be higher than the initial estimate and quoted a figure of Rs 2,80,000. The writer was surprised as there had been no complications in her aunt's health. When the writer requested a detailed bill, the invoice showed numbers under different headings but did not provide any details as expected. The writer noticed that the hospital had billed for 44 PPE kits and 230 gloves for a routine 14-day stay, which seemed excessive, and the consultant doctor's charges were Rs 4000 per day, which appeared high. After crosschecking with doctor friends, the writer found that senior consultants typically charged Rs 1500 to Rs 2000. Additionally, the hospital had charged for oxygen for four days, but the writer's aunt confirmed she had not received any oxygen, which was also confirmed by the hospital desk.

During the two weeks that my aunt was hospitalised, we found the experience frustrating. Care centres for COVID-19 patients, both government-run and private, do not allow visits from caretakers. There was a lot of opaqueness because we were not allowed to go inside to check on our patient, and had to rely solely on the doctor and the hospital staff for updates. My aunt, being old and disoriented, couldn't tell us who was checking on her because everyone was wearing PPE and masks. However, the false billing for the oxygen caught my attention and prompted me to investigate further.

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

I contacted the local MLA, who I knew from my work, and he informed me that he had received similar complaints in the past few months. He had set up a special grievance cell to register complaints and resolve disputes with hospitals. I filed my case with this cell, and they arranged a meeting with the hospital administrator. During the meeting, it was established that the hospital had overcharged me. The government had issued guidelines capping the prices of COVID-19 treatment in private hospitals, and the hospital had violated those guidelines. However, the administrator argued that private hospitals were under a lot of pressure and were helping the government to deal with the COVID-19 burden. Therefore, he felt that they should not be penalized for overcharging.

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

I informed the hospital administrator that I was willing to pay the bill, as long as the charges were valid and fair. A few days later, I received a revised bill of Rs 2,45,000, which omitted the fees for the consultant doctor. I did not accept this bill and informed the hospital that I had not received any of the documents and explanations that I had requested.

Unsatisfied with the hospital's response, I decided to approach the corporation directly and submitted a complaint to the Medical Officer. After a few days, the corporation's grievance cell determined that I was overcharged, and the hospital revised the bill to Rs 1,47,000. However, I still had unanswered questions about my aunt's treatment, and the hospital administrator was pressuring me to pay the remaining bill. I told them that I would only pay if my questions were answered, and I communicated this to the corporation's grievance cell.

When the lower-level officers did not follow up, I met with the Additional Commissioner of the city 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 unresolved medical cases.** As of now, my case is pending with this committee, and I have not received any communication from them or the corporation grievance cell. I also informed the hospital administrator that I will pay the pending bill only after hearing from the Technical Committee.

#### Gross negligence in patient care resulting in serious consequences

I want to share an incident that happened with my elderly aunt during her stay at a COVID-19 Care Centre. On the day of her discharge, it was raining heavily. She was taken in a wheelchair to the entrance of the hospital and then across the road to where the ambulance was parked. She was not provided any protection from the rain and got drenched completely. She fell sick with a bad cold and her oxygen levels decreased drastically, requiring her to be given oxygen for a month. When I complained to the hospital administrator, he was unaware of the situation and tried to play it down, saying she was not completely 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.

During her stay, I had also noticed inflated charges on the bill and had requested the hospital to provide all necessary documentation, which they failed to do. I approached the local MLA, who had set up a special grievance cell to register complaints and settle disputes with hospitals. The hospital was overcharging, which was clarified by the cell after a meeting with the hospital administrator. The bill was revised, but my questions regarding the excess medicines given to my aunt remained unanswered. I met with the Additional Commissioner of the city and my case was forwarded to the Technical Committee in Sassoon Hospital in Pune. The case is still pending with the committee.

I am aware that my access to officials and professional background helped me make progress, which may not be possible for everyone. The experience was stressful and frustrating, and I am still waiting to hear from the technical committee. I have shared my experience with others who were also overcharged and wanted to take action.

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

### Case synopsis

Manoj had to hospitalize his elderly mother Vimal, who was diagnosed with pneumonia. They took her to a private hospital where everyone was tested for COVID-19, and all reports came back positive. This caused some doubt regarding the authenticity of the test results, especially after some people who were retested in another center tested negative. Due to the unavailability of beds in any government hospital or COVID-19 Care Center, Vimal's family was forced to continue her treatment in the medium-sized private hospital. They paid the required advance deposit and had to pay additional money every couple of days to the hospital, without any contact with Vimal.

On the 12<sup>th</sup> day, Vimal was directly discharged from the ICU. Manoj managed to pay the hospital bill with difficulty after taking a loan. However, he was skeptical about the inflated charges for PPE. The family was unable to claim any benefit of free or subsidized treatment under the MJPJAY scheme.



### **CC** 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 of COVID-19 test results

After my mother Vimal was admitted to the private hospital, she was immediately tested for COVID-19. On the same day, all 24 people who were tested along with her received positive results. However, we later heard from others who were skeptical about the test results and got themselves tested elsewhere, and their

# results came back negative. This raises doubts about the authenticity of the initial test results, and we remain uncertain about whether or not my mother was truly positive for COVID-19.

What makes this even more perplexing is the fact that my mother used to sleep in the same room with her two granddaughters, yet they did not show any symptoms or signs of infection. This leads us to question how only my mother ended up with a COVID-19 diagnosis.

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

We decided to keep my mother in the private hospital as she was experiencing breathlessness and required oxygen support. Though we were concerned about the potential high cost of treatment, we explored other nearby cities like Pune and Kolhapur for oxygen beds in government hospitals and COVID-19 Care Centres. However, we found that there were no available beds in any of these places. Therefore, we decided that it would be better to seek emergency care at the private hospital in our village instead of wasting precious time searching 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 initially asked us for an advance payment of Rs 50,000, but we only paid Rs 20,000 since we knew the hospital owner. We continued to pay the hospital every couple of days, ranging from Rs 10,000 to Rs 20,000. The total hospital bill amounted to Rs 1,27,000. After negotiations with a journalist friend and because of our acquaintance with the doctor, we managed to pay only Rs 1,00,000, receiving a discount of Rs 27,000. In addition to the hospital bill, we had to pay Rs 80,000 for medicines, lab tests, investigations, and six injections. We were charged Rs 26,000 for PPE Kits for the 12 days my mother was in the hospital, along with all the other patients in the ward who were charged Rs 2200 per day for PPE. We were unsure if all the injections and medicines that the hospital asked us to buy every day were necessary or even used, as we were not allowed to visit her due to COVID-19 restrictions.

### I took loan to settle hospital bill

I had to take out a loan of Rs 1,00,000 against a fixed deposit that my mother and I held jointly. I couldn't surrender the FD because I needed my mother's signature for it. It was extremely challenging to manage financially because I had no source of income since my shop was closed due to the lockdown. It has been a nerve-wracking time for us as we

didn't know how to raise the funds to pay for my mother's treatment or repay the loan we had taken.

### No benefits from government schemes for COVID-19 relief

The government announced schemes for free or subsidised treatment of COVID-19, including one by the Zilla Parishad at the district level and the state MJPJAY scheme. However, we were unable to benefit from either of these schemes and had to pay for the entire treatment ourselves. It was disheartening to see that the costs of private hospitals were not regulated by the government, and the schemes were not accessible to everyone during the pandemic.

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# chaos and fake reports

### Case synopsis

During the epidemic, many people with non-COVID-19 emergencies faced difficulties due to a lack of hospital beds and timely treatment. The overwhelmed public and private health system struggled to cope with the influx of COVID-19 patients. In rural Maharashtra, Ramdas, a farmer, urgently needed blood transfusions due to critically low hemoglobin levels. However, all hospitals in his district were occupied with COVID-19 patients, making it challenging to find a willing facility. Eventually, the family managed to convince one doctor to admit Ramdas and provide the necessary blood transfusion.

A few days later, Ramdas developed symptoms resembling COVID-19 and was tested. Shockingly, the family was informed that he had tested positive and were asked to purchase expensive drugs and injections. As his condition deteriorated, he was transferred to a government hospital with ICU facilities, but unfortunately, he passed away shortly after. It was later revealed that the family had been shown a fake positive COVID-19 test report. The hospital also refused to provide them with Ramdas' medical records and issued an incomplete bill, leaving them confused about the true cause of his death and without any supporting evidence to claim state benefits available for COVID-19 victims.



### **CC** Testimony

Ramdas, my brother-in-law, was a small-hold farmer who also worked as a watchman to supplement his income. Unfortunately, his health had been deteriorating over the past year due to his struggle with hemorrhoids (piles). In September 2020, we discovered that he was severely anemic, with his hemoglobin level dropping as low as 4 gm %. His appearance was pale, and he experienced breathlessness, indicating a critical condition. The doctor urgently recommended a blood transfusion to save his life.

Desperate for a hospital that could accommodate his needs, we reached out to multiple medical facilities in our district and even in the nearby city of Pune. However, given the ongoing epidemic, all the hospitals were overwhelmed and unable to admit Ramdas.

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

Many hospitals had been converted into COVID-19 Care Centers and were unwilling to admit patients for any other reason. They outright refused to admit even critical patients. In Pune, when we approached one hospital, they demanded an advance deposit of Rs 4,00,000 before considering admission. We were disheartened and had to bring him back to our village since we didn't have that amount of money.

Eventually, we found a 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 after much persuasion, the doctor agreed, even without COVID-19 testing. He was admitted on September 2<sup>nd</sup>, 2020. The treatment began immediately, and he received two units of the three units of blood we had obtained for him. His Haemoglobin levels showed a slight improvement, reaching 5.3 gm%. His breathlessness also decreased slightly, giving us hope that further blood transfusions would lead to his improvement.

