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SECURING RIGHTS OF PATIENTS IN INDIA

Lessons from rapid surveys on peoples' experiences of Patient's Rights Charter and the COVID-19 vaccination drive

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Executive Summary

The COVID-19 pandemic has devastated families and communities and disrupted societies and economies. Patients had to endure various indignities in both public and private hospitals without protections or recourse to adequate preventive and redressal mechanisms. While, the COVID-19 vaccine is seen as a solution to the pandemic, its roll-out has also been rife with inequalities. However, many of the problems we have seen at this time stem from the deep-rooted problems in the public health system. A critical look at India's health system from the perspective of its patients is overdue.

Oxfam India undertook two rapid surveys on Patient's Rights Charter and COVID-19 vaccination through self-administered questionnaires, covering 28 states and 5 Union territories; as such, this bears the limitations arising from it being a self-selected sample. The former was done between February and April 2021 and received 3890 responses while the latter was done between August and September 2021 covering 10,955 respondents. Given the distinctive focus of each survey, both are presented separately.

Key findings of survey on Patient's Rights

This captures some of the experience of patients with both the public and private healthcare system over the last decade with focus on the provisions of the Patients' Rights Charter.

Some of the key findings include

- **Right to Confidentiality, Human Dignity and Privacy:** Over a third of women (35%) said that they had to undergo a physical examination by a male practitioner without another female present in the room.
- **Right to Information:** 74% people said that the doctor simply wrote the prescription or treatment or asked them to get tests/investigations done without explaining their disease, nature and/or cause of illness.
- **Right to Informed Consent:** More than half of the respondents (57%) who were themselves/their relatives had been hospitalised did not receive any information about investigations and tests being done.
- **Right to Second Opinion:** At least a third of respondents who had themselves/their relatives hospitalised said their doctor did not allow a second opinion.
- **Right to Non-Discrimination:** A third of Muslim respondents and over 20% Dalit and Adivasi respondents reported feeling discriminated against on the grounds of their religion or caste in a hospital/by a healthcare professional.
- **Right to Choose Source of Obtaining Medicine or Test:** 8 in 10 respondents reported being asked to get tests/diagnostics from one place only.
- **Right to Transparency in Rates and Care According to Prescribed Rates:** 58% people of those who had themselves/their relatives hospitalised, said that they were not provided with an estimated cost of treatment/procedure before the start of treatment/procedure. Three in every 10 people surveyed reported being denied case papers, patient records, investigation reports for treatment/procedure by the hospital even after requesting the same.
- **Right to Take Discharge of Patient or Receive Body of Deceased from the Hospital:** 19% of respondents whose close relatives were hospitalized said that they were denied release of dead body by the hospital.

The COVID-19 pandemic has deepened existing structural inequalities in the healthcare system. The report recommends:

- MoHFW should set up a mechanism to review the present status of adoption of the Patient's Rights Charter (PRC) in all states and UTs and order its immediate adoption. It should include the PRC in the Clinical Establishment Act (CEA) and issue a letter to the states and Union territories (UTs) for displaying PRC in all private and public hospitals in view of the unprecedented crisis induced by the COVID-19 pandemic, particularly for hospitals taking part in the Pradhan Mantri Jan Arogya Yojana (PMJAY).
- State and UT governments should issue orders to display the PRC in all private and public hospitals irrespective of adoption of CEA and ensure grievance redressal mechanisms for patients, through the appointment of an internal grievance officer within every public and private clinical establishment.
- National Medical Commission should introduce mandatory modules on patients' rights in the healthcare curriculum.

Key findings of rapid survey on COVID-19 vaccination drive

Some of the key findings from the survey of the experiences of the vaccination drive were:-

- Eight out of 10 people said that they do not think that the government will be able to vaccinate all adults by December 2021.
- 80% people believed that it is more difficult for a daily wage worker to get the vaccine as compared to a salaried, middle-class person. Most did not think that the experience was equitable.
- With respect to how the government should address inequity in vaccination, some specific suggestions were
 - o 83% believed that all vaccination should be done completely free of cost through the government, like previous vaccination drives.
 - o Only 2% of respondents were in favour of tax on essentials like fuel to fund the vaccination. 55% believed that imposing a one-time tax of 1% on the net-worth of India's richest 1000 families was the best mode of funding.
 - o 89% people said that the operational hours of vaccination centres should be expanded beyond 9 AM-5 PM.
 - o 95% people from all age categories felt that vaccination must be brought closer to the elderly, persons with disabilities and informal sector workers by making use of mobile vans, vaccination camps and home-based vaccination.
 - o 88% believed that the government must ensure that marginalized groups such as street dwellers, migrant workers, immigrants, refugees and asylum seekers are given access to vaccination without having to furnish documentation.
 - o Improve information about vaccination. 74% respondents earning less than INR 10,000 per month and over 60% respondents from marginalized and minority communities felt that the government has failed in informing them about how and when to get vaccinated. Eight in 10 felt that government had been changing its COVID-19 vaccine policies too frequently.
 - o 89% people said that the government must do more to ramp vaccine production, especially through public sector companies.
- The experiences of vaccination show the
 - o **Challenges with vaccination:**
 - 29% said that they either had to make multiple visits to the vaccination centre or stand in long queues.
 - 22% faced issues in booking the slot online or had to try for multiple days ahead to get a slot.
 - 9% people said that they had to lose a day's wages to get themselves vaccinated.
 - o **Reason for not getting vaccinated:**
 - 43% respondents stated that they could not get vaccinated because the vaccination center had run out of vaccines when they visited the center.
 - 12% did not get vaccinated because they could not afford the high prices of vaccine.

The lessons from the COVID-19 vaccination drive, would not only help to improve the current response, but can derive learnings improving equitable administration of any vaccine in future.

- All vaccination should continue to be done completely free of cost through the government system; avoid the use of private hospitals to deliver vaccination;
- Proactively release timely information on vaccination strategies, modalities and accomplishments in disaggregated, user-friendly and open source formats;

- Prioritise allocation, distribution and administration of vaccines for marginalized, poor, vulnerable, excluded communities first, of course along with for those who are at risk;
- Maintain record and release disaggregated data on vaccination coverage based on social and economic groups including Dalits (Scheduled Caste), Adivasis (Scheduled Tribes), Muslims, and Persons with Disabilities (PwD);
- Bring vaccination closer to the vulnerable and extend operational hours of vaccination centres beyond 9 AM-5 PM to allow for vaccination without a loss of wages;
- Improve information dissemination about vaccination; existing technology-based mechanisms for disseminating information about vaccination centres locations and availability of vaccines is not sufficient. It would be important to build a robust and functional grievance redressal mechanisms, from national to local, to address emerging challenges. Adequate flexibility must be given to local health administrations to adapt to local circumstances;
- Further ramp up vaccine production, especially through the use of public sector companies.

In conclusion

Both surveys have the common thread of 'Violation of Patients 'Rights'. The letter to states requesting them to notify the Patients 'Rights Charter was one of the first actions of the newly elected Modi government. We hope that the governments live up to this early promise by taking rights of patients seriously by notifying and implementing the Patients 'Rights Charter. It would need to also develop robust mechanisms for addressing violations of patients 'rights and to provide space for patients ' voice to be heard in the health system; more robust grievance redress mechanisms are needed to avoid some of the gross rights violations India saw during the course of the second wave of the pandemic. It is also time to start capturing the differential experiences and challenges of patients who are rich or poor, of men and women, or the privileged and marginalized communities. This needs to, in turn, become the basis of strategies to ensure that the system becomes responsive to their individual needs and contexts. In so doing, it would be important to ensure that patients 'rights are protected not just in the public healthcare, but also more critically, in private hospitals. This calls for more robust process of monitoring and enforcing regulations related to non-discrimination and protecting citizens from commercialisation in these settings. Last but not the least, this is predicated on developing a process for building awareness on the health rights of citizens and patients' (especially the Charter) among citizens and health providers, alike. This can be done collaboratively with communities and civil society in order to hold providers responsible.

Background

The COVID-19 pandemic has brought into sharp relief the extent to which rights of patients are violated across India. The pandemic has stretched beyond breaking an already abysmal state of patient rights in the India's healthcare system. In this period, patients had to endure various indignities including being denied essential healthcare services, being forced to pay inflated hospital bills in the private sector, and being refused admission for emergency services without a COVID-19 test. Additionally, marginalized communities like Dalits, Adivasis and religious minorities like Muslims faced new forms of violence, and discrimination in both public and private hospitals.

However, these issues might have come to the fore during the pandemic but have always been around. In most states, there are no well-defined preventive and redressal mechanisms against such violations. The National Human Rights Commission (NHRC) has long taken up the patients' rights issue as a human rights issue. In August 2018, the Ministry of Health and Family Welfare (MoHFW) released India's first [Patients' Rights Charter \(PRC\)](#)¹ with 13 patients' rights incorporating the recommendations from NHRC. Health is a state subject. In June 2019, the MoHFW issued a letter requesting State governments to adopt the Charter. Two years have now passed since the States were directed to adopt the Charter but they are yet to be adopted by states and Union territories (UT) in India.

This is not the only instance of how citizen voice goes unheard in the healthcare system. India's vaccination drive has been dogged by a range of problems arising from the limited extent to which India's citizens were consulted in the initial stages of the COVID-19 vaccination roll out.

All this is particularly critical to understand in the context of India's increased reliance on private healthcare providers. Formal mechanisms for citizen participation and redressal, to an extent, exist in the public health system but not in private hospitals. The [75th National Sample Survey](#)² (NSS) found that out of the total hospitalisations in rural areas 54% were in the private sector; the corresponding figure was 66% in urban areas. While the poorest two income quintile groups tend to rely on public sector providers for inpatient hospitalisation in rural areas, for outpatient care, both rural and urban population across all income quintile groups depend more on [the private sector](#)³ (72% in rural and 79% in urban sector). This makes it necessary to critically examine the track record of the private healthcare sector.

Oxfam India has undertaken two surveys — one, looking at the reality of implementation of the Patients' Rights Charter and second, another eliciting citizens' perspectives regarding the COVID-19 vaccination roll out. The former is intended to provide a national snapshot of the extent to which patients' rights have been respected, especially at this time in history. Given the distinctive focus of each survey, both are presented separately. The report concludes with recommendations.

¹ <http://clinicalestablishments.gov.in/WriteReadData/8431.pdf>

² http://mospi.nic.in/sites/default/files/publication_reports/KI_Health_75th_Final.pdf

³ <https://d1ns4ht6ytuzzo.cloudfront.net/oxfamdata/oxfamdatapublic/2020-10/NHRC-guidelines-related-to-health-and-child-rights.pdf>

PART 1: Rapid Survey Of Experiences Of Patients Based On Patients' Rights Charter

Background

The right to health is a fundamental human right recognised as part of the right to an adequate standard of living under the [Universal Declaration of Human Rights](#)⁴ (1948, Article 25). The most widely used articulation of the right to health is set out in the International Covenant on Economic, Social, and Cultural Rights (ICESCR). [ICESCR's Article 12](#)⁵ provides that, 'The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'. In addition to the above, a range of international treaties provide those using the healthcare system with specific rights including right to privacy and confidentiality, non-discrimination and equality and freedom from torture and degrading treatment, among others. **Governments must respect and protect** fundamental human rights of patients when they provide health and care services and take **positive steps** to ensure that patients' human rights aren't breached.

In India, there are various legal provisions related to Patient's Rights which are scattered across different legal documents including the [Constitution of India, Article 21](#)⁶, Indian Medical Council (Professional Conduct, Etiquette and Ethics) [Regulations](#)⁷ 2002; The Consumer [Protection](#)⁸ Act 1986; [Drugs and Cosmetic Act](#)⁹ 1940, [Clinical Establishment Act 2010](#)¹⁰ and rules and standards framed therein; various judgments given by Supreme Court of India and decisions of the [National Consumer Disputes Redressal Commission](#)¹¹ also cover specific dimensions of patient's rights. While having this range of legislative provisions is welcome, India has missed a comprehensive and legally binding framework.

In 2018, MoHFW adopted and released its Patients Rights Charter drawing on the [first draft charter](#)¹² prepared by the NHRC. This provides a consolidation of various rights which enables the assurance of protection and promotion of Human Rights of patients and works as a guidance document for the Union and State governments to formulate concrete mechanisms so that patient rights are given adequate protection.

⁴ https://www.un.org/en/udhrbook/pdf/udhr_booklet_en_web.pdf

⁵ <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

⁶ <https://legislative.gov.in/sites/default/files/COI-updated.pdf>

⁷ http://www.nihfw.org/Legislations/THEINDIANMEDICALCOUNCILACT_1956.html

⁸ http://ncdrc.nic.in/bare_acts/Consumer%20Protection%20Act-1986.html

⁹ <https://legislative.gov.in/sites/default/files/A1940-23.pdf>

¹⁰ <http://www.clinicalestablishments.gov.in/cms/Home.aspx>

¹¹ <https://www.mondaq.com/india/healthcare/747800/ministry-of-health-releases-first-patient39s-charter-in-the-country>

¹² https://nhrc.nic.in/sites/default/files/charter_patient_rights_by_NHRC_2019.pdf

Nearly six months after the peak of the first wave of COVID-19 in India, NHRC released a [Human Rights advisory on Health For All](#)¹³ in the context of COVID-19 (NHRC, 2020). The advisory dated 28 September 2020, advised state governments to display Patients' Rights Charter as per the order issued by MoHFW to all the states/UTs dated 2 June 2019. Later, during the second wave of Covid pandemic, a [second advisory on Right to Health](#)¹⁴ was issued by NHRC, dated 4 May 2021.

While these provisions are made, it is not always clear to what extent they are realised in practice. Limited research has been undertaken on this topic. Most [research](#)¹⁵ available in the public domain focusses on the extent of awareness of [patients' rights](#)¹⁶ among patients and doctors. Most are, fairly localised looking at individual cities. Existing research on awareness on patients' rights suggests that women are more aware of their rights than men; younger adults are more aware than older age groups and patients admitted to more expensive wards had higher [awareness](#)¹⁷. Those who are financially better off presumably had a higher degree of awareness of their rights. However, no large-scale research exists that looks at the realisation of patients' rights, especially across multiple states.