#### Lack of ICU facilities to handle COVID-19 Complications

Over the next few days, Ramdas did not show the expected signs of improvement and developed a dry cough, although he had no fever or cold symptoms. Concerned about his breathlessness and cough, the doctor advised us to have Ramdas tested for COVID-19. On September 5<sup>th</sup>, a lab technician came to collect his swab, and the sample was sent to a private lab in Pune for analysis.

On the afternoon of September 7<sup>th</sup>, the doctor contacted us and showed us a photo of the test report on his phone. To our dismay, Ramdas had indeed tested positive for COVID-19. The doctor then informed us that it was crucial to obtain expensive injections to ensure Ramdas's survival. We spent nearly the entire day driving around, and miraculously managed to acquire three vials on September 7<sup>th</sup>, and the remaining two on September 8<sup>th</sup>. The total cost amounted to approximately Rs 32,000.

### Our last hope was the government hospital

However, on September 8<sup>th</sup>, Ramdas' condition worsened significantly, and his oxygen levels dropped to 75%. Due to his hospital's lack of ICU facilities, the doctor advised us to transfer him to the government COVID-19 Care Centre for further treatment. At that point, he required ventilation as he was only receiving oxygen support. Unfortunately, no ambulance was available, so we had to drive him to the government hospital in my car. Despite being conscious, Ramdas was weak, and we had to walk to the center.

Upon arrival, we were shocked to find the hospital incredibly crowded, and we had to wait for hours before he was finally admitted at 11 pm. When the doctors examined him, they immediately informed us that his condition was extremely critical, and the chances of his survival were slim. We pleaded with them to do everything possible, but despite their efforts, Ramdas passed away the following morning on September 9<sup>th</sup>. He had been at the hospital for a mere six hours before his untimely demise.

#### Our indebtness to settle the hospital bill

The bill for ten days at the private hospital amounted to Rs 1,04,000. The hospital stay cost Rs 36,000, the medicines cost Rs 50,000, and there were additional costs for investigations. We paid the entire amount in cash, utilizing our personal savings and borrowing the remaining sum from family and friends.

#### No access to medical records and given incomplete bills

The hospital withheld any medical records following his discharge, despite our repeated requests and multiple confrontations with both the hospital and the doctor. They adamantly refused to provide any documentation regarding his one-week hospitalization, leaving us without any evidence of the treatment he received there. They did provide a receipt for the outstanding balance of Rs 25,000 at the time of discharge, but failed to issue a receipt for the initial payment of Rs 32,000.

When we insisted on obtaining the records and a detailed bill, the doctor scolded us, emphasizing that he was the sole healthcare provider who had agreed to admit our critically ill patient, and we should express gratitude for the one-week treatment. Feeling unable to argue with a doctor, we remained silent. We acknowledged our indebtedness to the doctor for admitting Ramdas and aiding us during the challenging COVID-19 crisis. Therefore, despite their refusal to share records or issue a proper bill, we chose not to pursue the matter any further.

#### Fake COVID-19 reports

There is also the unresolved issue regarding the COVID-19 test report, which we never received. I was merely shown the report on the doctor's phone without being provided with a copy of the original document. When I requested the doctor for it, he responded by saying that he hadn't received the reports from the lab in Pune either. Curiously, upon closer examination of the report, I noticed that only the patient's name was visible at the top, while the ID appeared smudged. To verify Ramdas's test report, I accompanied the doctor to the diagnostic center in Pune, only to discover that all the reports were fraudulent. The ID number did not exist in the lab's records, and the technician responsible for the tests had disappeared.

In fact, the doctor went so far as to file a complaint against the lab for issuing falsified reports. As a result, I am left uncertain whether Ramdas actually succumbed to COVID-19 or if his demise was related to complications from his piles. Unfortunately, there was insufficient time to retest him at the government hospital, as he passed away too early.

#### What we expect?

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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### We were Cheated by a corporate hospital

### Case synopsis

When Devdas Randive, a 60-year-old physician, was diagnosed with COVID-19, his family tirelessly searched through all the hospitals in Nashik until they finally found an available bed in a corporate hospital. However, upon admission, the hospital demanded a deposit of Rs 2,50,000, even though the family had mediclaim coverage. Amidst a chaotic admission process, the family was rushed to sign multiple papers, and Dr. Randive was admitted. A few days later, due to his deteriorating condition, he was transferred to the ICU as his condition was deemed critical.

As each day passed, Dr Randive's condition worsened, and the hospital consistently called his son to settle the daily bills in cash, threatening to halt the treatment if the dues were not cleared. Unfortunately, after 25 days, Dr Randive passed away, and the family had depleted all their savings to cover the expenses. When his son raised concerns about the exorbitant billing with both the hospital and the corporation's grievance redressal cell, he discovered that the consent papers they were hurriedly made to sign during admission stated that they were aware that their father was being admitted under the 20% (uncapped) price category of the hospital. In reality, they had no knowledge of such a state order of rate regulation even existing. The hospital had failed to inform or explain the implications of this consent, thus misleading the Randive family into paying exorbitant amounts for irrational care.



# **CC** 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

Although my father had no desire to be admitted to a hospital, we decided to search for available beds in nearby hospitals. Unfortunately, all of them were occupied. However, we received word that there was one bed available in a prominent corporate hospital, so we immediately took my father there.

Conditional admission based on ability to pay upfront **During our initial phone call** with the hospital management, they made it abundantly clear, "Bring your patient here only if you have the money to pay." When I arrived at the hospital with my father, the first question they posed was, "Have you brought Rs 2,50,000 with you?" I explained that my father had Mediclaim and we had the cashless claim facility. However, the cashier shook his head, stating, "You still need to pay the advance deposit. You can seek reimbursement through Mediclaim later. The advance payment is mandatory." Reluctantly, we paid the Rs 2,50,000.

Lengthy wait and rushed paperwork We reached the hospital around 9 pm that night, but my father was not admitted until approximately 11 pm. We sat among a crowd of people for over three hours, along with five or six other patients also awaiting admission. There was only one person at the admission desk, managing the formalities for all of us. Everyone was eager to be admitted as soon as possible. Amidst the ensuing chaos and confusion, the hospital staff made me sign several documents without providing any time to review them.

Realization of deceptive practices and exploitation In hindsight, I realized that administrative staff at corporate hospitals are skilled in deceiving patients and exploiting them during their most vulnerable moments. They are not trained to assist the sick and suffering; instead, they are trained to profit from them. This realization left me deeply troubled.

Treatment and escalating costs for the first five days, my father was given supplemental oxygen. As his breathing deteriorated, he was transferred to the ICU and put on a ventilator. Out of the 25 days he spent in the hospital, 21 were spent in the ICU. Sadly, his condition worsened each day, and the hospital bill increased accordingly.

Deceptive consent for admission in uncapped price category without accurate information Later, I discovered that the form I had hastily signed during the admission process was a disclaimer stating that we were aware of the state government's regulation that capped prices for 80% of bed occupancy in private hospitals, while the rates for the remaining 20% were determined by the hospital. We unwittingly consented to admitting our father in the 20% category, despite being unaware of such a regulation. The hospital rushed us through the entire admission process, denying us sufficient time to review the forms.

#### Implications and exploitation through lack of information

It was only when we filed a complaint about excessive billing and later spoke to an official who explained the form to us that we realized the implications. This was, in fact, a form of deception. By obtaining consent without providing patients like us with accurate information and not allowing us to read the form thoroughly, the hospital staff cheated and exploited ordinary people. If we had known about the 80/20 allocation system, we would have ensured that our father was admitted in the 80% category, allowing him to receive treatment for a longer duration.

#### No treatment without settling the bill

We used to receive daily phone calls from the hospital administration, stating, "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." This was an extremely distressing time, as we were forced to make daily cash payments. Both my savings and my father's savings were completely depleted. Despite our requests, the hospital did not provide us with a detailed bill, promising to give it to us upon discharge.

#### Hefty bills and indifferent staff

Towards the end, when my father's condition became critical, we considered transferring him to another hospital. However, we had already run out of money. The hospital staff displayed indifference, stating, "You can transfer him if you want to."

The bill had accumulated to Rs 14,00,000 by then. With no funds remaining, we were at a loss, unsure of how to proceed in this final stage, feeling helpless due to our financial situation. We ultimately moved him to a hospital affiliated with a medical college, but unfortunately, he passed away after only eight hours.

### Inflated billing and irrational treatment

We consulted a lawyer who highlighted glaring instances of overbilling in the hospital bill. There were charges for 75 PPE kits, each costing Rs 1000, and 177 masks. Did they genuinely require that many PPE kits and masks daily for a single patient? Another bill itemized costs for three Remdesivir injections from the hospital, along with a request for us to procure an additional ten injections from outside as their supply had run out. There were also charges for an injection called Tocilizumab, amounting to Rs 40,000, and 114 multivitamin injections.

#### Corporation Grievance Redressal Cell dismisses the case

I approached the Grievance Redressal Cell of the municipality to file a complaint regarding the exorbitant billing by the hospital. It was during this process that an official showed us the form where I had to select the admission category. "Didn't you read this form?" he asked dismissively before swiftly dismissing our complaint. It was futile to explain that I had been rushed to sign the form, as my signature was already on it. We were unable to pursue the complaint any further.

### Corporate hospitals are engaging in organized exploitation of patients

The government needs to pay close attention to corporate hospitals and their management. There should be widespread awareness campaigns to ensure that people are informed about various government schemes for free or subsidized treatment. The staff working in such hospitals often neglect to inform patients about these schemes. The government should take strict action against hospitals that fail to inform people seeking admission about government schemes or pressure them into signing consent forms without providing complete information.

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

### Case synopsis

Datta Patil, a farmer and social worker from a village near Pune, dedicated himself to serving as a 'Gram Doot' (People's Representative) during the COVID-19 lockdown, assisting the local administration with critical relief work. However, when he himself tested positive for COVID-19, the lack of available beds in government hospitals forced him to seek care at a private hospital. Regrettably, he had to bear the burden of Rs 2,20,000 for his treatment, as the MJPJAY and Zilla Parishad schemes were deemed invalid at the time of his admission. Like many others, Datta Patil was compelled to borrow money to cover his medical expenses.



# **CC** Testimony

I am a 52-year-old farmer and social worker in my village. In March 2020, when the epidemic broke out and the lockdown was imposed, I was appointed as a 'Gram Doot' by the Tehsildar (collector) of our village. From March to June 2020, I dedicated myself tirelessly to working with the Gram Panchayat. We distributed medicines, Public Distribution System (PDS) rations, and food donations from companies and NGOs to COVID-19 infected patients and those in need. Additionally, I assisted around 650 migrant workers from Uttar Pradesh and Bihar, who were employed in our area, in arranging transportation to their native places by organizing buses with the *Tehsildar*'s support. The Gram Panchayat recognized my efforts and acknowledged me as a 'COVID warrior for my contributions during and after the lockdown.

### "No beds in government hospitals left us with no choice"

Given my constant movement and interactions with numerous people, I believe I may have contracted the virus. Towards the end of August, I started feeling unwell, and despite seeking treatment from a local doctor, my health deteriorated. On August 29th, I developed a cough and experienced breathlessness. I got tested for COVID-19 at the government center, and when the result came back positive, I attempted to secure a bed at the district government hospital. However, there were no available ventilators there. We then tried inquiring about bed availability at larger hospitals affiliated with medical colleges in Pune, the nearest city to my village. Unfortunately, there were waiting lists everywhere. With my condition rapidly worsening, my family had no choice but to admit me to a private hospital in a nearby town that still had a few vacant ventilator beds.

I was immediately admitted to the ICU and given oxygen due to my alarmingly low oxygen levels of 70%. As I struggled to breathe, I was placed on a ventilator. The following days were a haze as I drifted in and out of consciousness. I spent 13 days in the ICU on the ventilator, which accounted for almost two-thirds of my three-week hospital stay. After my condition stabilized, I was transferred to the general ward. Finally, on September 17th, I was discharged.

### "An illness of three weeks wiped out all my savings"

To my shock, I was presented with a bill of approximately Rs 3,10,000. The hospital stay for three weeks amounted to Rs 1,89,000, while the costs for medications and personal protective equipment (PPE) added an additional Rs 1,18,000. I also had to pay for various lab tests and x-rays separately. This hefty amount was overwhelming, especially since all work had come to a halt since March 2020. We approached the doctor in charge and pleaded for a reduction in the bill. Fortunately, the doctor was understanding and provided us with a discount, taking into account my background in social work. The revised bill came to Rs 2,23,000. I utilized my personal savings to pay a portion of the bill in cash, but it was not sufficient. I had no choice but to borrow money from friends and relatives. In fact, I still owe Rs 10,000 to the chemist, whose bill I have been paying off in installments since September 2020.

#### "Government schemes were of no use to us"

Just two days after my discharge, the MJPJAY scheme was launched in our *Taluka* (Block), but unfortunately, it came too late for me. There was also a *Zilla Parishad* scheme for subsidized COVID-19 treatment, which could have provided a reimbursement of Rs 1,00,000, but it had expired on July 31<sup>st</sup>.

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# Advance 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. Despite his family's best efforts to provide him with optimal treatment, his condition continued to worsen during his stay at a private COVID-19 Care Centre in a small village and later in Kolhapur. Tragically, he passed away on September 19<sup>th</sup>, 2020. The experiences of Pavan's brother regarding the exploitative practices in the hospitals where Pavan was admitted are representative of the suffering endured by thousands of people who were forced to bear exorbitant costs for emergency healthcare during the lockdown.

These experiences include the requirement of upfront deposits prior to admission, inflated billing, substandard quality of care, lack of communication with the patient's family, and refusal to provide essential documents and case files. Pavan's distressing story sheds light on the realities of healthcare in rural Maharashtra and exposes a private health sector that prioritizes profits over patients, even in the midst of a public health crisis.



# **CC** Testimony

My younger brother, Pavan, was a healthy 30-year-old man who had never required medication in his life. He was married with two small children and worked as a farmer while also assisting me in my small shop.

#### Advance deposits for patient treatment with no guarantees

In early September, Pavan developed a mild cold and fever for which our family doctor provided treatment. As he began to experience coughing and difficulty breathing, he underwent a rapid antigen test, which came back negative. However, due to his worsening condition, the doctors recommended a CT scan of his lungs, which revealed a concerning score of 30. This prompted us to search for available hospital beds. Unfortunately, the government hospitals in our taluka town had no vacancies. Eventually, we discovered a hospital in a nearby village, approximately 70 km away, that had a COVID-19 Care facility. The staff assured us they had beds, ventilators, oxygen, and specialist doctors.

On September 7<sup>th</sup>, 2020, we admitted Pavan to that hospital. Upon arrival, we learned that the COVID-19 Care Centre had only opened two days prior, making Pavan one of the first patients there. However, **before admission**, **we were required to pay an advance deposit of Rs 1,50,000**, **covering his hospital stay and medications**. We were also compelled to sign forms absolving the hospital of any responsibility due to the critical nature of Pavan's condition, despite him not being critical at the time. Refusal to sign would have meant denial of admission, leaving us with no alternative but to comply.

#### "We had no clue what was going on"

Initially, Pavan's condition showed improvement, but he later complained of breathlessness. The doctor requested Remdesivir for him, prompting us to search for the medication through different chemists. We managed to obtain nine vials, each costing Rs 4000-4500. Due to Pavan's oxygen saturation hovering between 55 to 60%, the doctors advised us to acquire an emergency injection priced at Rs 40,000. We managed to obtain that as well, but unfortunately, his condition did not improve despite receiving these treatments. It is important to note that we never witnessed the administration of these injections, as visitors were not allowed inside the center. When I inquired about the number of doses Pavan had received, the doctor seemed unaware.

Pavan had mentioned to my sister that the staff turned off his oxygen supply at night, exacerbating his struggles. When we addressed this concern, they claimed he was restless and did not allow the nurses to put him on the ventilator during those times. However, we questioned why he was compliant during the day. **Additionally, we discovered that the hospital had misrepresented the type of ventilators they possessed when we initially contacted them.** 

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

Despite our repeated inquiries and requests, the doctors failed to provide any explanation for Pavan's deteriorating health. On September 17<sup>th</sup>, Pavan begged us to transfer him to another hospital, expressing dissatisfaction with his treatment and fear upon witnessing other patients' deaths.

### "We won't discharge your patient until you settle your bills!"

Feeling the same way, we informed the management that we wanted Pavan to be discharged. It took them an entire day to prepare our bill. On the morning of September 18<sup>th</sup>, without any prior notice over the past ten days, they presented us with a bill of Rs 86,000 for medicines!! We were completely taken aback because the management had never mentioned separate charges for medications. They had overcharged us for everything, including PPE kits, tests, and medicines. We were in shock, but the administration was heartless; if we wanted to transfer Pavan to another hospital, we had to pay up. Somehow, we managed to gather

the necessary funds by borrowing from relatives and friends. Ultimately, Pavan's ten-day stay in that hospital cost us a total of 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, approximately 20 km away. Upon arrival, we were informed that the ICU treatment would cost Rs 30,000 per day, excluding medicines and PPE kits, which would incur additional charges. To secure admission, we had to pay an initial deposit of Rs 2,00,000. It dawned on me that even during this pandemic, doctors and hospitals seemed more focused on making money than saving lives. They showed little concern for my brother's condition and insisted on receiving payment upfront.

Finally, Pavan was admitted to the ICU in the evening after completing all the necessary procedures and paying the deposit. The following morning, we received a call from the hospital informing us that his condition was critical. Observing him in the ICU, connected to a ventilator and unresponsive, we could see that Pavan was already gone despite receiving oxygen. By midday, they declared him dead. We were devastated, unable to comprehend how everything had unfolded in just two weeks. At such a moment of crisis, who has the time to inquire about schemes or focus on anything other than 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 had barely been there for a day. We resigned ourselves to the fact that they were determined to extract as much money as possible. The stress of negotiating and arguing with the doctors and hospital management took a toll on me, resulting in a weight loss of 12 kgs that month. In total, we were billed Rs 3,00,000 at the first hospital and Rs 63,000 at the second hospital. We had to borrow from relatives and friends and exhaust our meager savings. Nobody informed us about any government schemes that offered free COVID-19 treatment or that private hospital costs were regulated by government rules. We had no knowledge of these schemes, nor was any information available at the hospitals we visited.

### "We didn't even receive a proper bill."

The hospital didn't even provide a bill for the Rs 63,000. Despite my repeated requests, they did not hand over any reports, including those from the previous hospital. In the midst of our shock and grief, we didn't think to approach them again. Our experience has left us deeply scarred to the point where I believe it would be better to die peacefully at home rather than seek treatment in a hospital, where all they seem to want is to extract as much money as possible from you.