In this context, an explorative rapid survey was conducted by Oxfam India with the objective of understanding the experiences of patients or their relatives while availing the healthcare services and perception about the violations of patients' rights.

¹³

<https://nhrc.nic.in/sites/default/files/NHRC%20Advisory%20on%20Right%20to%20Health%20in%20context%20of%20covid-19.pdf>

¹⁴ https://nhrc.nic.in/sites/default/files/Human%20Rights%20Advisory%20on%20Right%20to%20Health_2021_May.pdf

¹⁵ <https://link.springer.com/article/10.1007%2Fs11948-016-9776-z>

¹⁶ <https://www.sciencedirect.com/science/article/pii/S2210909915000041>

¹⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5713758/>

Methodology and limitations

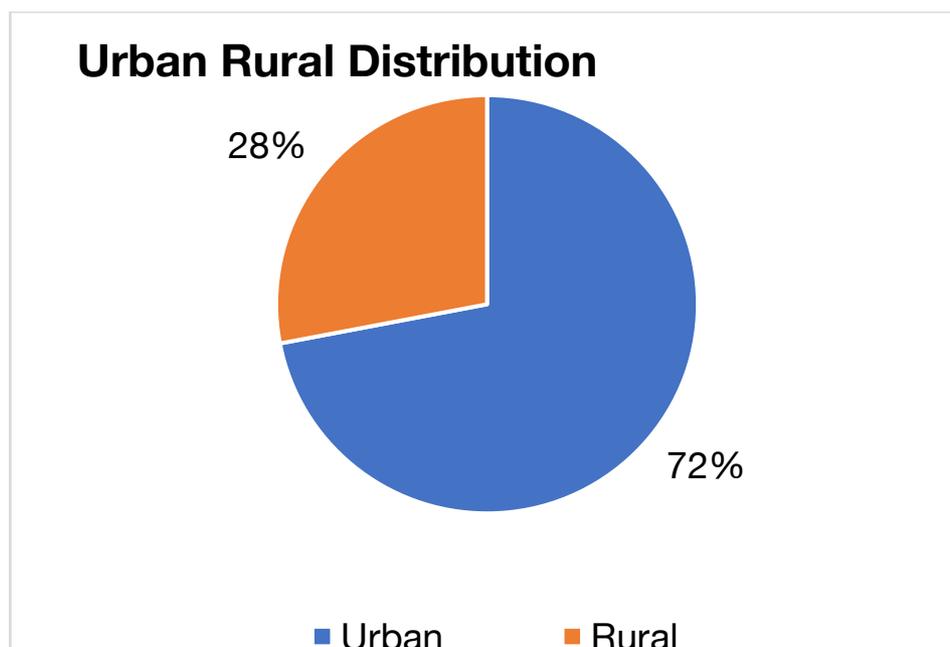
A total of 3890 responses were recorded from 28 states and 5 Union territories in India through a self-administered questionnaire. A questionnaire was designed to understand their experiences on parameters pertaining to rights of patients in line with the Patients' Rights Charter (PRC). Respondents were asked for their experiences or experience of their close relatives. Data was collected online via Google Forms.

It must be stated upfront that this is a rapid survey and not a research study, and thus suffers from multiple limitations. The study was conducted with a self-selected sample and therefore, it makes no claim to be representative of India's diversity. Out of 3890 respondents, 3242 respondents were men; only 643 were women and only 5 were transgenders. This is possibly reflective of the prevalence of the digital divide which has left women with limited access to a digital device and internet. This skewed sample may also impact the overall trends, given the preliminary evidence that awareness of patients' rights may be unequal across the population.

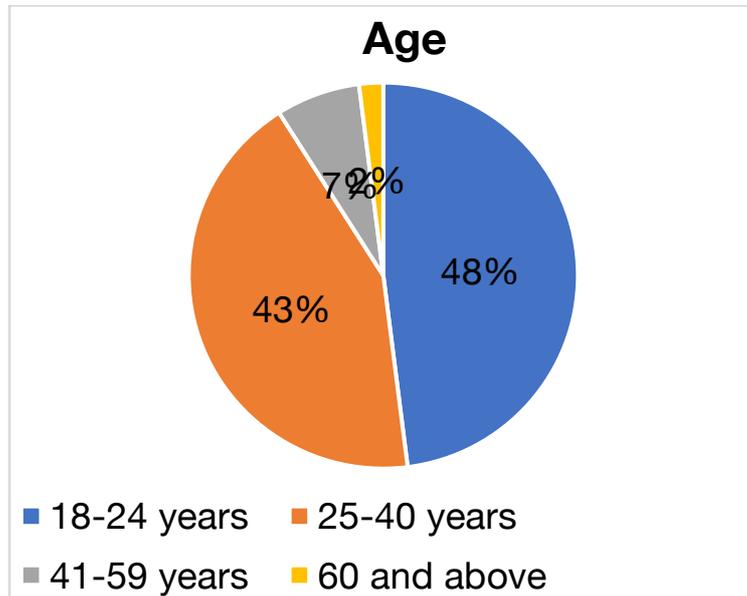
However, the study still offers a fair overview of the status vis-à-vis patient's rights in India. It highlights not just the overall levels, but also captures the extent of inequality in the quality of the healthcare experience based on the grounds of gender, religion, caste, and disability. It must also be highlighted that while the study was conducted during the pandemic, it asked respondents about their experiences with health professionals and hospitals in the past ten years. Thus, these findings must be viewed, not just in the context of Covid but also in the period preceding it.

Socio-demographic details of respondents

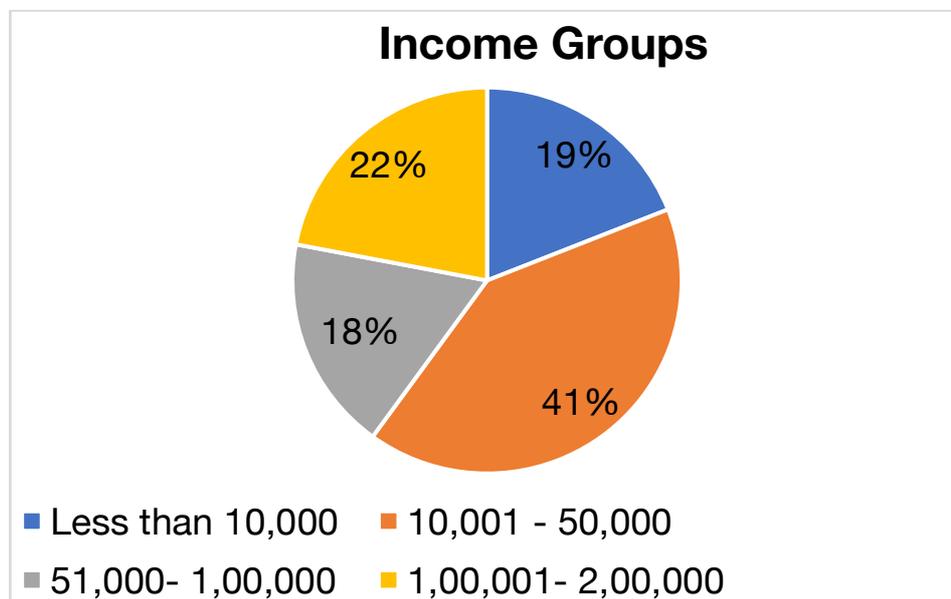
Citizens between 18-24 years (48%) formed the biggest category of respondents, followed by 25-40 years (43%). Involvement of youth is maximum as this demographics may have more access to smart phones and internet.



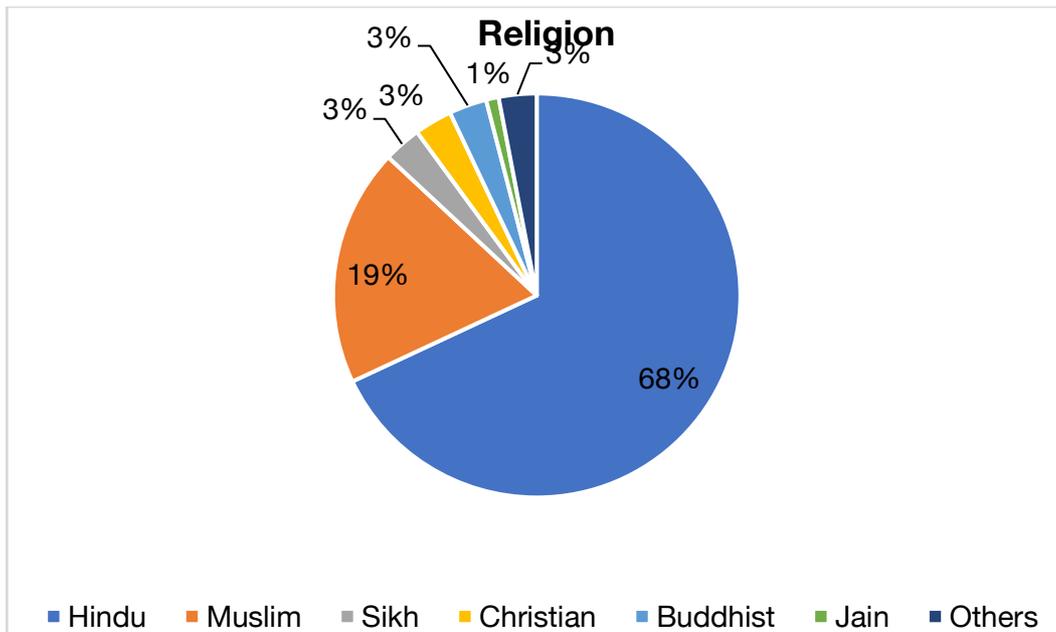
At the level of rural and urban distribution, 72% respondents were from urban areas whereas 28% were from rural areas.



The monthly income of 41% (maximum) of the respondents was between INR 10,001 to INR 50,000 whereas 19% of respondents were earning less than INR 10,000 per month. As such, this offers a decent cross-section of income groups in India.



Disaggregating by religion, the maximum number of respondents i.e. 68% were Hindu, followed by 19% Muslim. With respect to respondents' caste profile, 50% were from the general category, 27% were Other Backward Class (OBC), 11% Dalits (also, Scheduled Caste) and 9% Adivasis (also, Scheduled Tribe).



The sample was, therefore, urban with most respondents earning INR 10000-50000 per month with a decent representation of different religions and social groups.

Inpatient and outpatient experiences

Of the respondents, 15% had experienced hospitalisation during the last 10 years. As such, the survey captures both inpatient and outpatient experiences.

Findings of the survey

The analysis of the data has been done on the basis of perceptions/opinions shared by the respondents on the some of the key patients' rights given in the Charter. An attempt was made to see the trend/linkages between violations of patients' rights in the context of gender, income status, rural-urban and religion/caste front.

Right to Confidentiality, Human Dignity and Privacy

Provision of the PRC:

'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'

This is in accordance with the [MCI's code of ethics](#)¹⁸ clause 2.2, 7.14 and 7.17 and the Annexure-8 of [Standards for Hospital level 1 by National Clinical Establishments Council](#)¹⁹ set up as per Clinical Establishment Act 2010.

Question asked in the survey (only to women respondents)

Have you undergone a physical examination by a male practitioner without any other female present in the room?

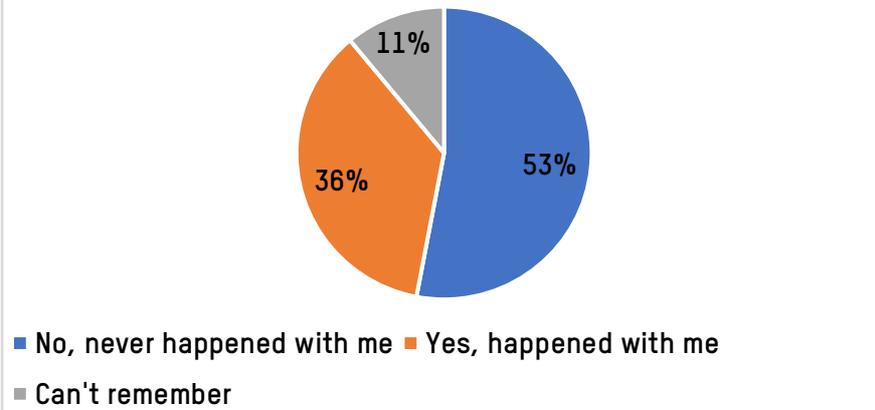
- Yes, it happened with me
- No, it never happened with me
- Can't remember

35% women underwent physical examination by male attendant without a female present in the room

¹⁸<https://wbconsumers.gov.in/writereaddata/ACT%20&%20RULES/Relevant%20Act%20&%20Rules/Code%20of%20Medical%20Ethics%20Regulations.pdf>

¹⁹<http://clinicalestablishments.gov.in/WriteReadData/147.pdf>

Physical examination by male attendant without a female present in the room



Of the women surveyed, over one-third (36%) reported that they had to undergo a physical examination by a male practitioner without any other female present in the room. This is not just an issue of privacy and dignity, but women's health and safety. Studies have demonstrated time and again that most women are not comfortable with being treated by male doctors without the presence of another woman in the room (Yanikkerem, 2010)²⁰. Women were more likely to go for gynaecological examinations when norms and standards related to privacy are maintained. Districts with higher women physician availability in rural primary care reported higher reproductive and maternal health care utilisation (e.g., modern contraceptive use, antenatal care, skilled birth attendance and maternal postnatal care) (Bhan, 2020)²¹. Incidents²² of mistreatment have been reported against male doctors for alleged molestation in the guise of physical examination. In most cases, especially in the private sector, there is no accountability²³ mechanism in place to ensure justice for victims. In fact, often private hospitals protect their staff despite such acts being in direct violation of MCI's code of ethics under the Indian Medical Council (Professional conduct, Etiquette and Ethics) Regulations, 2002.

Interestingly, while over 40% women whose monthly income ranges from INR 10,000 to INR 200,000 per month said that they had to undergo a physical examination by a male practitioner without any other female present in the room, only 21% women who reported earning less than INR 10,000 per month had the same experience.