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### Advance deposits were compulsory despite cashless mediclaim

### Case synopsis

The COVID-19 pandemic and the practices followed by many private hospitals regarding payment of bills came as a harsh surprise to numerous families who believed that their Mediclaim policies would cover the expenses of COVID-19 treatment. Sumit's father's hospital admission was met with astonishment when the hospital insisted on an advance deposit of Rs 2,00,000, despite having a cashless Mediclaim policy. With limited time and dwindling options, Sumit had no choice but to comply with their demands and scramble to borrow money in order to make the cash deposit. Despite numerous requests, the hospital failed to provide a clear breakdown of the bill and also delayed the refund of the deposit, even after the insurance company approved the claim.



# **CC** Testimony

My father, who was above 60 years old, fell ill and began experiencing persistent coughing. Since it was the weekend and everything was closed, we decided to take him to the hospital on Monday. The local doctor initially diagnosed him with typhoid, but later changed the diagnosis to pneumonia. On October 19, 2020, we visited the outpatient department (OPD) of a corporate hospital, where he underwent a COVID-19 test. Although the results of the test would take a day to come, his CT scan score revealed a severity level of 17, and we were informed that his condition was critical and required immediate hospitalization.

### Forced to pay a hefty deposit despite having cashless Mediclaim

After spending an entire day contacting various hospitals, we finally secured a bed for my father at a renowned corporate hospital around 9 pm. Despite having a Mediclaim policy that covered cashless treatment up to Rs 3,00,000, the hospital demanded an advance deposit of Rs 2,00,000 before commencing his treatment.

We informed the hospital management about our insurance coverage, but they remained adamant in their stance. **They continuously pestered us, questioning our refusal to pay the deposit and requesting written proof of our ability to settle the bill.** It felt like mental torture, especially considering my father's critical condition. With time running out and no alternative options available, I emptied my bank account and borrowed the remaining amount to pay the deposit.

#### Lack of quality care in branded corporate hospitals

Due to hospital regulations, we were unable to visit my father in person during his stay. Our only means of communication were video calls. Additionally, the hospital's hygiene and sanitation standards were disappointing. Leaks occurred in the roof when it rained, and it took multiple calls to summon the sweeper. The wards lacked resident doctors, with nurses being the primary caregivers. Doctors made only one daily visit at 11 am, leaving nurses to handle orders for the rest of the day over the phone. Instead of supervising, senior nurses would assign junior nurses to monitor patients. During one instance, a junior nurse failed multiple attempts to insert an Intravenous (IV) drip needle, resulting in wasted time and my father's hand becoming swollen.

#### Arguments over overbilling and lack of billing transparency

After my father was transferred from the ICU to the general ward, the bill amounted to Rs 2,14,000. However, just two days later, I received a revised bill for Rs 3,19,000. I requested a breakdown of the expenses from the hospital management, and when they returned Rs 64,000, I sought clarification on the billing particulars. Despite receiving no response, I consulted a doctor affiliated with the corporation, who clarified that bedside charges had been applied. It seemed as though the hospital was taking advantage of the COVID-19 situation to exploit common individuals.

When my cashless claim was finally approved, I approached the hospital management to refund the upfront deposit I had paid. The majority of the amount was borrowed from relatives and friends, which I needed to repay. However, the accounts personnel were incredibly rude and dismissive. The billing department also spoke aggressively, questioning why I brought my father to the hospital if I couldn't afford the treatment or deposit. After numerous requests and a threat of legal action, I finally received a refund of the Rs 2,00,000 deposit.

Potential exploitation by hospitals during the COVID-19 crisis **To this day, I remain** unsure if my father was truly COVID-19 positive or not. My mother, sister, her children, and I all tested negative for the virus at a government testing center. I wonder if my father's positive test result was influenced by his sample being taken at a private hospital.





# 16 Cash and connections for COVID-19 care

### Case synopsis

In September 2020, Dadasaheb Chauhan, a 65-year-old individual, began experiencing breathlessness. Doctors conducted a CT scan and suspected COVID-19, advising immediate admission to a hospital with ICU facilities. Unfortunately, after frantic inquiries, the family discovered that there were no available oxygen beds in any government COVID Care Centre, including the nearby towns and Kolhapur.

Relying on data from the District Health Officer (DHO) dashboard, the family drove to a private hospital that supposedly had 13 available beds. However, upon arrival, they were informed that there were no beds available. It took the intervention of political connections and the mandatory advance deposit to secure a bed at that hospital, which occurred after a frustrating seven-hour wait.

Throughout this ordeal, Mr. Chauhan's family actively sought information about the MJPJAY scheme from the hospital management, as they received no communication about it. Despite their efforts, Dadasaheb tragically passed away after a week of treatment. Shockingly, the hospital refused to release his body until a sum of Rs 1,41,000 was settled. They claimed that the publicly funded health insurance scheme (MJPJAY) would not cover the entire amount. Only through political intervention was the hospital persuaded to negotiate the bill down to Rs 40,000. Finally, after a 14-hour delay, they released the body for the final rites.



### Testimony

In September 2020, my father, Dadasaheb Chauhan, who was 65 years old, began experiencing weakness and fatigue. His condition worsened, and he started feeling breathless. We consulted a local doctor in our village who recommended a HRCT scan of his lungs. The scan revealed a score of 20 out of 25, indicating a possibility of COVID-

19. The doctor advised immediate admission to a hospital with oxygen and ventilator facilities.

However, when we tried to secure an oxygen bed in the government COVID-19 Care Centres in Sangli and Meeraj, we were informed that they were completely occupied, with long waiting lists for admission. Left with no choice, we turned to private hospitals. Despite checking the District Health Officers dashboard, which indicated available beds, the first two private hospitals denied us admission, claiming that all beds were already allocated. We then drove to a big private hospital in Sangli city, relying on the dashboard's information of 13 available beds. To our surprise, the hospital staff stated that no beds were available and provided no explanation for the discrepancy. Desperate, we waited outside the hospital for six and a half hours, contacting influential individuals in our network who could assist us in securing a bed.

Finally, through political connections and direct intervention with the hospital owners, we managed to secure a bed at 6:30 in the evening. We paid an advance deposit of Rs 15,000, despite them initially demanding Rs 25,000.

During his admission, we discovered the government MJPJAY scheme covered COVID-19 treatment costs even in private hospitals, providing us with a sense of relief. However, the hospital had not publicized the scheme, and it was only after our inquiry that they acknowledged its applicability. We provided my father's Aadhar and Ration cards for enrollment in the scheme.

For the first three days, he was in the isolation room, and we could communicate with him over the phone. However, when he was moved to the ICU, all contact was lost as phones were not allowed. He received Remdesivir injections, which we had to purchase from external pharmacies.

Despite efforts, his condition deteriorated rapidly, and the doctors prepared us for the worst, as his vital signs were extremely poor. In the early morning of September 28<sup>th</sup>, we received the devastating news of his passing.

The hospital bill amounted to Rs 1,41,000. We were informed that the MJPJAY scheme would cover only a small portion of the bill, leaving us responsible for the remainder. Shockingly, the hospital stated that they would not release the body for final rites until the bill was settled. This was unexpected, as we believed the MJPJAY scheme would cover the majority of the treatment costs.

Seeking assistance, we reached out to political connections who intervened on our behalf. After negotiations, we paid Rs 40,000, and the hospital finally released the body after a 14-hour delay, around 8:30 in the evening. The hospital bill mentioned the amount received from the patient as Rs 39,800 and acknowledged the coverage under the MJPJAY scheme. However, the management never provided an explanation for the additional amount we had to pay.

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### 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.



# **C** Testimony

I am a 60-year-old resident of a small village in Bhor block in Pune district. In October 2020, I developed a severe cold, so my family took me to a local doctor's clinic. The doctor had tested positive for COVID-19, so his wife and nurse were examining patients. They gave me medication and injections through saline for five days. But my chest congestion and cough had increased, and I had an infection of the lungs, similar to pneumonia. We had spent around ten thousand rupees by then, but I didn't see any improvement.

The doctor advised me to get admitted to a hospital for further treatment. We went to the government hospital, where I was admitted to the COVID-19 Care Centre on October 27, 2020. However, my oxygen saturation levels dropped so much that even after two hours of supplemental oxygen, my breathlessness persisted. The doctors informed my family that I needed ICU facilities and a ventilator, which were not available there. They gave us

three options - to take me to Sassoon hospital or Aundh Chest hospital in Pune, which were almost three hours away, or to a private hospital in Bhor. My family decided to admit me to the private hospital in Bhor, where I was immediately tested for COVID-19 on admission. My entire family was tested as well, and their reports came back negative.

I stayed in the hospital ICU for 12 days, during which I was on a ventilator for the first four to five days and later only on oxygen. My wife had to purchase injections from outside, and my family was not allowed to visit me. I was discharged directly from the ICU.

The pharmacy bill alone amounted to Rs 1,90,000, and the hospital bill came to Rs 1,80,000, with the ICU and oxygen costing Rs 7,500 every day. We are small-hold farmers, and my son had just joined the army, so we had to borrow money from his friends to pay the hospital bills. We still owe them a considerable sum.

### We asked the hospital to enroll us in the MJPJAY scheme, but we were informed that the scheme had expired and no longer covered COVID-19 treatment costs.

The daily PPE bill was Rs 1,200, and we paid around Rs 10,000 to Rs 15,000 to the hospital every two days.

On the last day, we paid the balance amount of Rs 65,000 before I was discharged. We pleaded with the hospital management and the doctor for some concession, but we only received a discount of Rs 8,000. We had to pay the hospital and pharmacy bill in full.

I stayed in isolation at home for the next one and a half months because my daughter-inlaw was pregnant. I still experience breathing difficulties and feel breathless when I walk.

We are still struggling financially, and the medical expenses continue to burden us. I don't understand why the scheme benefits were withdrawn when so many people needed help with medical expenses. Instead, we are straddled with debt now and wondering how to repay the borrowed money.





### No schemes for critical patients

### Case synopsis

Leelatai, an ASHA worker in a village in Kolhapur district, faced a challenging situation in September 2020 when her 75-year-old mother-in-law fell ill. Observing her low oxygen saturation levels, they transferred her to the nearest government COVID-19 Care Centre. However, even after receiving supplemental oxygen, her oxygen levels did not improve. Recognizing the severity of the situation, the family decided to transport her in an ambulance to a private hospital in the closest city.

Throughout the day, they went from hospital to hospital in search of an available ventilator bed. Finally, towards the end of the day, they found a hospital with an available bed. Initially hesitant to admit such a critical case, the family pleaded with the hospital management until they finally agreed. For the next 17 days, Leelatai's mother-in-law remained in the hospital without any contact with her family.

Upon admission, Leelatai had submitted all the necessary documents for entitlements under the MJPJAY scheme, as this hospital was empanelled with the state for MJPJAY. Unfortunately, their efforts to avail the scheme benefits were in vain, and they had to bear the entire cost themselves. The family could only manage to pay Rs 1,00,000 out of the total bill of Rs 3,00,000. To cover the remaining amount, they had to borrow money from various relatives and commit to repaying it in instalments. Regrettably, the hospital did not provide them with the medical records of their patient, adding to their distressing experience.



### **LL** Testimony

Leelatai, an ASHA worker residing in a village in Kolhapur district, faced a distressing situation in September 2020 when her 75-year-old mother-in-law fell ill. She experienced dizziness and fainted, prompting Leelatai to check her oxygen saturation levels using a pulse oximeter. Alarmed by the low levels, they decided to admit her to test for COVID-19.

Recognizing the seriousness of her condition, they immediately called for an ambulance, which arrived within 30 minutes. They transferred her to the nearby government COVID-19 Care Centre, where she received oxygen. However, her oxygen levels did not improve despite the treatment. It became evident that her condition was critical, and the Care Centre lacked the necessary resources like investigations and ventilators to address her condition effectively. Consequently, they decided to shift her to a government hospital in the closest city.

After arranging an ambulance with oxygen support, they transported her to a private hospital for better care. However, finding a ventilator bed proved to be an arduous task, as they went from hospital to hospital in search of availability. Eventually, they managed to secure a ventilator bed in a multispecialty private hospital. Although they observed that the hospital was approved for subsidised treatment through the government scheme, the initial reluctance of the hospital staff to admit such a critical case required persistent pleading from Leelatai and her family.

Despite their admission to the hospital, they faced challenges accessing information about treatment under the government scheme. With limited communication and no personal belongings allowed, they received daily updates on her condition over the phone. However, they remained unaware of her experiences, the food provided, and the treatment administered. All medications and injections were supplied within the hospital.

The hospital bill amounted to Rs 5,60,000, a staggering amount that the family could not afford. **In their desperation, they reached out to relatives and friends, managing to borrow Rs 1,00,000.** They committed to paying the remaining amount in monthly instalments to secure her discharge. Unfortunately, they received no subsidised treatment under any scheme, and they were responsible for the entirety of the expenses.

Upon discharge, they were not provided with detailed medical records, including reports of investigations and treatment. The hospital retained the medical file, closely guarding it and not releasing it to any patient upon discharge.

As an ASHA worker, Leelatai was aware of government schemes aimed at assisting individuals with medical expenses during the pandemic. However, she found herself helpless when it came to emergency hospitalisation, with the hospital staff offering little cooperation in accessing the available schemes. She emphasized the need for regulated and transparent costs in private hospitals to protect common people from exorbitant charges. The varying rates and package demands during admission raised concerns about affordability for those without substantial funds.





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

### Case synopsis

In August 2020, Vitthalrao Deshmane fell ill with flu-like symptoms, prompting his family to seek medical assistance from a local doctor. As his condition deteriorated, the doctor recommended transferring him to a better-equipped hospital. His son then took him to Kolhapur, the nearest city, in an ambulance. Unfortunately, they faced rejection from multiple hospitals due to the critical nature of Vitthalrao's condition. Eventually, a private hospital agreed to admit him but demanded a package cost of Rs 3,50,000. With limited options and growing desperation, Vitthalrao's son reluctantly agreed to pay the quoted package cost and admitted his father.

Throughout his hospitalization, the family was unable to visit Vitthalrao due to restrictions. They only received periodic updates about his condition from the doctors. It was only a day before his passing that the family discovered the existence of the MJPJAY scheme and approached the hospital management to process their claim. They had already paid around Rs 1,00,000 in cash for Vitthalrao's five-day stay, uncertain whether they had paid the package price or the subsidised MJPJAY rates.

The Deshmane family, like many others who experienced the challenges of seeking medical care during the epidemic, reflected on the overwhelming sense of helplessness they felt while driving from one hospital to another in search of an available bed with their ailing father in the ambulance. They also expressed their frustration with the profit-oriented approach of the hospitals that turned them away.



# **C** Testimony

A simple cold turned into severe pneumonia, and my father's health began to deteriorate rapidly. We sought medical help from a local doctor in our village, who recommended an X-ray. The X-ray revealed signs of pneumonia in his lungs. Initially, the doctor assured us that he would recover within two days with medication. However, after four days, his condition worsened instead of improving. At a loss, the doctor advised us to take him to the nearest city, Kolhapur, for a CT scan and further treatment as soon as possible.

We arranged for a private ambulance and brought him to Kolhapur, where we conducted the CT scan, costing us Rs 6000. From there, we embarked on a challenging quest for a hospital bed. We went from one hospital to another, desperately inquiring about the possibility of admission. Many hospitals turned us away outright, while others briefly assessed my father's oxygen levels and CT scan results before informing us that they couldn't accommodate such a critical case. We felt helpless and frustrated as no one took the time to examine my father's condition. He remained in the ambulance throughout the ordeal.

Finally, in one private hospital, a doctor evaluated my father's vital signs and oxygen levels. They informed us that a bed was available, but they made it clear that admission would only be possible if we could afford their package charges, amounting to Rs 3,50,000. With time running out and the urgency to start treatment, we reluctantly agreed to their conditions and admitted my father there.

It was only on the last day of his stay that we discovered the existence of government schemes providing subsidised treatment for COVID-19. Regrettably, no one informed us about these schemes earlier. Frustrated, we realized we could have applied for these benefits throughout his hospitalization.

Once my father was admitted, we were unable to see him in person. We relied on daily calls to the doctor for updates on his condition. Initially, we were informed that his condition was critical, preparing us for the worst outcome. Nonetheless, we held onto hope that he would recover. In the first three days, we were able to speak with him over the phone. However, his health deteriorated rapidly, rendering him unable to communicate. We never heard his voice again. Throughout his hospitalization, we remained unaware of his state within the hospital.

Shortly before his passing, we received a call from the hospital notifying us of his critical condition. At that point, they finally allowed us to see him. It was then, **one day before** his demise, that we learned about the government scheme offering subsidised treatment costs in private hospitals. Upon inquiring with the hospital management, they confirmed the existence of such a scheme and requested our Ration Card and Aadhar Card for processing. We pleaded with them to facilitate our participation in the scheme, hoping to benefit from reduced charges.

Ultimately, we paid Rs 78,000 for his hospital bill and an additional Rs 25,000 for the pharmacy expenses. Losing my father was devastating, and the memory of the frantic search for a hospital bed while he lay in the ambulance will forever haunt me. The experience raised troubling questions. What if we couldn't afford the exorbitant package rates? Does that mean we wouldn't deserve treatment? It is crucial for the government to ensure that treatment in private hospitals is affordable and transparent, protecting patients from exploitation during desperate and urgent times.





# 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 getting drenched in the rain. Seeking medical assistance, he consulted a local doctor in August 2020. However, when his condition didn't improve, he decided to visit a private hospital. At the hospital, he underwent an X-ray and a CT scan, which prompted the doctor to recommend immediate admission to a specific hospital. Chandu was assured that he would receive quality and affordable treatment at that facility. Acting upon the advice, Chandu got admitted to the recommended private hospital and underwent a COVID-19 test upon admission.

Throughout his five-day stay, Chandu continuously inquired about his COVID-19 test results, but the hospital staff provided him with various excuses and failed to disclose the outcome. It was only on the day of his discharge that Chandu received a negative test report, leading him to realize that he had been treated as a COVID-19 patient despite testing negative. Moreover, despite repeated requests, the hospital refused to provide him with an itemized bill for the charges amounting to Rs 1,25,000. When he finally received the bill, he was shocked to discover that he had been billed for five days of ICU stay, even though he had stayed in a general room and did not receive any ICU services. The hospital management disregarded his complaint regarding the inflated charges, leaving Chandu feeling helpless and unsure of the available grievance redressal processes.

Left with no other option, Chandu had to settle the hospital bill in cash by borrowing the required amount from his family and friends. The entire experience was deeply troubling and financially burdensome for Chandu, who had to rely on his social circle to meet the unexpectedly high expenses.



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# 2 | 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 seek admission to a private hospital where his friend was also receiving treatment for COVID-19. Prior to his admission, the hospital management explicitly informed Dnyaneshwar that he should only proceed if he could afford the treatment there. Despite experiencing mild COVID-19 symptoms and having normal oxygen levels, Dnyaneshwar was put on oxygen and received over six Remdesivir injections, which triggered a severe reaction and caused a persistent rash all over his body.