Similarly, on the caste front, in comparison with 39% women from general caste, 29% women from marginalized communities (30% from OBC, 28% Adivasis and 29% Dalits) said that they too had to undergo physical examination in the absence of a female in the room. This is an interesting trend calling for more analysis of the relative experiences of women of different social-economic status on the healthcare system. It is possible that this could be a result of the poorer communities (marginalized communities such as Dalits and Adivasis) to be dependent on the public health system with a substantially feminized workforce. However, more research needs to be done in this regard.

²⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2801597/>

²¹ [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(20\)30053-5/fulltext#seccesectitle0021](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(20)30053-5/fulltext#seccesectitle0021)

²² <https://www.newindianexpress.com/states/tamil-nadu/2018/sep/24/woman-alleges-doctor-molested-her-in-the-guise-of-physical-exam-1876294.html>

²³ <https://www.newindianexpress.com/states/tamil-nadu/2018/sep/24/woman-alleges-doctor-molested-her-in-the-guise-of-physical-exam-1876294.html>

Right to Information, Informed Consent and Second Opinion

Right to information

Provision of PRC-

'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'.

This right is in line with [The Consumer Protection Act 2019²⁴](#), MCI Code of Ethics and [the Annexure-8 of Standards for Hospital level 1](#) by National Clinical Establishments Council set up as per Clinical Establishment Act 2010.

Question asked in the survey

You went to the doctor and explained your condition. Doctor simply wrote the prescription/treatment or asked you to get tests/investigations done without explaining you about your disease, nature and/or cause of illness.

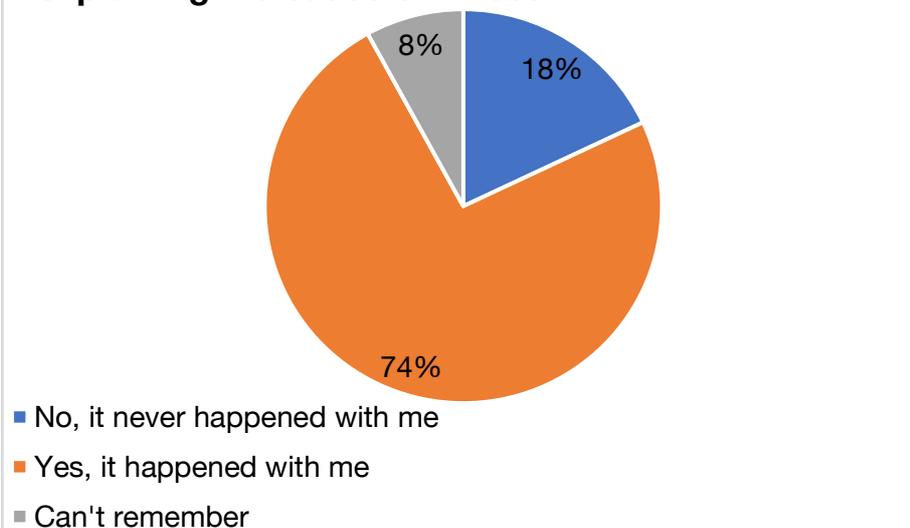
- Yes, it happened with me
- No, it never happened with me
- Can't remember

74% of Patients did not get explanation about their condition of illness from their doctors

74% people said that when they went to the doctor and explained their condition to them, the doctor simply wrote a prescription, prescribed treatment or asked them to get tests/investigations done without explaining their disease, nature and/or cause of illness.

²⁴ <https://egazette.nic.in/WriteReadData/2019/210422.pdf>

Doctor wrote the prescription or investigations to be done without explaining the cause of illness



This violation of patients' right to information is rampant in both rural and urban areas. 75% and 74% of respondents living in rural and urban areas respectively were not explained anything about their condition or illness by the doctor.

Rates of violations were high across the board for all groups; indeed, they were reported to be higher for those who were richer (74% for those earning between INR 1-2 lakhs, compared to 68% for those under INR 10,000 per month), came from a higher caste (80% for the general category, compared to 75% for Adivasis) or were better educated (75% for postgraduates, compared with 54% who were uneducated). This is probably a reflection of different expectations that social status brings into the engagement with medical professionals. It also mirrors the anticipated higher levels of awareness of patients' rights in these groups. Reporting is presumably higher among the more aware, educated patients who are better aware of their rights and can pinpoint violations.

[Studies](#)²⁵ have shown that access to information about patients' illness and treatment is linked to patient satisfaction (Goel, 2014). According to one such [study](#)²⁶, two aspects of care which rank most highly in terms of importance by patients were 'the information and explanation given' and the 'doctor's attitude' (Souter, 1998). In rural India, cases of 'forced sterilisation' and 'hysterectomy' among women are a result of patients being provided incomplete information by the providers, often to meet targets in public sector and for profits in private sector. In India, one of the major barriers to implementation of medical ethics is the information asymmetry between patients and healthcare providers which is more likely to be unequal for the poor and marginalized.

The failure to seek informed consent while providing care is rampant in India. Women, transgender people, minority religious groups and marginalized caste groups are denied complete information about treatment. This leads to clear cut breach in right to informed consent and bodily autonomy.

²⁵ <https://www.omicsonline.org/open-access/predictors-of-patient-satisfaction-in-three-tiers-of-health-care-facilities-of-north-india-2161-0711.S2-002.php?aid=24810>

²⁶ <https://www.ncbi.nlm.nih.gov/pubmed/9740434>

[Evidence](#)²⁷ shows that physicians in India have always held disproportionate power over their patients, mostly by virtue of their class, caste and gender as a majority of physicians in India belong to general castes, and are predominantly males. This leads to skewed power dynamics among patients and doctors both in public and private sector. This translates into widespread violation of patients' right to information.

In 2019, [news](#)²⁸ surfaced from the Beed district in Maharashtra's Marathwada region reporting high rate of hysterectomies among women, primarily among those who migrate to neighbouring districts to work as sugarcane cutters. Civil rights organizations allege that the hysterectomy rate in Beed was 14 times that of Maharashtra or the country. An [expert committee](#)²⁹, was set up under the guidance of the deputy chairman of the Maharashtra Legislative Council, which looked into the social and medical factors surrounding the hysterectomies in Beed. It found that as many as 13,500 women had undergone hysterectomy in the past 15 years in Beed.

Most stories were similar. Many women suffered from reproductive health issues like vaginal discharge and extreme pain during menstrual period. This would affect their work and would lead to significant loss of wages. They were advised by local doctors to undergo the removal of the uterus or hysterectomy to get rid of the problem. However, they were never given adequate information about the side-effects and the complication of the surgery (such as hormonal imbalance, calcium deficiency and constant bodyache etc.) A large share of the [women](#)³⁰ who have undergone hysterectomies were under 30 and did not need the surgery, ignoring the considerable side effects that come with the operation.

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 and that consent forms with protocol for seeking informed consent are provided for patients in an obligatory manner'.

[Article 21](#)³¹ of India's constitution covers the right to live with human dignity. Any act which damages, injures, or interferes with the use of any limb or faculty of a person, either permanently or temporarily is deemed to be inhibitory of Article 21 (Francis Coralie Mullin v. The Administrator, Union Territory

²⁷ <http://www.mfcindia.org/main/bgpapers/bgpapers2014/am/bgpap2014a.pdf>

²⁸ <https://www.thehindu.com/news/national/other-states/in-beed-a-harvest-of-crushed-hopes/article28969404.ece>

²⁹ <https://www.hindustantimes.com/pune-news/committee-report-states-13-500-cases-of-hysterectomy-in-beed-district-in-last-15-years/story-KtKYkE9QGcgCZCbn9wzPeO.html>

³⁰ <https://www.downtoearth.org.in/news/health/-they-stole-my-womb-doctors-mislead-thousands-of-women-to-get-their-uterus-removed-69579>

³¹ <https://indiankanoon.org/doc/1199182/>

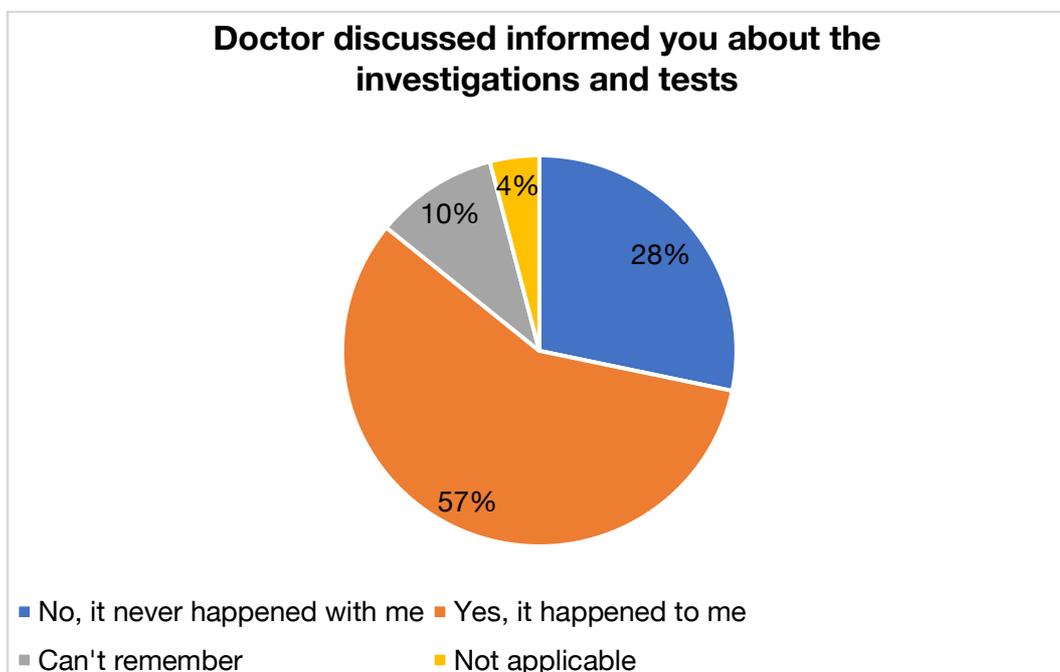
Delhi³²). [Drugs and Cosmetic Act \(1940\), Rules \(2016\)](#)³³ on Informed Consent also make it an obligation for healthcare professionals to seek informed consent from patients.

Question from the survey (asked in the form of a multiple choice grid)

While you/your close relative were receiving treatment for a serious illness, the doctor did not discuss with you or inform you about :

- The investigations or tests he/she wants to do
- Probable complications that may occur during the course of treatment/procedure
- Any other alternative treatment options or modality available apart from the treatment you or your close relative are/going to receive

57% of respondents did not receive information about investigations & 55% not informed about probable complications.



More than half of the respondents (57%) reported not receiving any information about investigations and tests done. 55% of respondents reported that they were not informed about probable complications that can occur during the course of treatment for a serious illness for themselves or a close relative.

48% respondents said that they were denied information about alternative treatment options or modality apart from the treatment that was being provided to them or their close relatives. This has been seen across social classes and was prevalent in both rural and urban areas.

When it comes to education, 17%-18% of those who completed 10th standard experienced absence of informed consent, compared to 28% of those who were educated below the 10th standard or 25%

³² <https://indiankanoon.org/doc/78536/>

³³ https://cdsco.gov.in/opencms/export/sites/CDSCO_WEB/Pdf-documents/acts_rules/2016DrugsandCosmeticsAct1940Rules1945.pdf

who classified themselves as uneducated. This is in line with existing research where doctors appear to have more meaningful discussions on treatment options with those who are more educated.

This violates the principle of personal liberty and principle of autonomy which is enshrined in the Article 21 of the Indian Constitution. Doctors are expected to seek informed consent and provide proper information under the Section 13 of the [Indian Contract Act \(1872\)](#)³⁴. However, in India, in most cases, 'implied consent' and 'proxy consent' is taken and hence, denying the right to comprehensible information about diagnosis, investigations, treatment and probable complications or informed consent. At the same time, further research would be beneficial to understand what level of information was deemed to be adequate for patients of different educational qualifications and social-economic status considered to feel adequately informed. Expectations may vary with educational and class status.

Instances of inadequate informed consent were frequently reported in the media during the pandemic. One [report](#)³⁵ from March 2020 is of Sreenivas (name changed), a 30-year-old nurse, who heard that the Mumbai government hospital where he worked was giving resident doctors a course of the anti-malarial drug hydroxychloroquine (HCQ).

The hospital said it was following [a one-page advisory](#)³⁶ from India's apex medical research agency — the Indian Council of Medical Research (ICMR) to administer the drug as prophylaxis for COVID-19. By then, the number of people confirmed to have COVID-19 in India had begun to grow fast in Mumbai. Major shortages of HCQ has been declared by hospitals, so several nurses purchased HCQ from medical stores instead of waiting for the hospital to replenish its stock.

After all, ICMR had recommended the drug: that must mean HCQ worked, Sreenivas said. However, no one from the hospital's administration had said anything about the drug being experimental — that it could be useless in preventing the disease. The hospital also didn't talk about [the drug's side-effects](#)³⁷ either, from milder ones like nausea and stomach ache to severe ones like hypoglycaemia and heart-rhythm abnormalities. He added that his experience is no different from that of thousands of healthcare workers across India, who were told by their hospitals to take HCQ.

The push to take HCQ may have been in line with the ICMR's advisory, which says a doctor must prescribe the drug, but did not negate the need for a discussion to ensure informed consent. Everyone consuming a drug must do so only after fully understanding its benefits and harm.

³⁴ <https://legislative.gov.in/sites/default/files/A1872-09.pdf>

³⁵ <https://thewire.in/health/experimental-drugs-india-covid-19>

³⁶ https://www.icmr.gov.in/pdf/covid/techdoc/HCQ_Recommendation_22March_final_MM_V2.pdf

³⁷ <https://science.thewire.in/health/coronavirus-covid-19-hydroxychloroquine-icmr-guidelines-long-qt-syndrome/>

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 as per the charter.