Although dissatisfied with the quality of service provided and the hospital's insistence on daily investigations, Dnyaneshwar remained in the hospital for two weeks. However, he was shocked to discover that he had to pay a total of Rs 1,76,000 for his stay. Furthermore, his Mediclaim was rejected as the hospital denied treating him for COVID-19. Dnyaneshwar is currently in the process of resolving the confusion between the insurance company and the hospital, hoping to have his hospital bill reimbursed and the issue clarified.



I am 43 years old and reside with my family in Nashik. In early August 2020, I started experiencing symptoms such as body ache, dizziness, and weakness. Concerned, I decided to undergo a COVID-19 test at the corporation testing center on August 7th. Unfortunately, the result came back positive the following day. Around the same time, I learned that a friend of mine had also tested positive and was admitted to a nearby private hospital. Taking their experience into consideration, I decided to seek admission there as well.

Questionable Treatment and Unforeseen Complications Upon reviewing my blood tests, the doctors at the hospital informed me that my white cell count had decreased and

prescribed medications accordingly. **Strangely, despite having normal oxygen levels, I was given oxygen therapy daily without any explanation.** While my blood cell count did improve, I did not experience a significant improvement in my overall condition.

I remained in the hospital from August 8<sup>th</sup> to August 17<sup>th</sup> and received six doses of Remdesivir injections. Unfortunately, I had a severe reaction to the injections, resulting in a widespread rash that has left dark black marks on my body. The doctor assured me that the marks would fade within a week, but even after four months, they persist. The hospital has refused to acknowledge any responsibility for this complication, leaving me to seek and fund my own treatment for the marks. I have spent nearly Rs 5,000 on consultations and treatments, yet the marks remain.

#### **Substandard Services Impacting Health**

The hospital's amenities were subpar, particularly the food provided. It was both unappetizing and insufficient in quantity. Many of us went hungry, which further weakened our already compromised health. I recall being so hungry one night that I resorted to eating some dates at 2 am. Unfortunately, the next day, my blood sugar levels increased.

#### "Admit only if you can afford the treatment"

Despite having mild COVID-19 symptoms and being placed in the general ward, I was administered numerous medications, including tablets and various intravenous injections. Additionally, I underwent daily testing, including blood tests, X-rays, and CT scans. The total bill for my 14-day stay amounted to Rs 1,76,000, and an advance deposit of Rs 25,000 was required upon admission. The hospital management made it clear that the daily cost of treatment would reach approximately Rs 15,000, with the final bill ranging from Rs 1,50,000 to Rs 2,00,000. They emphasized that admission should only be pursued if one could afford such expenses. It appeared that regardless of the severity of the illness, the starting package for treatment was Rs 1,50,000 or more.

#### Mediclaim rejection based on false grounds

I possessed a Mediclaim policy from a private insurance company with coverage up to Rs 5,00,000. Naturally, I expected to be able to claim my treatment costs. However, when I submitted the claim, I was informed that there were no medical records of a patient with my name at the hospital, and the hospital had outrightly denied treating me for COVID-19. I was astonished to learn that my claim had been rejected based on this false premise. When I approached the hospital's claims processing department for clarification, they denied issuing such a report to the insurance company in question. I am currently striving to resolve the confusion between the hospital and the insurance company, all while having paid the entire bill out of my own pocket and now seeking reimbursement.

"



# Mediclaim License to loot patients

# Case synopsis

Sunil, 24 years old, and his mother both tested positive for COVID-19 in August 2020. They were admitted to a private hospital in Nashik, which exclusively accepted patients with medical insurance. Despite Sunil having no symptoms, he was not provided with supplemental oxygen or IV fluids. On the other hand, Sunil's mother received six Remdesivir injections, with the first two being purchased under another patient's name.

Both Sunil and his mother were dissatisfied with the quality of service at the hospital. They felt hesitant to approach the main doctor, who was always accompanied by a bouncer-like person. Sunil raised concerns about the irrational and inflated billing they received. Notably, he was charged for oxygen, IV fluids, injections, and even mineral water bottles, even though he never received any of these during their stay. Furthermore, they were not provided with any lab reports and had to repeatedly request a detailed bill from an indifferent administration.

As the insurance company refused to reimburse them for certain items, Sunil and his mother had to pay Rs 42,000 out of pocket.



# **Testimony**

I live in Nashik with my mother. On August 7th, 2020, my mother tested positive for COVID-19 and we admitted her to a private hospital the following day. She was discharged after a ten-day stay. I also tested positive and was admitted to the same hospital, although I didn't experience any symptoms. I was discharged five days later after testing negative.

During my hospital stay, I never required supplemental oxygen as I didn't experience any breathing difficulties. I was only given tablets and not IV fluids or injections. To my surprise, I found that I was being charged for both oxygen and injections that were never provided to me. Additionally, we were billed for mineral water bottles that were never delivered.

The quality of service at the hospital was poor. It was challenging to get the attention of the hospital staff, and the resident doctor didn't visit us throughout our stay. We felt that the nurses were managing the hospital instead. The food was consistently served cold, and there were delays in its delivery.

We couldn't understand why our blood sugar levels were checked daily, as neither of us had diabetes. Furthermore, my mother received Remdesivir injections before her swab test results came in. The first two injections were bought in another patient's name because my mother's report hadn't arrived yet. As a result, we couldn't claim the costs through insurance. In total, my mother received six injections.

We didn't feel comfortable approaching the doctor because he was always accompanied by a bouncer during his rounds. The presence of the bouncer made us feel intimidated, and we hesitated to discuss any concerns or questions with the doctor.

We never received the reports for the lab investigations and other tests we paid Rs 17,600 for. We wanted to make a complaint, but we felt outnumbered and too weak to argue with the hospital's management.

After our discharge, we requested a detailed breakdown of the bill, which appeared inflated and included items we hadn't received. We were charged Rs 2,500 daily for PPE, which seemed excessive. When we raised our concerns with the hospital administration, they rebuked us and suggested we let it go, stating that others had already settled their bills.

Our total bills amounted to Rs 2,35,000 (Rs 1,60,000 for my mother and Rs 75,000 for myself). However, our Mediclaim only covered expenses up to Rs 1,91,000, refusing to pay the additional Rs 42,000 for items like oxygen. The hospital had initially refused to admit us without Mediclaim, but even after complying with their conditions, we faced difficulties settling the bill after our discharge.

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

# Case synopsis

In November 2020, Govind Achekar, a 62-year-old farmer from a small village in Kolhapur, fell ill. When his condition didn't improve with local treatment, his family decided to take him to Kolhapur city in an ambulance. They visited several hospitals, but due to the critical nature of his condition, they were refused admission.

Eventually, he was admitted to a private multi-specialty hospital's ICU, where he received treatment for a viral infection. The hospital administered plasma therapy and dialysis, although the family was never informed about the exact cause of his illness. Unfortunately, they were not allowed to visit him due to COVID-19 restrictions in the hospital.

During his 16-day stay in the ICU, Govind developed a bed sore that didn't heal even after a week. As the family's financial resources were depleted, they had no choice but to request Govind's discharge after 26 days. The hospital bill amounted to Rs 6,00,000, and to settle it, they were compelled to sell their farm. The hospital management informed them that Govind's illness was not covered under any MJPJAY category, and they were unsure whom to approach for assistance with the scheme.



My father, Govind Acharekar, was 62 years old and worked as a farmer. He received a monthly pension of Rs 1,700 from his previous job at a sugar factory. We lived in a village near Kolhapur.

In November 2020, my father started experiencing stomach pain and bloating. We took him to a local doctor, who initially prescribed some medicines. However, when his condition worsened with a cold and fever, we consulted a specialist doctor. The doctor assured us that my father would recover in four days, but if not, he would admit him and

provide IV fluids and antibiotics. As his condition didn't improve, we visited the doctor again on the 29<sup>th</sup> and 30<sup>th</sup> of November. After conducting blood tests, the doctor informed us that my father's oxygen levels and platelet count had dropped significantly, and advised us to take him to Kolhapur. During this time, my father had a minor convulsion and received emergency first aid treatment at a hospital.

In Kolhapur, we faced rejections from a couple of hospitals as they only accepted non-critical cases. Eventually, we found a private multi-specialty hospital with available beds, and my father was admitted there on December 1<sup>st</sup>. By then, his oxygen levels were very low. He stayed in the hospital for almost 26 days, and upon admission, he underwent COVID-19 testing, blood and urine tests, and a CT scan.

During the first few days, my father was in a coma, and the doctors struggled to diagnose his condition. On the fifth day, they determined that he had a viral infection in his blood and required plasma therapy and dialysis due to kidney failure. We received notes from the hospital staff instructing us to purchase the prescribed medicines from their in-house medical store, which we then handed over to the ICU nurse on the second floor.

Due to COVID-19 restrictions, we were not allowed inside the hospital premises and had limited knowledge of the investigations being conducted. We only received daily updates, informing us that my father was conscious, able to open his eyes, and move all four limbs. Despite not responding well to plasma therapy initially, my father's condition gradually stabilized.

On the 16<sup>th</sup> day, when he was transferred from the ICU to the general ward, we discovered a large bed sore on his back. The doctor reassured us that it was a normal occurrence after prolonged bed rest in the ICU and would heal with dressing and treatment within a few days. However, even after a week, the bed sore remained a four-inch-wide and deep wound, causing my father immense pain. A doctor visited daily to dress the wound, but it became apparent that it would take much longer to heal.