The right to second opinion is strengthened by [The Consumer Protection Act, 2019](#)³⁸. As well as in the Annexure 8 of standards for Hospital level 1 by National Clinical Establishments Council set up as per [Clinical Establishment Act 2010](#)³⁹; also given in [The Consumer Protection Act, 1986](#)⁴⁰.

Question asked in the survey (to those respondents who themselves/their relatives had been hospitalised in the past ten years)

The doctor did not allow you to seek a second opinion?

- Yes, it happened to me
- No, it never happened with me
- Can't remember

One-third of respondents stated feel they were not allow for a second opinion

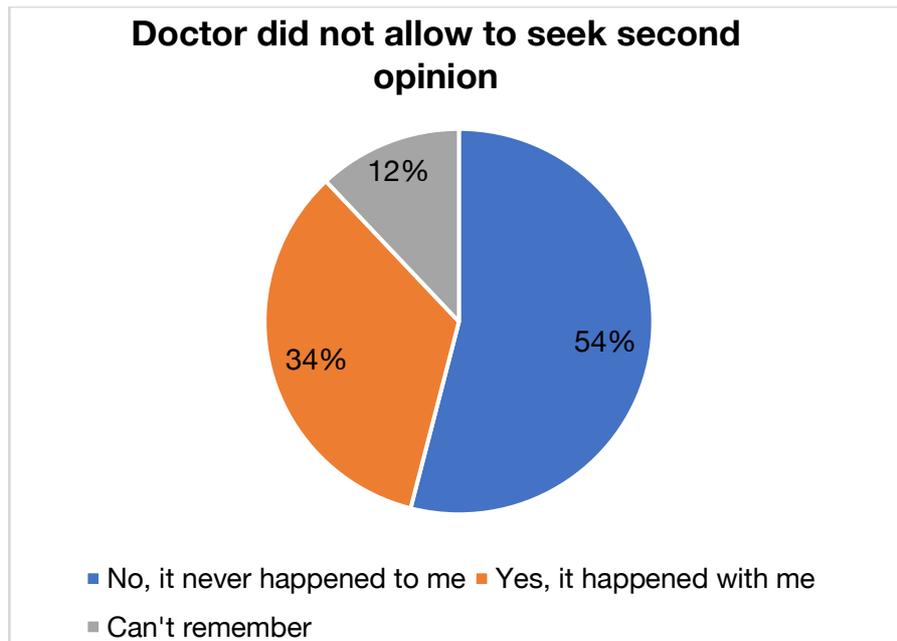
One-third of the respondents who were either themselves or had their relatives hospitalised in the past ten years, stated that their doctor did not allow them to seek a second opinion.

30% of those earning INR 100,001 to INR 200,000 per month reported facing denial of the right to take a second opinion regarding their test/treatment, as contrasted with 42% of those earning less than INR 10,000 per month. More of those who are poor found themselves denied the right to have a second opinion. Being denied the right to seeking a second opinion was broadly consistent across different genders and locations (urban vs rural).

³⁸ <https://egazette.nic.in/WriteReadData/2019/210422.pdf>

³⁹ <http://clinicalestablishments.gov.in/WriteReadData/2591.pdf>

⁴⁰ http://ncdrc.nic.in/bare_acts/Consumer%20Protection%20Act-1986.html



Many [studies](#)⁴¹ have shown that a large number of patients 'believe that physicians suggest unnecessary diagnostic and treatment procedures, particularly in the private sector. A number of [studies](#)⁴² have reported that misdiagnosis of various health conditions remains a major challenge in India. This could lead to delay in receiving appropriate treatment. In conditions like cancer, hypertension, and diabetes delay in diagnosis and hence receiving treatment can heavily jeopardise patient's health outcome (Ramchandran, 2016).

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 right to non-discrimination is highlighted in the Annexure-8 of [Standards for Hospital level 1 by National Clinical Establishments Council](#)⁴³ set up as per Clinical Establishment Act 2010.

⁴¹ <https://health.economicstimes.indiatimes.com/health-files/doctors-dilemma-and-patients-right-to-second-medical-opinion/676>

⁴² https://www.jcdr.net/article_fulltext.asp?id=8823

⁴³ <http://clinicalestablishments.gov.in/WriteReadData/147.pdf>

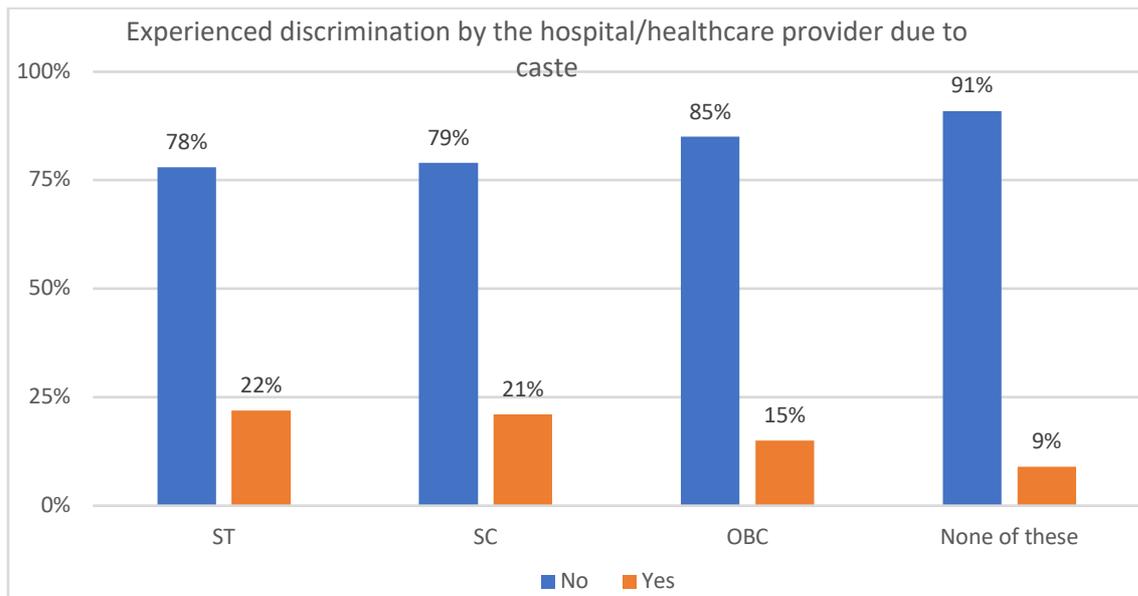
Question asked in the survey (Multiple choice grid)

Have you experienced discrimination from the hospital/healthcare professional?

- Due to your health condition or illness?
- Due to your religion?
- Due to your caste?
- Due to your age?
- Due to your gender?
- Due to your sexual orientation?
- Due to language you speak?
- Due to your economic status?
- Due to your HIV Status?

33% of Muslim respondents felt discriminated on grounds of religion; over 20% Adivasis and Dalits discriminated due to their caste

In the survey, a third of Muslim respondents reported that they felt being discriminated against on the grounds of their religion in a hospital or by a healthcare professional.



At the same time, a significant share of Dalits and Adivasis respondents have experienced caste based discrimination. 22% people belonging to the Scheduled Tribes (ST) and 21% belonging to the Scheduled Castes (SC) said that they have been discriminated by healthcare providers or in a hospital setting due to their tribal identity/caste. 15% people belonging to Other Backward Class (OBC) said they felt discriminated because of their caste. The survey also showed that 28% people from Karnataka, 24% from Gujarat, 21% people in Maharashtra, and 20% people in Uttar Pradesh, Bihar, Jharkhand and Rajasthan reported facing discrimination by healthcare professionals due to their language, which reflects on anti-migration sentiments of healthcare professionals.

These findings are consistent with studies looking at the experiences of Dalits, Adivasis and religious minorities in the health system. Health outcomes are consistently [lower for Dalits⁴⁴](#), Adivasis and Muslim minority communities.

A [study⁴⁵](#) exploring religion-based discrimination in health facilities in Mumbai showed that many Muslim women felt that there was a difference in the way the staff at the public health facilities spoke to them when compared to how they spoke to people belonging to their caste or religion (Khanday, 2020). The pandemic has further deepened the systemic islamophobia within country's health system.

A series of events that happened in Nizamuddin with the gathering of people from the Muslim organisation Tablighi Jamaat, was given a communal turn. This further fuelled the Islamophobia which has become rampant in the country. [Reports⁴⁶](#) of hospitals refusing to admit Muslim patients became common. This was [noted⁴⁷](#) by the Supreme Court later in the pandemic. In response to the [inquiry⁴⁸](#) made to the Centre by Supreme Court in April 2021 the MoHFW [formulated⁴⁹](#) and later revised the 'national policy for admission of Covid patients to various categories of Covid facilities.' This seeks to ensure 'prompt, effective and comprehensive treatment' of COVID-19 patients (PIB, 2021). In its directive, the Centre mandated the following guidelines to be adhered to by all hospitals under the Central govt, State Govts and UT administrations, which included private hospitals handling COVID-19 cases. This included "hospitals can't refuse service, including oxygen or essential drugs, to any patient on 'any count' including religion, caste, and ability to pay or migrant status".

The findings of the survey are similar to those reported by the Human Rights Watch (HRW) published in 2001. The report said that people belonging to the Scheduled Castes are frequently denied admission in hospitals. Similarly, [Untouchability in Rural India⁵⁰](#) survey found that Dalit communities were denied entry into private health centres or clinics in 21% of villages. A [study⁵¹](#) conducted in Attapadi, Kerala showed that Adivasi communities experienced discrimination at the hand of healthcare professionals. They believed that non-tribal healthcare professionals spoke to them in a

⁴⁴ <https://www.oxfamindia.org/knowledgehub/workingpaper/inequality-report-2021-indias-unequal-healthcare-story>

⁴⁵

https://www.researchgate.net/publication/308356827_Exploring_Religion_based_Discrimination_in_Health_Facilities_in_Mumbai

⁴⁶ <https://www.thenewsminute.com/article/religious-discrimination-hospital-karimnagar-allegedly-refused-treat-muslims-122500>

⁴⁷ <https://www.livehindustan.com/national/story-news-shown-in-section-of-media-bears-communal-tone-which-could-bring-bad-name-to-country-observes-sc-on-plea-of-jamiat-in-tablighi-case-4494462.html>

⁴⁸ <https://www.livewlaw.in/top-stories/supreme-court-covid19-national-policy-admission-guidelines-for-all-hospitals-173420>

⁴⁹ <https://www.livewlaw.in/top-stories/supreme-court-covid19-national-policy-admission-guidelines-for-all-hospitals-173420>

⁵⁰ <https://www.jstor.org/stable/44259050>

⁵¹ <https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-020-01216-1>

condescending manner and looked down upon them (George, 2020). Several [reports](#)⁵² have shown that during the time of the first lockdown in the country, migrant workers (mainly those belonging to SCT, ST, OBC group) returning to their home states, faced discrimination at the hand of the community and healthcare providers alike.

In recent months, several reports have emerged on discrimination against transgender patients by the medical community. While revealing the findings of the [study](#)⁵³ a transgender narrated her story of discrimination. Three years ago, an HIV-positive transwoman from Kolkata, visited a government hospital for an HIV test. She said the doctor and her assistant laughed at her, saying, “*Agar yeh sab bimari tumko nahin hoga toh aur kisko hoga?*” (If you people are not infected with such diseases, then who is?). Discrimination against transgender people gets worse if they are HIV-positive. “If you are a transgender with HIV, then you face double the discrimination,” In medical ward of hospital, male patients are uncomfortable with our presence or pass sexual comments, and females do not want us around them either. Most doctors, knowingly or unknowingly, do not ask them which ward, male or female, they might prefer.

Right to Choose Source of Obtaining Medicine 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 obtaining medicines or tests 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 obtain this investigation from any registered diagnostic centre/laboratory having qualified personnel and accredited by [National Accreditation Board for Laboratories \(NABL\)](#)⁵⁴. 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 way adversely influence the care being provided by the treating physician or hospital.’

This is in congruence with various judgments by the National Consumer Dispute Redressal Commission (CDRC) and [The Consumer Protection Act, 2019](#)⁵⁵ The MCI's [code of ethics regulations](#)⁵⁶ says in clause 6.4.2 under ‘unethical acts’ that a physician shall not offer or receive any ‘commission’ or ‘bonus’ or ‘split’ any fee for referring a patient or recommending a diagnostic test. However, the code is hardly enforceable in the private sector. Apart from a matter of ethics, the issue is also a matter of patients’

⁵² https://www.business-standard.com/article/current-affairs/for-millions-of-migrant-workers-covid-19-brought-caste-discrimination-back-120082100542_1.html

⁵³ <https://scroll.in/pulse/856285/transphobia-among-indian-doctors-study-aims-to-uncover-reasons-for-bias-against-transgender-people>

⁵⁴ <https://nabl-india.org/about-nabl/about-nabl-2/>

⁵⁵ <https://egazette.nic.in/WriteReadData/2019/210422.pdf>

⁵⁶

<https://wbconsumers.gov.in/writereaddata/ACT%2520&%2520RULES/Relevant%2520Act%2520&%2520Rules/Code%2520of%2520Medical%2520Ethics%2520Regulations.pdf>

rights to choose which can be covered under the Clinical Establishment Act. States like Chhattisgarh have a provision to effectively deal with it in terms of Patients' Rights Charter ('Obligation to Secure Patients' Convenience') under State's [CEA](#)⁵⁷. It must be noted that only 10 states and 6 UTs have adopted the Clinical Establishments Act as per latest (2020) [information](#)⁵⁸ from the website of Directorate General of Health Services (DGHS).

Question asked in the survey

The doctor asked to get tests/diagnostics done from one particular place ONLY

- Yes, it happened with me
- No, it never happened with me
- Can't remember

8 in 10 respondents reported being asked to get tests/diagnostics services from one particular place only.

This trend remained fairly high for all demographics, with over 70% women, men, Dalits, Adivasis, and even respondents across different income groups, all reporting that they were asked to get tests done from a particular place only.