Considering our financial constraints, we reluctantly informed the doctors that we could no longer afford my father's hospital stay. The cost of the general ward alone was Rs 4,500 per day, and if the bed sore took a month or longer to heal, we had no means to sustain the expenses. Consequently, we requested a discharge on December 26<sup>th</sup>.

Throughout his hospitalization, the authorities did not provide any information about the government's MJPJAY scheme. As we were MJPJAY beneficiaries, we inquired with the hospital if my father's condition would be covered. Unfortunately, they informed us that his viral illness did not fall under any MJPJAY category, and we were responsible for paying the bill ourselves. We were unsure how to further pursue the matter.

The bills we received were substantial. The hospital bill amounted to Rs 3,12,500, the pharmacy bill was Rs 1,57,000, and the investigation costs totaled Rs 1,25,000. In order to settle these bills, we were forced to sell a portion of our ancestral land.

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# Analytical reflections



staff Uphill struggle to avail entitlements of Publicly Funded Health Insurance Schemes

Analytical reflections Commercialised private

sector blatantly defying the state regulatory and harrowing indebtedness Lack of transparency and insensitive behaviour by staff Uphill struggle to avail entitlements of Publicly Funded Health Insurance Schemes



# Analytical reflections

## **Analytical reflections**

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 sector<sup>1</sup>. 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 states<sup>2</sup>. 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 treatments<sup>3</sup>. 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 during the pandemic period<sup>4</sup>. 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

<sup>&</sup>lt;sup>1</sup> Bhuyan, A. (2020, Sep 23). Covid-19 impact: Private hospitals running losses, despite 'high' prices. *The business standard*. <a href="https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-hospitals-running-losses-despite-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-high-prices-120092300233">https://www.business-standard.com/article/current-affairs/covid-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-private-high-prices-19-impact-privat

<sup>&</sup>lt;sup>2</sup> Sundaram, R. (2020, July 8) Private hospitals in Tamil Nadu oppose insurance council's unrealistic covid treatment rates. *Times of India*. <a href="http://timesofindia.indiatimes.com/articleshow/76846218.cms?utm\_source=contentofinterest&utm\_medium=text&utm\_campaign=cppst">http://timesofindia.indiatimes.com/articleshow/76846218.cms?utm\_source=contentofinterest&utm\_medium=text&utm\_campaign=cppst</a>

<sup>&</sup>lt;sup>3</sup> In the high court of judicature at Bombay Nagpur Bench, Nagpur Writ Petition No. 1936 of 2020.

<sup>&</sup>lt;sup>4</sup> Public private partnership towards universal healthcare in India (2020). National law school of India University Bengarulu https://ahpi.in/pdf/PPP-UniversialHealthCare-in-India ver-27Oct2020.pdf

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 costs<sup>5</sup>. 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.

# 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 state<sup>6</sup>, 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

<sup>&</sup>lt;sup>5</sup> Sundararaman, T. (2015). Falling Sick, Paying the Price. Economic & Political Weekly. <u>Vol. 50</u>, Issue No. 33.

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

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

After market disaster, what is the way forward?



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 Legal regulation: Enactment and effective implementation of appropriate Clinical Establishments Act (CEA) Universal implementation and social awareness regarding Patient Rights Charter 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 disaster, what is the way forward?

# 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 elsewhere 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 Polanyi<sup>2</sup> 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**' 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

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

<sup>&</sup>lt;sup>2</sup> Polanyi, K. (1944), The Great Transformation, Beacon Press, Boston

<sup>&</sup>lt;sup>3</sup> 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

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 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-forprofit) 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' , 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').

<sup>&</sup>lt;sup>4</sup> Polanyi, K. (1944), The Great Transformation, Beacon Press, Boston

#### 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 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

<sup>&</sup>lt;sup>5</sup> SATHI (2021). Growing Corporatisation of Private Healthcare in India and its Implications. Policy brief. Pune, September 2021.

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.

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 forprofit 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-forprofit, 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 process<sup>6</sup>

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.

<sup>&</sup>lt;sup>6</sup> 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

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.

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<sup>7</sup>. 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.

#### 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.<sup>8</sup>

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 Brazil<sup>9</sup> and Health Assemblies in Thailand 10 can provide useful inputs in creating spaces for meaningful engagement of people with policy making processes. Based on the principle of

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

<sup>&</sup>lt;sup>8</sup> 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

<sup>&</sup>lt;sup>9</sup> 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

<sup>&</sup>lt;sup>10</sup> 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.

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**. <sup>11</sup>

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.

https://bulletin.ids.ac.uk/index.php/idsbo/article/view/2970

<sup>&</sup>lt;sup>11</sup> 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.

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.

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Advisory on Right to Health kormtext of COVID-19 pandemic (Advisory 2.0) Advisory on Ricardo Health in context of COVID-Charter of Paticets' riorys and rysponsibilities to be displayed videobserves by ahelealthoare estagnisments, as committeltistion holder governgovernolatte Profile of respondents Chianaccountability Regulation Advisory on Picit to Hebe integrated with public displane and observertion implementation regulation displane and observertion implements the regulation Charter of Patients' red, in and responsibilities to be

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# Annexure A - Profile of respondents

	Age of patient (Years)	of patient	Sex Geographic Occupation of location of patient of patient		rypes of health institution accessed for treatment	of the incidence	morbidities care interv	care intervention	(in Rs)	Deposit taken by hospital (in Rs)	of days of hospita- lisation	outcome	nedressal t mechanisms approached, if any
4	48	Σ	Kolhapur	Teacher	Rural hospital and big private hospital	Sep 2020	O <sub>Z</sub>	COVID -19	Rs 14,21,000	Rs 1,50,000	25 days Death		ON
0	65	ш	Pune city	House-wife	Big charitable trust hospital	2020 2020	Diabetes, BP	COVID	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	15 days Recovered	MJPJAY district co- ordinator, Deputy collector, the local corporator and other political leaders
	40	Σ	Bhor, Pune	Service in co-op society	Private hospital- approved as COVID center	Aug 2020	0 Z	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	
	30	Σ	Kolhapur	Small shoe shop owner	3 small-med private hospitals	Oct 2020	ON.	COVID -19	Rs 1,50,000	Rs 50,000	2 days	Death	
	38	Σ	Kolhapur	Labour	Govt covid care then to small private hospital	July 2020	No	COVID	Rs 2,95,000 plus medicines Rs 89,000	Rs 50,000	9 days	Death	
	72	L	Yavatmal	Senior	Small private hospital	Aug 2020	Yes	COVID	Rs 1,48,000	Rs 80,000	5 days	Death	ON

Redressal mechanisms approached, if any	Complaint letter submitted to MJPJAY district Committee	ON	Complaint submitted to Redressal Grievance Cell of Pune Municipality	O <sub>Z</sub>	O <sub>N</sub>	Complaint submitted to Mumbai Municipality Grievance Cell	O Z	ON
Health outcome	Recovered	Death	Recovered	Recovered	Death	Death	Recovered	Death
Number of days of hospita-lisation	15 days	4 days	15 days	12 days	10 days	25 days	18days	10 days
Deposit taken by hospital (in Rs)	Rs 35,000	Rs 1,00,000	Rs 50,000	Rs 50,000	Not mentioned	Rs 2,50,000	Rs 50,000	Rs 20,000
(in Rs)	Rs 1,13,000	Rs 73,000 (inclu. Rs 16,000 of ambulance, Rs 1,500 of gloves) plus medicines- Rs 1,30,000	Rs 2,80,000	Rs 1,27,000 plus medicines Rs 80,000	Total Rs 1,04,000	Rs 1,40,000	Total- Rs 3,00,000 Hospital bill- Rs 1,89,000, for medicines- Rs 1,18,000	Rs 3,25,000 plus Rs 63,000
Health- care intervention	COVID -19	Asthma, pneumonia	COVID-19	COVID-19	COVID-19 positive	COVID-19	COVID-19	COVID-19
Co- morbidities	plus other medical condition	Asthma	O <sub>Z</sub>	O <sub>N</sub>	Severe Anaemia, Piles	Yes	O <sub>N</sub>	ON
Date of the incidence	Dec 2020	Sep 2020	July 2020	July 2020	Sep 2020		August 2020	Sep 2020
Geographic Occupation Types of health location of institution of patient accessed for treatment	Big Charitable trust hospital, Private Medical college hospital	Govt and small hospital	Big corporate hospital	Small private hospital	Small private hospital and then govt COVID center	Corporate hospital	PHC then small private hospital	Two medium sized Private hospital
Occupation of patient	Waste picker	Not working. senior citizen	Retired	Small ladies shoppie	Watchman	Doctor	Farmer	Mobile repairer
Geographic location of patient	Pune -urban	Yavatmal	Pune	Pune, Nasarapur	Bhor, Pune Watchman	CIDCO, Belapur	Bhor, Pune	Kolhapur- Rural
Sex of patient	ட	ட	ш	ட	Σ	Σ	Σ	Σ
Age of patient (Years)	65	29	82	99	55	09	52	30
Code Story title	Health insurance coverage denied to eligible patient despite efforts	Did my mother really die of COVID-19?	Exorbitant yet negligent hospital and disappointment with grievance redressal forum	No COVID-19 scheme benefits, no beds in government hospitals	COVID-19, cha.os and fake reports	We were cheated by a corporate hospital	Debt and disease go hand in hand in my village	Advance cash deposits first
Code	7.	ထ်	ത്	10.	1.	12.	<u>.</u>	14.