This points to the ubiquitous nature of 'referral fee' in India. [Referral fee practice and commissioning](#)⁵⁹ is the norm rather than the exception and applies to all healthcare providers, radiology centres, pathology laboratories and hospitals. The practice is in violation of patients' rights to referral and transfer without perverse commercial influences. It leads to excessive expenditure by patients as they

⁵⁷

https://www.indiacode.nic.in/bitstream/123456789/12781/1/cg_upcharyagrih_%26_rogopchar_sambandhi_sthapnaye_anugy_apan_adhinyam%2c_2010_no._23_of_2010_date_15.09.2010.pdf

⁵⁸ https://dghs.gov.in/content/1361_3_NationalCouncilClinicalEstablishments.aspx

⁵⁹ https://main.sci.gov.in/supremecourt/2020/8430/8430_2020_34_1501_25340_Judgement_05-Jan-2021.pdf

are denied the choice of a more affordable option. While referrals are also done to cross-check the accuracy of investigations/tests, in most instances they come with a referral fee.

This practice can take [many forms](#)⁶⁰. Dr Akash Rajpal of Ekohealth said in a media interview “a doctor may be ‘rewarded’ for referring a patient to another doctor, diagnostic facility, nursing home or hospital. Cash, cheques (in the guise of professional fee), expensive gifts and dinners, sponsorship to attend conferences, etc., are some of the common rewards. Sometimes, this gratitude is expressed differently. Reciprocal referral amongst doctors is commonplace. For example, a general surgeon and a cardiologist could agree to send each other patients from their respective specialties. It would, of course, be justified if each of them felt that the other was the best in that field, but not if they were simply scratching each other’s backs”. Commissions paid to doctors add significantly to the cost of treatment when catastrophic health expenses make a significant contribution to the fact that 39 million are pushed into poverty each year. Estimates of cost mark-up vary from 20% based on the estimate published in the [Indian Journal of Medical Ethics](#)⁶¹ or higher.

⁶⁰ <https://scroll.in/pulse/817908/the-anatomy-of-cut-practice-an-inside-story-of-unethical-medical-commissions>

⁶¹ <https://www.dailyo.in/politics/the-ethical-doctor-medicine-corruption-cut-practice-referral-diagnosis-hospitals/story/1/13219.html>

Right to Transparency in Rates and Care According to Prescribed Rates

'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 itemised 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.'

Failure to provide information about the rates of each type of service provided by hospital is against the MCI Code of Ethics section 1.8 regarding [Payment of Professional Services](#)⁶², Section 9(i) and 9(ii) of the [Clinical establishments \(Central Government\) Rules, 2012](#)⁶³, [Drug Price Control Order \(DPCO\) Act, 2013](#)⁶⁴ and the [Consumer Protection Act, 2019](#).⁶⁵

Question asked in the survey:

The healthcare facility/hospital did not provide you with

- An estimated cost of treatment/procedure before the start of treatment/procedure
- Bill with detailed cost of each item/service used by you/your close relative during the treatment (a bill that is paid while still admitted or at time of discharge)
- With copies of case papers, patient records, investigation reports, etc. for treatment/procedures/tests done by the hospital

This question is asked of respondents who themselves/their relatives had been hospitalised in the past 10 years; it was asked in the form of a multiple choice grid.

58% respondents were not provided with estimated cost of treatment; 31% were denied case papers and other documents even after requesting for the same.

58% respondents said that they were not provided with an estimated cost of treatment/procedure before the start of treatment/procedure when they or their close relatives were hospitalised in the past 10 years. 31% respondents reported being denied case papers, patient records, investigation reports for treatment/procedure by the hospital even after requesting for the same.

⁶²

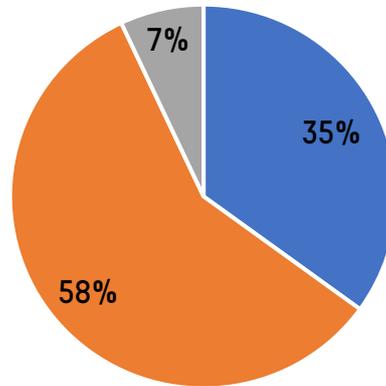
<https://wbconsumers.gov.in/writereaddata/ACT%2520&%2520RULES/Relevant%2520Act%2520&%2520Rules/Code%2520of%2520Medical%2520Ethics%2520Regulations.pdf>

⁶³ <http://clinicalestablishments.gov.in/WriteReadData/386.pdf>

⁶⁴ <https://lexlife.in/2020/04/21/drugs-price-control-order-dpco/>

⁶⁵ <https://egazette.nic.in/WriteReadData/2019/210422.pdf>

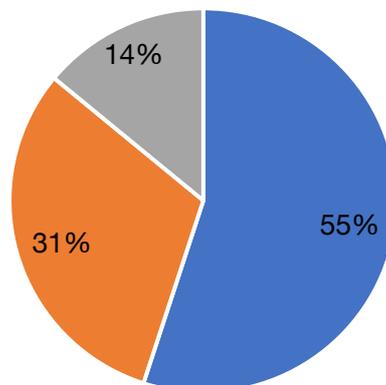
Doctor did not give information about estimated costs for treatment procedure before hand



■ No, it never happened with me ■ Yes, it happened with me
■ Don't remember

The failure to provide detailed cost of treatment was fairly uniform across the board holding for rural (58%) and urban areas (59%) and irrespective of the family income, although the rates were somewhat higher for those who were poorer and more disadvantaged. 53% of respondents earning less than INR 50,000 per month said that they didn't receive case papers/investigation reports by the hospital. Over 59% Dalit respondents reported the same.

Hospital denied diagnosis and treatment related records even after asking for it



■ No, it never happened with me ■ Yes, it happened with me
■ Can't remember

Such [practices](#)⁶⁶ existed even prior to the pandemic, however, the situation has become particularly grave during the COVID-19 pandemic. This forced many states to take steps to curb malpractices by the private sector. Thus, in October 2020, Telangana used their Clinical Establishments Act to punish hospitals that failed to provide detailed bill to the patients and show cause notices were issued to 105 hospitals guilty of overcharging.

In Andhra Pradesh, 16 hospitals were [fined](#)⁶⁷ amounts ranging INR 200,000 to 600,000 for overcharging COVID-19 patients; 46 hospitals were booked for violating government rules and regulations, while another 50 hospitals were issued show cause notices in May 2021.

In Maharashtra, Municipal Corporations in many cities like Pune and Pimpri Chinchwad established [committees](#)⁶⁸ to audit bills issued by private hospitals; most of these were not itemised. In the audits conducted for 75 cases, the committee found that the bills were inflated by INR 50 Lakh.

States like Chhattisgarh [appointed](#)⁶⁹ Nodal Officers for private hospitals (including hospitals empanelled with PMJAY and state insurance scheme 'Khubchand Baghel Swasthya Sahayata Yojana') in each district. These officers were responsible for coordination, facilitation and overseeing of compliance to government order related to price-capping. In Karnataka, High Court had to [intervene](#)⁷⁰ as despite capping of treatment charges, unlike the first wave, enforcement of the guidelines were weak in the second wave. The High Court ordered the state to expeditiously create a mechanism for grievance redressal over allegations of some private hospitals overcharging hapless patients for COVID-19 treatment.

The [second advisory on Right to Health](#)⁷¹ issued by NHRC, dated 4 May 2021 advocated for capping of treatment charges including charges of oxygen cylinders and essential medicines, as well as following Standard Treatment Guidelines to avoid unnecessary use of Covid related medications, irrational prescription of expensive medicines, especially by the private sector (NHRC, 2021).

⁶⁶ https://www.business-standard.com/article/pti-stories/fortis-overcharged-dengue-patient-s-family-as-high-as-1700-117121501441_1.html

⁶⁷ <https://indianexpress.com/article/india/andhra-pradesh-telangana-crack-down-on-hospitals-overcharging-covid-patients-7341668/>

⁶⁸ <https://timesofindia.indiatimes.com/city/pune/pvt-hospitals-inflated-bills-by-rs-50l-pmc-pcmc-audit/articleshow/77751452.cms>

⁶⁹ <https://www.bhaskar.com/local/chhattisgarh/bhilai/news/nodal-officers-appointed-for-kovid-hospital-in-durg-district-private-hospitals-complain-if-more-bills-or-any-problem-direct-helpline-number-issued-128450576.html>

⁷⁰ <https://www.thenewsminute.com/article/karnataka-hc-asks-govt-help-covid-19-patients-overcharged-pvt-hospitals-153177>

⁷¹ https://nhrc.nic.in/sites/default/files/Human%20Rights%20Advisory%20on%20Right%20to%20Health_2021_May.pdf

Media reports have long appeared regarding inadequate transparency in billing and overcharging in big corporate hospitals. Dinesh was one of many [people](#)⁷² overcharged at an hospital. He was admitted to Max Hospital Saket in May 2020. Dinesh was slapped with a bill of INR 410,000 at the time of his discharge. The hospital charged INR 80,000 for PPE kits for nine days. It is alleged that for the first two days they charged INR 4,300 and then for the remaining seven days, they charged INR 8,900 for each kit which was being used. The hospital also reported to have charged INR 55,000 for doctors' visits; the summary of the bill listed 22 doctors' visits. However, according to the patient, the doctor only visited him five to seven times. As per the patient's relatives, the patient tested negative on day six, but he was kept in the hospital for four more days. In its defense, the hospital management had responded saying that they charged the overall consumption of PPEs during a 24-hour cycle, which is approximately nine PPEs per day per person in the ICU. The PPEs are charged at approximately INR 1,200 per PPE per day and 'are in line with the costs incurred by the hospital in sourcing the PPEs'; they did not furnish any proof for the same.

⁷² <https://www.indiatoday.in/india/story/dehi-max-hospital-saket-deny-overcharge-allegation-coronavirus-patient-recovery-1681677-2020-05-25>

Right to Take Discharge of Patient or Receive Body of Deceased from the 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 non-payment/dispute regarding payment of hospital charges against wishes of the caretakers.'

The act of denying to release the dead bodies is in violation of the prohibition of wrongful confinement under [Section 340-342⁷³](#) of the Indian Penal Code, and many other statements of the Mumbai High Court.

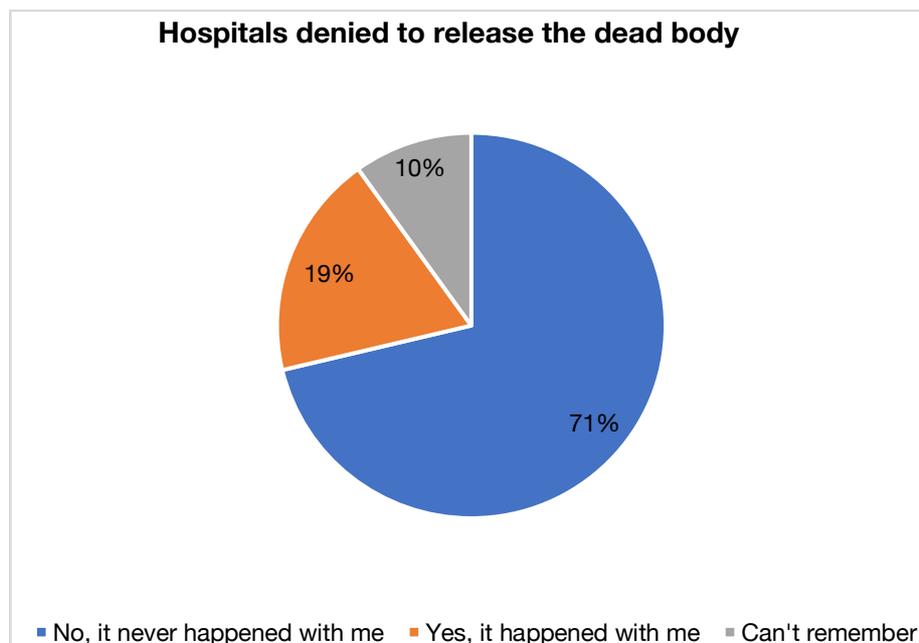
Question asked in the survey

The hospital denied release of dead body

- Yes, it happened with me
- No, it never happened with me
- Can't remember

19% people said they were denied release of dead body by the hospital.

19% of respondents said they were denied release of dead body by the hospital. However, in practical terms, this figure is likely to be much higher because not all respondents who were hospitalised experienced the death of a close relative after the hospitalisation.



⁷³ <https://www.aaptaxlaw.com/IPC/section-340-342-ipc-wrongful-confinement-punishment-sec-343-348-of-indian-penal-code-1860.html>

Nearly equal numbers of people in rural (19%) and urban (18%) areas experienced the denial of release of dead body.

While this inhuman practice was experienced by people from all strata of the society, the heaviest brunt was borne by the poorest — 23% of those earning less than INR 10,000 had faced the issue of denial of release of dead body, unlike 15% of those earning over a lakh per month.

20% men and 11% women responded in the affirmative, suggesting men were more likely to be targeted. 29% of respondents in Jharkhand and 21% in Odisha, Uttar Pradesh and West Bengal, 20% from Maharashtra and 16% people Gujarat were denied dead body of the deceased by the hospital.

It must be highlighted that while the pandemic saw multiple instances of the dead body being held back by private hospitals, this issue persisted before the pandemic as well. Further, the survey reflects the experiences of people with hospitals over the past ten years and not just during the pandemic.

The media reported many incidents of hospitals refusing to release dead body of those who died during the pandemic. Thus, a [private hospital](#)⁷⁴ in rural part of Pune district of Maharashtra, refused to release the body of a 50 years old patient who died due to COVID-19, as his family was unable to pay the medical bill of INR 70,000. The body was released after the intervention by a Member of Parliament who took the issue to the Chief Minister's office; as a result of the intervention by the district administration the bill had waived and the dead body has released. In [Vapi, Gujarat](#)⁷⁵ the private hospital management asked the family to keep their car as a guarantee to get the body of the patient who died due to COVID-19. The family filed a case against the private hospital; following a police investigation, the dead body and the car were handed over to the family.

⁷⁴ <https://indianexpress.com/article/cities/pune/hospital-refuses-to-release-covid-19-victims-body-for-three-days-relents-after-mp-intervenues-7301717/>

⁷⁵ <https://zeenews.india.com/india/hospital-denies-to-hand-over-covid-patients-body-seizes-family-car-over-pending-bills-in-this-city-2354979.html>

Conclusion and Recommendations

The survey shows that the basic rights of patients 'in India are being routinely denied in healthcare facilities. Skewed power dynamics with respect to class, caste, religion, and gender between the healthcare providers and patients, have deepened existing structural inequalities in the health system. However, as this survey shows, India's middle class is also not exempt from extreme violations. The COVID-19 pandemic has only further thrown into sharp relief the extent of vulnerability of Indian patients to the violation of their rights, especially, for the private sector.

A formal adoption of Patients 'Rights Charter by Indian States will be a critical step in ensuring enforcement of these rights and proving Indian citizens with mechanisms for redress when their rights are violated.

MOHFW should:-

- Set up a mechanism to review the present status of adoption of the Patient's Rights Charter in all the States and UTs and order those who have not adopted the PRC yet, to do so;
- Include the PRC in the Clinical Establishment Act given that it offers the most robust existing mechanism for regulation of private healthcare systems; doing so would make the existing Act more comprehensive and inclusive in terms of rights and responsibilities of patients;
- Issue a letter to the States and UTs for displaying the Charter in all private and public hospitals in view of the unprecedented crisis induced by the COVID-19 pandemic and particularly, for hospitals empanelled in PMJAY.

National Medical Commission should:-

- Introduce mandatory modules of patients' rights in healthcare curriculum including sensitisation in health equity and social justice.

State and UT governments should:-

- Issue orders to display the PRC in all private and public hospitals irrespective of adoption of CEA. The Health Department in each State/UT should issue guidelines/orders to start displaying the Charter in government hospitals and private hospitals that receive state subsidies in any form or charitable hospitals even in states that do not have the Clinical Establishments Act;
- Ensure grievance redressal mechanisms for patients. The first step is to appoint an internal grievance officer within every clinical establishment i.e. in each public and private hospital. If this officer fails to resolve the problem, it can be escalated to the district registering authority, failing which a patient can approach the state councils and expect resolution within 30 days.

District administrations should:-

- Initiate awareness activities for the communities on the PRC in the form of campaigns where various innovative methods like poster exhibition, *kala jathas*, street plays, competitions among the youth and school children around the issue are organised;
- The role of Civil Society Organisations (CSOs) will be crucial to facilitate the communities around the PRC especially in the context of denial of patients' rights in public and private hospitals. Hence, the state government can engage CSOs in capacity building activities and awareness programmes whereas the CSOs can initiate some activities independently in the form of documentation of denial of cases; facilitating dialogue between decision-makers and communities/patients.

PART 2 Is India's COVID-19 vaccination drive equitable and pro-people?

Key lessons from rapid survey on documenting the experiences of people during the Covid vaccination drive in India

Introduction

The COVID-19 pandemic has devastated families and communities and disrupted societies and economies. It has caused over [5 million deaths](#)⁷⁶ globally and left a disturbing burden of chronic morbidity. The number of [deaths](#)⁷⁷ due to COVID-19 in India stands at around 4.5 Lakh. By some [calculations](#)⁷⁸, life expectancy at birth for men and women declined from 69.5 and 72 years in 2019 to 67.5 and 69.8 years respectively in 2020. While people's vulnerability to infection, severe disease and death has generally been viewed in terms of age and comorbidities, these biological vulnerabilities are exacerbated and shaped by social and economic [inequities](#)⁷⁹ and oppressions of class, caste, ethnicity, disability, sexuality and gender and location among others. It is not without a reason that the COVID-19 pandemic has been referred to as the [inequality virus](#)⁸⁰.

[Vaccines](#)⁸¹ offer the possibility of returning to the pre-pandemic ways of living and working. This, however, is thwarted by a slow and unequal roll out of Covid vaccination. Only 3% of [lower-income countries](#)⁸² have fully vaccinated their citizens, compared to 24% for lower-middle income countries and 66% for high-income countries.

After a slow and delayed start, India is now starting to catch up, even though its immunization rate remains below the global average. Only 26.77% of Indians are fully immunized ([as on 17 Nov 2021](#)⁸³) but this should not by any means detract from the efforts made by India's public health workers to reach over a billion doses administered. This is more than twice than that administered by the United States of America, but is half of the doses administered by China (which has administered 2.36 billion doses)

⁷⁶ <https://www.reuters.com/world/global-covid-19-deaths-hit-5-million-delta-variant-sweeps-world-2021-10-02/>

⁷⁷ <https://www.mygov.in/covid-19>

⁷⁸ <https://timesofindia.indiatimes.com/city/mumbai/mumbai-life-expectancy-dips-by-2-years-amid-pandemic-says-report/articleshow/87213973.cms>

⁷⁹ https://d1ns4ht6ytuzzo.cloudfront.net/oxfamdata/oxfamdatapublic/2021-07/India%2520Inequality%2520Report%25202021_single%2520lo.pdf?nTTJ4toC1_AjHL2eLoVFRJyAAAgTqHqG

⁸⁰ <https://www.oxfam.org/en/research/inequality-virus#:~:text=The%20virus%20has%20exposed%2C%20fed,individuals%20and%20corporations%20%E2%80%93%20are%20thriving>.

⁸¹ <https://www.who.int/westernpacific/news/commentaries/detail-hq/covid-19-vaccines-offer-hope-but-other-prevention-measures-must-continue>

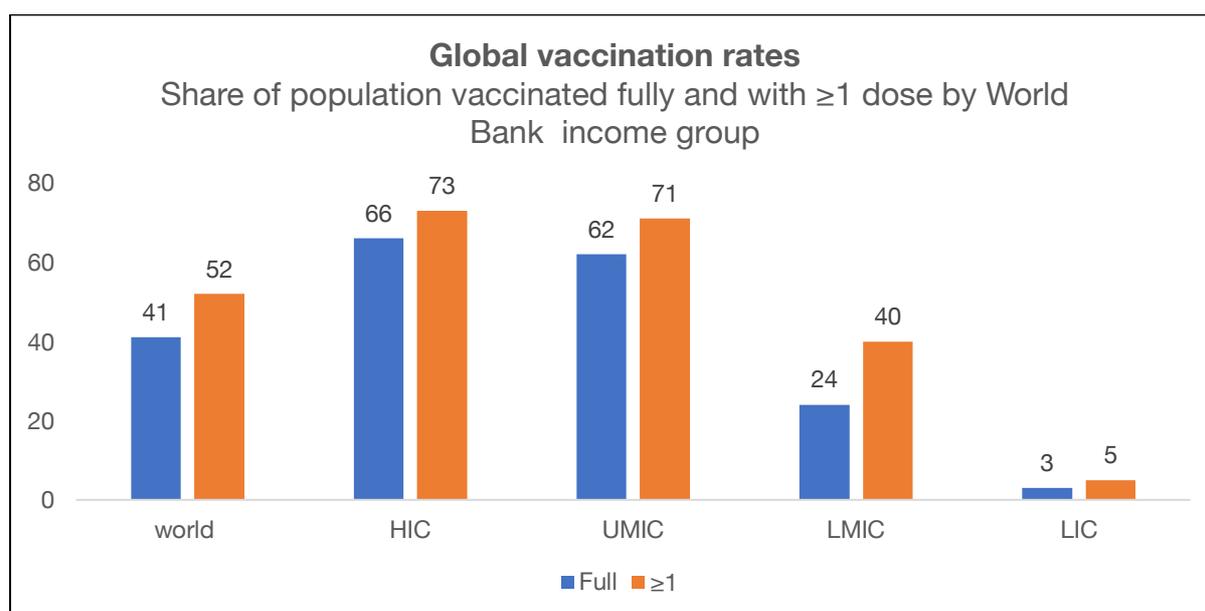
⁸² <https://pandem-ic.com/new-estimates-of-global-vaccination-progress/>

⁸³ <https://ourworldindata.org/covid-vaccinations>

History of India's COVID-19 vaccination drive

India launched its vaccination programme on 16 January 2021. In the first phase of the programme, the vaccine was administered to 30 million healthcare providers. This was followed by vaccination of people over the age of 60 and people between the ages of 45 and 60 with one or more comorbidities based on the protocol set by the MoHFW.

From March 2021, registration for vaccines began exclusively via the Aarogya Setu app and Co-WIN (Covid Vaccine Intelligence Work) website. This led to the exclusion of a large number of people who did not have access to digital devices, internet services, lacked Aadhar cards and/or did not know how to operate the devices.



Source⁸⁴- World Bank

In April 2021, the government announced a '[liberalized and accelerated](#)'⁸⁵ phase-3 strategy of COVID-19 vaccination in which the government stepped away from its commitment to free universal vaccination with distribution based on need and risk and announced that everyone over the age of 18 was eligible for vaccination. On 7 June 2021, the Prime Minister Narendra Modi announced several changes in India's vaccination policy, once again committing to centralised procurement of the vaccines, a price cap on sale of vaccines in private hospitals and their free distribution in the public sector to all above 18 years from 21 June 2021. In the subsequent weeks, as vaccine production was ramped up, At the end of [September 2021](#)⁸⁶, the average number of operational vaccination centres increased from 32,552 to 65,780 including allowing [door to door vaccination](#)⁸⁷; this helped vaccination rates to pick up. India reached the 100 crore vaccine dose milestone on 21 October 2021.

⁸⁴ <https://pandem-ic.com/new-estimates-of-global-vaccination-progress/>

⁸⁵ [Press Information Bureau \(pib.gov.in\)](https://pib.gov.in)

⁸⁶ [We have more vaccination sites now; we need to boost vaccinations too \(livemint.com\)](https://www.livemint.com)

⁸⁷ <https://www.timesnownews.com/india/article/door-to-door-covid-19-vaccination-allowed-in-india-guidelines-issued-dr-vk-paul/815797>

. On the occasion of this milestone, Prime Minister Narendra Modi said *“The country started the campaign of ‘Free vaccine, vaccine for everyone,’ by taking everyone along... There was only one mantra that if the disease does not discriminate, then there cannot be any discrimination in the vaccination. Therefore, it was ensured that the VIP culture did not dominate the vaccination campaign.” – Modi*

This survey was conducted to learn about people's experiences with vaccination, to understand the extent to which the experience of vaccination was equitable and to draw some suggestions on how vaccination experience can be improved. Hence, the study seeks to tease out some lessons emerging from the pandemic, especially, keeping in view the possibility of a third wave of COVID-19.

It is critical to remember that the government is committed to the 31 December deadline to get all Indians fully vaccinated i.e. with two doses. However, the latest predictions from the International Monetary Fund is that only [40% of Indians⁸⁸](#) would be immunized by this deadline. Which means there is time to ensure universal immunization.

⁸⁸ <https://www.imf.org/en/Publications/CR/Issues/2021/10/14/India-2021-Article-IV-Consultation-Press-Release-Staff-Report-and-Statement-by-the-492841>

Methodology and Limitations

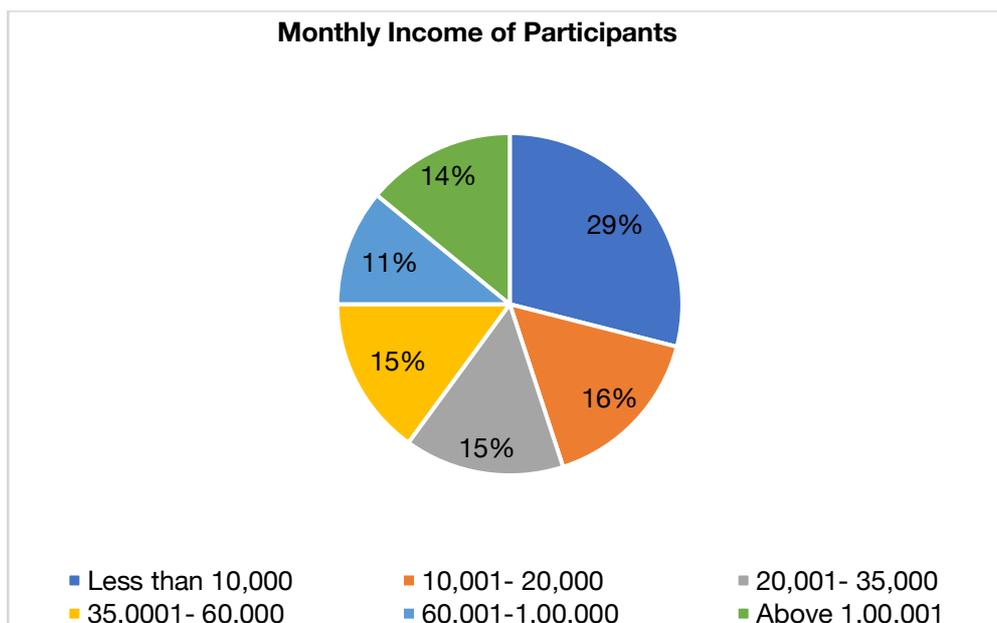
10,955 responses of individuals were analysed from 28 states and 5 Union territories in India through a combination of on-ground data collection and collection of online data through a self-administered Google form. The period of data collection for this online survey was from March to May 2021.

The study has some limitations arising from the fact that the online respondents are self-selected. As such, this is also not a representative sample as online respondents had access to a digital device and internet. The second round of offline data collection was undertaken to include the perspectives of those who lacked easy online access.

Despite these limitations the study does provide insights into the people's perspective on the vaccination policy and the barriers faced by them in receiving vaccines. It highlights the inequity in vaccine access due to systemic discrimination and puts forth solutions to improve the gaps in current vaccine policy and implementation.