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Redressal mechanisms approached, if any	ON	ON	ON	O <sub>Z</sub>	ON	O <sub>N</sub>	ON	ON	O <sub>Z</sub>
Health outcome	Recovered	Death	Recovered	Recovered	Death	Recovered	Recovered	Recovered	
Number of days of hospita- lisation	7 days	10 days	12 days	17 days	10 days	5 days	9 days	5 days	27days
Deposit taken by hospital (in Rs)	Rs 20,000	Rs 25,000	Info not available	Info not available	Info not available	Info not available	Rs 25,000	Info not available	available
Total bill (in Rs)	Rs 3,19,000 (Refunded Rs 2,00,000 after passing insurance)	Rs 1,41,000	Rs 1,90,000 inclu. medicines of Rs 90,000	Rs 5,60,000	Rs 1,03,000, inclu.medicines- Rs 25,000	Rs 1,25,000	Rs 1,76,000	Rs 75,000	Rs 3,25,000 inclu.diagnostic tests- Rs 1,57,000
Health- care intervention	COVID- 19	COVID-	COVID- 19	COVID-	Pneumonia	COVID-19	COVID-19	COVID-19	COVID-19 plus other complications- COMA, blood viral infection plasma therapy
Co- morbidities	Initial diagnosis was pneumonia	ON	ON	ON	ON	O <sub>Z</sub>	O <sub>N</sub>	ON	<u>0</u>
Date of the incidence	Oct 2020	Sep 2020	Oct 2020	Sep 2020	Aug 2020	Aug 2020	Aug 2020	Aug 2020	Nov 2020
Types of health institution accessed for treatment	Big Corporate hospital	Medical college private hospital	Medium private hospital	Govt COVID center then medium private hospital	Medium private hospital	Medium private hospital	Medium private hospital	Medium private hospital	Medium private hospital
Geographic Occupation location of patient patient	Service	Senior citizen	Senior citizen	Farmer	Info not available	Taxi driver	Info not available	Info not available	Worker in factory
Geographic location of patient	Nashik- Rural	Sangali	Bhor, Pune	Kolhapur	Kolhapur	Nashik	Nashik	Nashik	Kolhapur
Sex of patient	M	M	M	Щ	≥	≥	Σ	Σ	Σ
Age of patient (Years)	Above 60	65	09	75	Missing	48	43	24	62
Story title	Advance deposits were compulsory despite cashless mediclaim	Cash and connections for COVID-19 care	Government scheme failed, leaving us in debt	No schemes for critical patients	Is treatment only for those who can afford to pay hospital 'packages'?	I was never COVID-19 positive but treated for COVID-19	Exorbitant COVID care, failed health insurance	Mediclaim-License to loot patients	The price of my father's hospital stay was our ancestral land
Code	15.	16.	17.	18.	19.	20.	21.	22.	23.



Patients' Human

Charter of Patients' rights Rights for are adoption rights! 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 Commission' 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

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	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.  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.  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.  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.	1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010  2) MCI Code of Ethics 3) Patients Charter by National Accreditation Board for Hospitals (NABH) 4) The Consumer Protection Act, 1986
2	Right to records and reports	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.	1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up

No.	Rights of patients	Description of rights and associated duty bearers	Reference
		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.	as per Clinical Establishment Act 2010  2) MCI Code of Ethics section1.3.2  3) Central Information Commission judgment, Nisha Priya Bhatia Vs. Institute of HB&AS, GNCTD, 2014  4) The Consumer Protection Act, 1986
3	Right to Emergency Medical Care	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.  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.	1) Supreme court judgment Parmanand Katara v. Union of India (1989)  2) Judgment of National Consumer Disputes Redressal Commission Pravat Kumar Mukherjee v. Ruby General Hospital & Others (2005)  3) MCI Code of Ethics sections 2.1 and 2.4  4) Article 21 of the Constitution 'Right to Life'
4.	Right to informed consent	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.  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	1) MCI Code of Ethics section 7.16  2) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments

No.	Rights of patients	Description of rights and associated duty bearers	Reference
		and that consent forms with protocol for seeking informed consent are provided for patients in an obligatory manner. 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.	Council set up as per Clinical Establishment Act 2010  3) The Consumer Protection Act, 1986  4) Drugs and Cosmetic Act 1940, Rules 2016 on Informed Consent
5	Right to confidentiality, human dignity and privacy	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.  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.	<ol> <li>MCI Code of Ethics sections 2.2, 7.14 and 7.17.</li> <li>Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010</li> </ol>
6	Right to second opinion	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. 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.	1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010.  2) The Consumer Protection Act, 1986

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	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.  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.  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.	<ol> <li>MCI Code of Ethics section 1.8 regarding Payment of Professional Services</li> <li>Section 9(i) and 9(ii) of Clinical establishments (Central Government) Rules 2012</li> <li>Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010</li> <li>Various Drug price control orders</li> <li>The Consumer Protection Act, 1986</li> <li>Drugs Price Control Order (DPCO) section 3 of the Essential Commodities Act, 1955</li> </ol>
8	Right to non- discrimination	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.  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.	1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per Clinical Establishment Act 2010

No.	Rights of patients	Description of rights and associated duty bearers	Reference
9.	Right to safety and quality care according to standards	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.  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.	1) Clinical establishmen ts (Central Government) Rules 2012 2) The Consumer Protection Act, 1986
10.	Right to choose alternative treatment options if available	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.  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.	1) Annexure 8 of standards for Hospital level 1 by National Clinical Establishmen ts Council set up as per Clinical Establishmen t Act 2010 2) The Consumer Protection Act, 1986
11.	Right to choose source for obtaining medicines or tests	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	1) Various judgments by the National Consumer

No.	Rights of patients	Description of rights and associated duty bearers	Reference
		obtain this investigation from any registered diagnostic centre/laboratory having qualified personnel and accredited by National Accreditation Board for Laboratories (NABL). 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.	Dispute Redressal Commission  2) The Consumer Protection Act, 1986
12.	Right to proper referral and transfer, which is free from perverse commercial influences	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. 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.	1) Medical Council of India code of ethics section 3.6 2) World Health Organisation - Referral Notes 3) Various IPHS documents
13.	Right to protection for patients involved in clinical trials	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:  a) Participation of patients in clinical trials must always be based on informed consent, given after provision of all	1) Protocols and Good Clinical Practice Guidelines issued by Central Drugs Standard Control Organisation, Directorate

No. Rights of patients	Description of rights and associated duty bearers	Reference
	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.  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.  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.  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.  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.  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.  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.  h) After the trial, participants should be assured of access to the best treatment methods that may have been proven by the study.  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.	General of Health Services, Govt. of India  2) Amended Drugs and Cosmetics Act, 1940 and Rules, 1945 especially schedule Y  3) National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, Indian Council of Medical Research, New Delhi, 2017  4) World Medical Assembly Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects available at www.wma.net/en /30publications/ 10policies/b3/17 c.pdf

No.	Rights of patients	Description of rights and associated duty bearers	Reference
14.	Right to protection of participants involved in biomedical and health research	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.  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.  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.  The benefits accruing from research should be made accessible to individuals, communities and populations whenever relevant.  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.	1) National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, Indian Council of Medical Research, New Delhi, 2017  2) World Medical Assembly Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects available at www.wma.net/en/3 Opublications/ 10policies/b3/17c. pdf  3) Drugs & Cosmetic Act, Rules 2016 on Clinical Trails
15.	Right to take discharge of patient, or receive body of deceased from hospital	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.  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.	<ol> <li>Prohibition of wrongful confinement under Sec. 340-342 of IPC. Statements of Mumbai High Court.</li> <li>Consumer Protection Act 1986</li> </ol>

No.	Rights of patients	Description of rights and associated duty bearers	Reference
16.	Right to Patient Education	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.  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.	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	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.  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.  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.  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.	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.

- 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 multistakeholder 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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File No. R-18/5/2021- PRP&P

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 pandemie, 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.

Bimbadhar Pradhan) Secretary General

Encl: Advisory 2.0

- 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, GoI, 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.

Mayor

- (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, redeploying 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,
  - 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 2<sup>nd</sup> 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.

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# Advisory on Right to Health in context of COVID-19



## राष्ट्रीय मानव अधिकार आयोग National Human Rights Commission

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File No. R-17/8/2020-PRP&P-Part (1)

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.
- 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 <u>annexure</u>.
- 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

(Jaideep Govind) Secretary General

Secretary

M/o Health & Family Welfare D/o Health and Family Welfare Nirman Bhawan, C-Wing New Delhi-110001

Chief Secretary (All States UTs)



## **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 us 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 he 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 2<sup>nd</sup> 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 comorbidities, etc.
- 3,4 COVID Dashboards: The COVID-19 relased 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 in 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 sest 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 te 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, redeploying 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.



## 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

- 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.

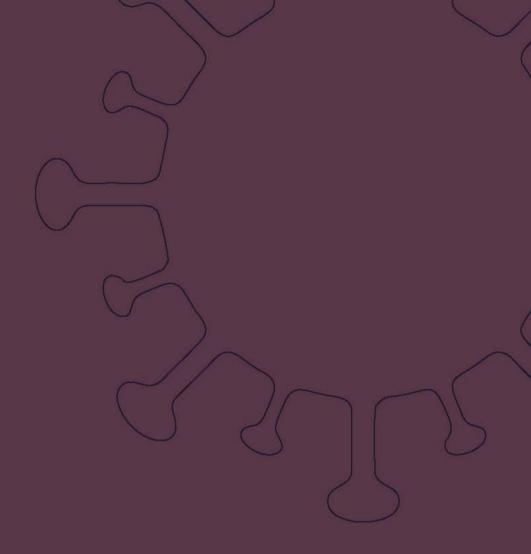


#### Patients' Responsibilities:

- 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 2<sup>nd</sup> 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.

NHRC





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