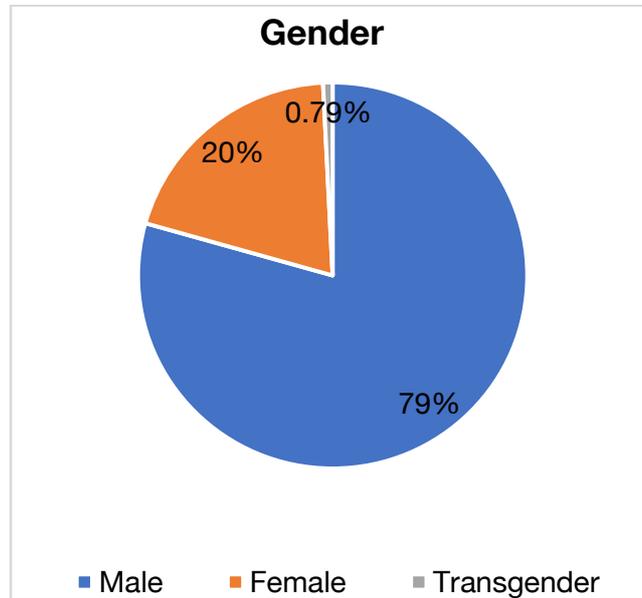
Socio-demographic details of the respondents

Out of total 10,955 respondents, 80% were men and 20% were women. This may point towards the limited access to smart phones and internet among women.

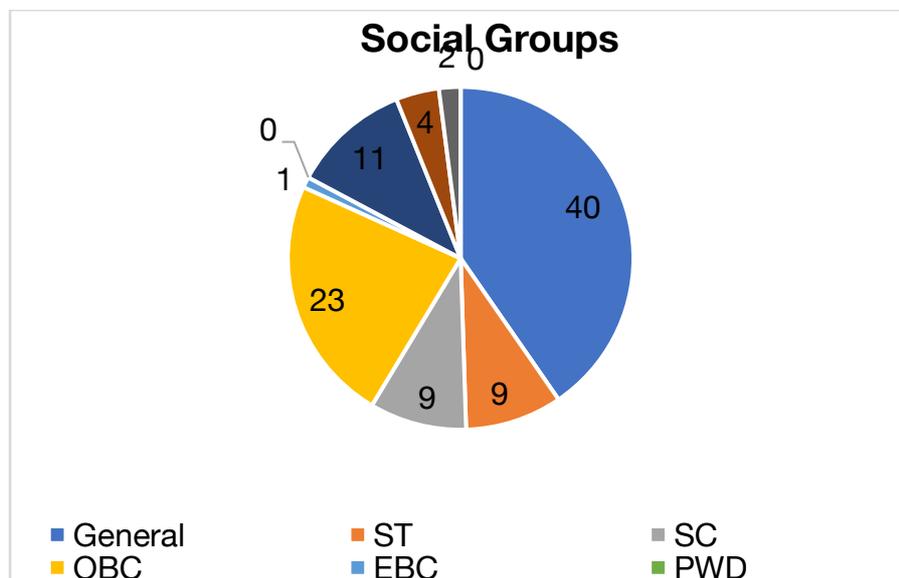


The highest number of respondents (29%) were those who earned a monthly income of less than INR 10,000 per month followed by respondents (16%) who fell in the monthly income category of INR 10,000 to INR 20,000 per month. This offers a decent cross-section of income groups in India.

At the level of rural and urban distribution, 64% of respondents were from urban areas whereas 36% were from rural areas. On education, 51% respondents were graduates whereas 37% respondents had higher secondary education (10th to 12th standard).



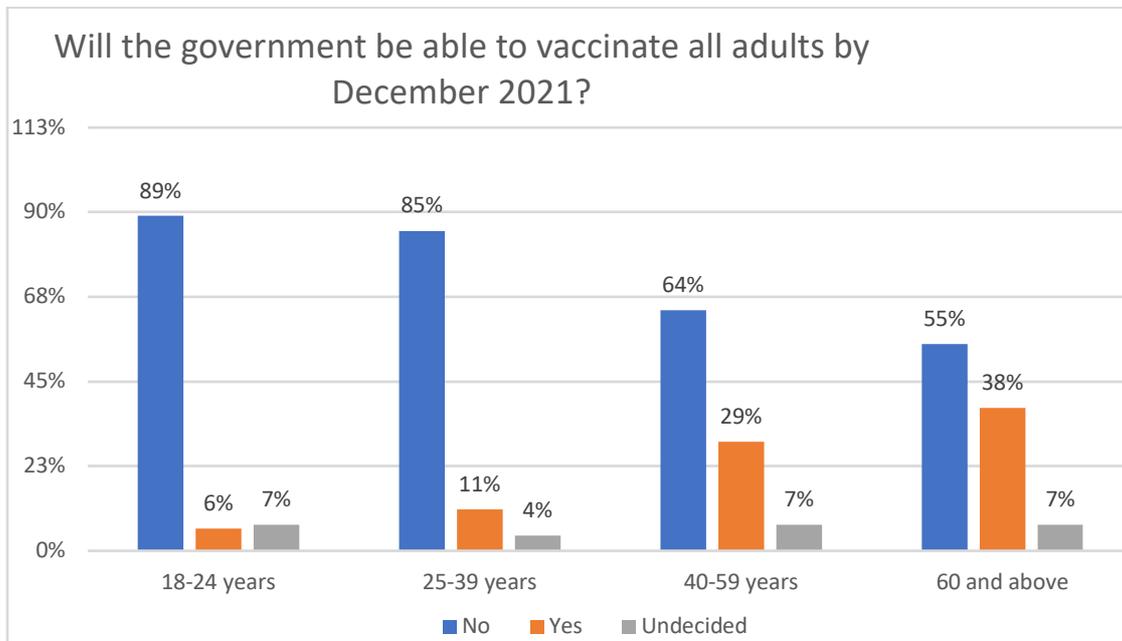
The maximum respondents (39%) belonged to the general category followed by Muslims (11%). On the caste front, 22% were OBCs, 15% were Dalits, and 9% were Adivasis.



80% of respondents felt that government will be unable to vaccinate all adults by 31 December:

Eight in 10 people said that they do not think that the government will be able to vaccinate all adults by 31 December 2021. This was the sentiment from the relatively under-vaccinated younger population. 87% respondents in the age group of 18-24 years and 85% of those in age group of 25-39 years said that it is unlikely that government will be able to vaccinate all adults by December 2021.

Objectively, at present India is vaccinating an average of 3.6 million people per day, compared to an estimated coverage of around [21 million people](#)⁸⁹ needed for achieving the target of vaccination of all adults by the end of 2021. At the same time, one has to recognise the reality of a 12 week waiting period between vaccine shots. 100% of the population would have to have been vaccinated with at least the first shot by early October to ensure that they received the second shot ahead of 31 December. But this has not happened.

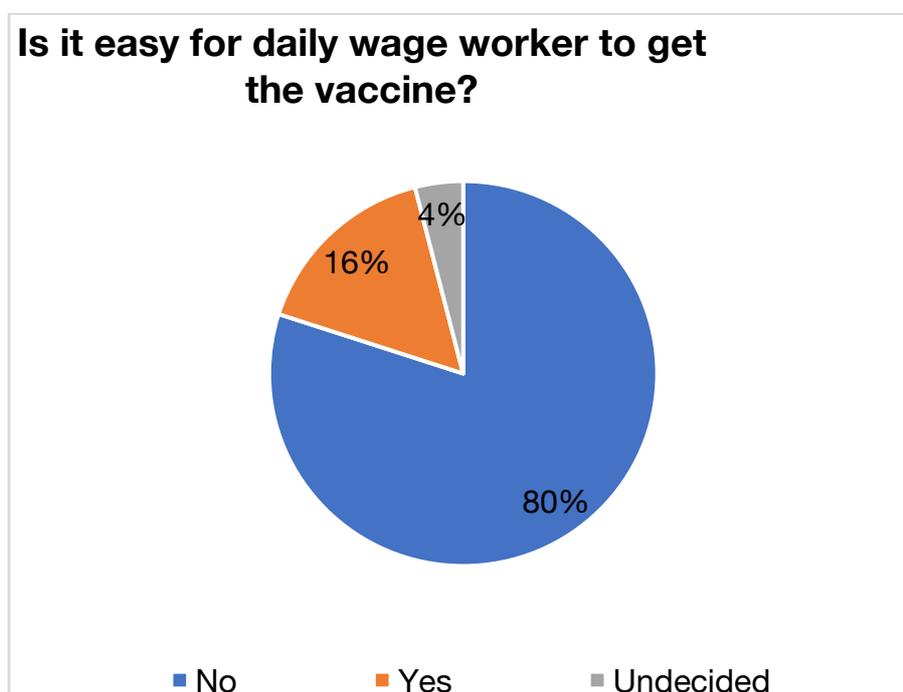


⁸⁹ <https://timesofindia.indiatimes.com/india/no-fixed-timeline-can-be-indicated-now-for-completing-covid-vaccination-but-all-18-plus-population-expected-to-get-jabs-by-december-21-centre/articleshow/84682953.cms>

Inequities in the vaccination drive

80% people believed that it is more difficult for a daily wage worker to get the vaccine as compared to a salaried, middle-class person.

Despite the Prime Minister's stated intention to not discriminate during the vaccination drive, most respondents did report that the drive was unequal. The experience of the drive shows that [vaccine availability](#)⁹⁰ has not been equal for Indians living in various states and Union territories. India does not maintain records of people vaccinated [disaggregated by income or social group](#)⁹¹ which would have been critical to tailor strategies to the specific population needs. Any commitment to equity on the vaccination drive would accordingly need to be rooted in an effort to track the relative progress of vaccination for India's rich and poor in the various social groups.



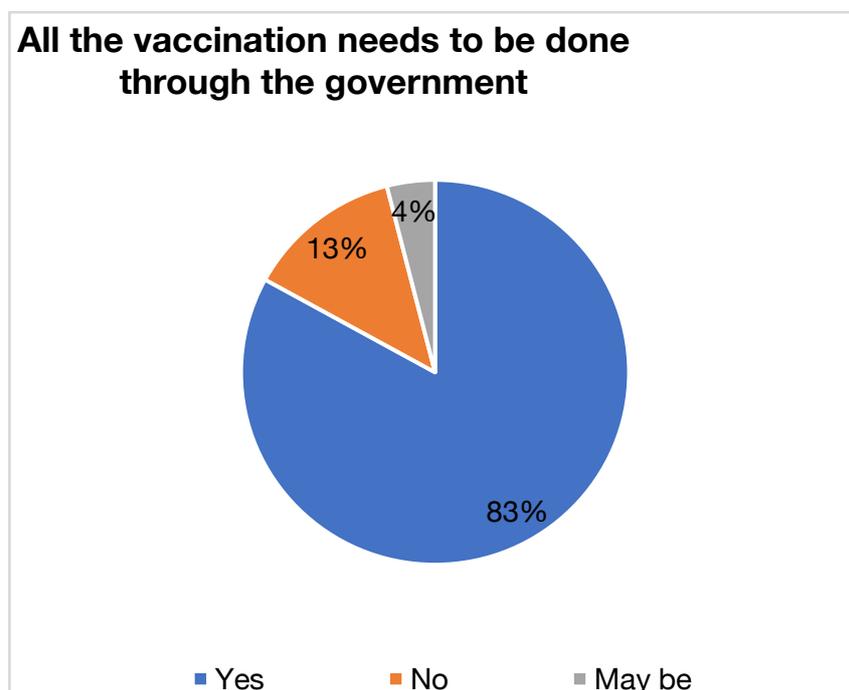
⁹⁰ <https://scroll.in/article/992921/fragmented-and-opaque-what-you-need-to-know-about-indias-baffling-new-vaccine-policy>

⁹¹ <https://www.oxfamindia.org/press-release/oxfam-india-and-fmes-welcomes-pms-announcement-vaccines>

What can the government do to address inequity in vaccination?

a) 83% people want the government to ensure vaccination through government centres

83% believed that all vaccination should be done completely free of cost through the government, like the Polio vaccination drive. Vaccines are global public goods, and it is the constitutional responsibility of the Government of India to provide them for free to everyone. Right to Health, in turn, flows directly from [Article 21 \(Right to Life\)](#)⁹² of the Indian Constitution. India's National Vaccine Policy enables access to free vaccination through its [Universal Immunization Programme](#) (UIP)⁹³. For all other national vaccination efforts the funds have come from the centre and have been largely free for India's citizens. India's National Vaccination Policy (2011) requires vaccines to meet UIP goals and follow [centrally-procured General Financing Rules](#) (GFR)⁹⁴. It would appear that the majority of respondents think that this practice should continue.



Limitations of private hospitals as modes of Covid vaccine delivery—76% want vaccine allocations to private hospitals to reduce

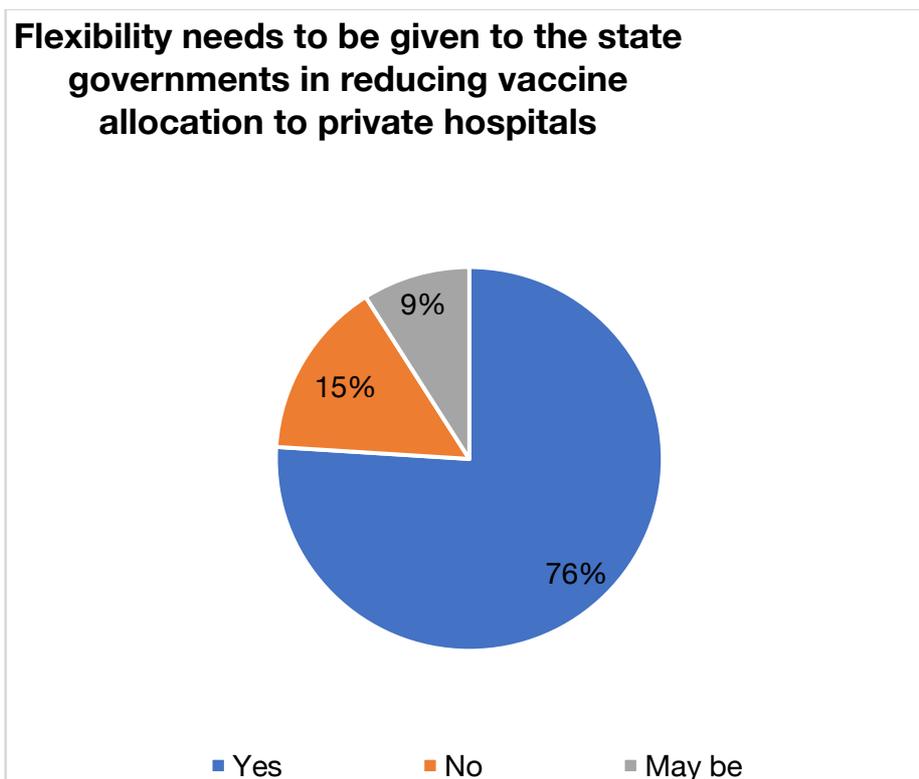
76% people believed that in order to advance equity in vaccination, state governments should be given the flexibility to reduce vaccine allocation to private hospitals to avoid possible shortages of free vaccines. This was a major ask of several states in the beginning of the current phase of vaccination; several states asked for a relaxation of the 25% cap. This was subsequently revised with India's health secretary stating in a press briefing that this is an “indicative percentage of what the government

⁹² <https://www.lawctopus.com/academike/article-21-of-the-constitution-of-india-right-to-life-and-personal-liberty/>

⁹³ https://www.nhp.gov.in/universal-immunisation-programme_pg

⁹⁴ <https://www.orfonline.org/research/covid19-vaccine-development-access-and-distribution-in-the-indian-context-69538/>

would procure and what would be available for the private sector to procure, not an [earmarked](#)⁹⁵ quota”.



Only 6% of the total vaccination in the country has been carried out in [the private sector](#)⁹⁶. The cost of vaccines in private hospitals remains prohibitively expensive. An Indian family with three adults will have to [pay INR 3600](#)⁹⁷ in a private hospital for a full course of the Covishield vaccine or INR 7200 for Covaxin. This amounts to 24% of their monthly income in case of Covishield and 48% in case of Covaxin. For the bottom 20% of households, this burden will be 43% and 86% of their monthly income, respectively. Thus, only the rich can really afford these rates. As an earlier analysis from Oxfam India had shown, these prices out a significant share of India’s population and contributes to artificial vaccine shortages. Equity issues also prevailed in states with a high share of private hospitals. One analysis of data for [Delhi showed](#)⁹⁸ that it had more sites and slots of free vaccines but most of these lacked doses. In contrast, 74% of the doses available on CoWIN were for paid doses which were also available days in advance given their high price.

⁹⁵ <https://www.moneycontrol.com/news/business/companies/governments-free-vaccination-drive-kills-market-for-private-hospitals-25-allocation-largely-unutilised-7504691.html>

⁹⁶ <https://www.newindianexpress.com/nation/2021/sep/28/private-hospitals-across-india-come-with-novel-ways-to-clear-covid-vaccine-stocks-2364688.html>

⁹⁷ <https://d1ns4ht6ytuzzo.cloudfront.net/oxfamdata/oxfamdatapublic/2021-07/India%2520vaccine%2520brief%2520-%252013%2520July.pdf?vd8V0cBMy58X6npADVQ8bvg8e03L0YFk>

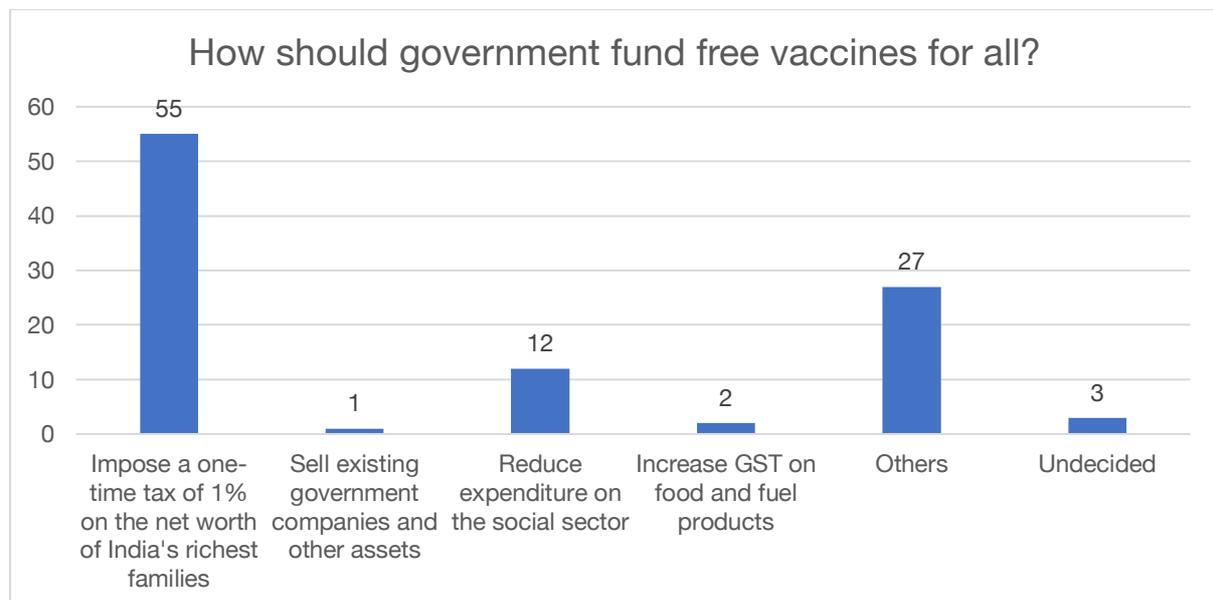
⁹⁸ <https://qz.com/india/2041072/indias-cowin-has-many-paid-vaccination-slots-despite-shortage/>

Given the prohibitive costs, private hospitals are struggling to [deliver](#)⁹⁹ their existing stock of vaccines and fears have been expressed about unopened vials [expiring](#)¹⁰⁰

The wealth and digital divide continues being a vaccine divide, despite the opening up of the option for walk-in registration.

Funding free vaccines for all fairly—55% are in favour of a 1% tax on India’s richest 1,000 families to fund a free vaccine

The Union Minister of State for Petroleum and Natural Gas [Rameswar Teli](#)¹⁰¹ was reported saying that people in the country are receiving free COVID-19 vaccines because of the taxes levied on diesel and petrol. “You must’ve taken a free vaccine, where will the [money](#)¹⁰² come from?”, he is reported as saying. The survey seeks to find an answer to this question.



Only 2% of the survey’s respondents were in favour of taxes on fuel and food being used to fund the vaccination drive. In contrast, 55% individuals believed that imposing a one-time tax of 1% on the net-worth of India’s richest 1000 families will be helpful. 12% felt that the government should reduce other social expenditure and 1% felt that the government should sell existing government companies to fund the vaccination drive. A sizeable 28% felt that other source of funding should be explored. Similar trends were found across all demographics of respondents.

Targeted taxation of India’s richest 1000 families emerged as the most popular source for funding India’s vaccination drive. Economists like S. Subramanian estimated that the total wealth of just 953 of India’s richest families on the Hurun Rich list must be approximately [INR 50.3 trillion \(around \\$684.6](#)

⁹⁹ <https://www.livemint.com/companies/news/pvt-hospitals-seek-a-solution-for-excess-doses-of-covid-vax-11633979442485.html>

¹⁰⁰ <https://www.telegraphindia.com/my-kolkata/news/kolkata-hospitals-worry-over-covid-vaccine-surfeit/cid/1833658>

¹⁰¹ <https://www.indiatvnews.com/news/india/mos-petroleum-rameswar-teli-himalaya-water-costlier-than-petrol-fuel-rates-taxes-739865>

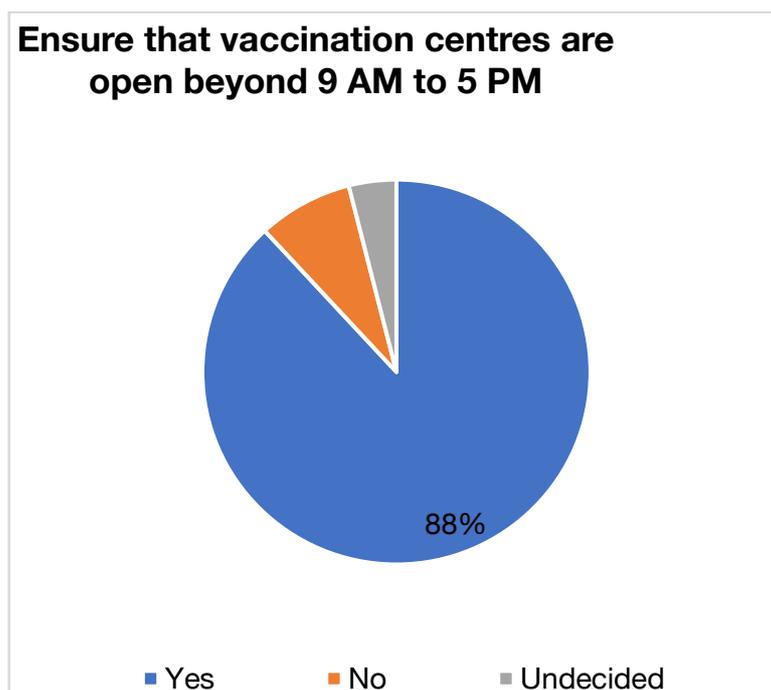
¹⁰² <https://www.timesnownews.com/india/article/where-the-money-for-free-covid-vaccine-comes-from-union-minister-on-fuel-price-hike/822706>

billion)¹⁰³. Health economist Indranil Mukhopadhyay has estimated¹⁰⁴ that cost of vaccinating the 1.3 billion population of India ranges between INR 500 billion to INR 800 billion. By taxing just 1 percent of the wealth of these super rich families India could fund its entire vaccination programme cost of INR 500 billion (\$6.8 billion).

In recent times, many researchers and economists have been touting progressive wealth tax¹⁰⁵ as the best solution to fund COVID-19 response in the pretext of the financial stress caused by the pandemic. Latin American countries like Argentina adopted a one-off special levy the ‘millionaire’s tax ’that has brought in around \$2.4 billion to pay for pandemic recovery (Landais, 2020). Policymakers, leading economists, CSOs, the United Nations, IMF and the World Bank are calling for one-time ‘solidarity tax ’ and longer-term wealth tax to mitigate the economic impacts of the pandemic and reduce inequalities by funding vaccination. There is clearly an increase in popular sentiment in this regard.

Increase operational hours of vaccination centres — 89% believe vaccination centres should be kept open beyond 9 AM-5 PM

89% people said that the government must ensure that vaccination centres are kept open beyond 9 AM-5 PM to enable those in full-time employment and informal workers to get vaccinated without having to take leave. Keeping centres open for longer hours will prevent loss of wages suffered by informal workers. It will also prevent crowding in the vaccination centres allowing the recipient to have a hassle-free experience at government vaccination centres.



Urban local bodies like Bruhat Bengaluru Mahanagara Palike (BBMP) and Brihanmumbai Municipal Corporation (BMC) took an initiative¹⁰⁶ to increase the operational hours of vaccination centres with an aim to increase vaccination as it allows more number of people to walk-in and get vaccinated. This

¹⁰³ <https://scroll.in/article/959314/doing-the-maths-why-india-should-introduce-a-covid-wealth-tax-on-the-ultra-rich>

¹⁰⁴ <https://www.downtoearth.org.in/news/health/why-experts-are-not-happy-with-india-s-covid-19-vaccine-procurement-pricing-policy-76731>

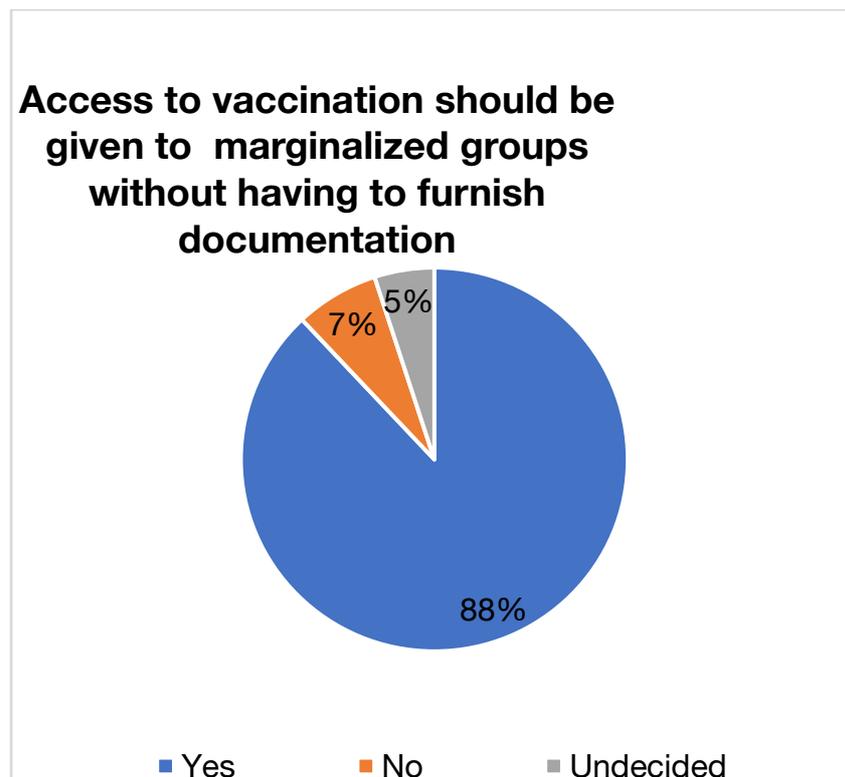
¹⁰⁵ <https://voxeu.org/article/progressive-european-wealth-tax-fund-european-covid-response>

¹⁰⁶ <https://www.india.com/maharashtra/mumbai-coronavirus-maharashtra-lockdown-corona-vaccine-news-today-latest-update-24x7-vaccine-centres-to-boost-coronavirus-vaccination-drive-4481901/>

could be particularly useful for the poorest who are more likely to be working in the informal sector; 83% of respondents earning less than Rs. 10,000 per month said that the government should extend the timings of vaccination centres beyond 9 AM-5 PM.

Address the needs of the vulnerable to ensure vaccine delivery

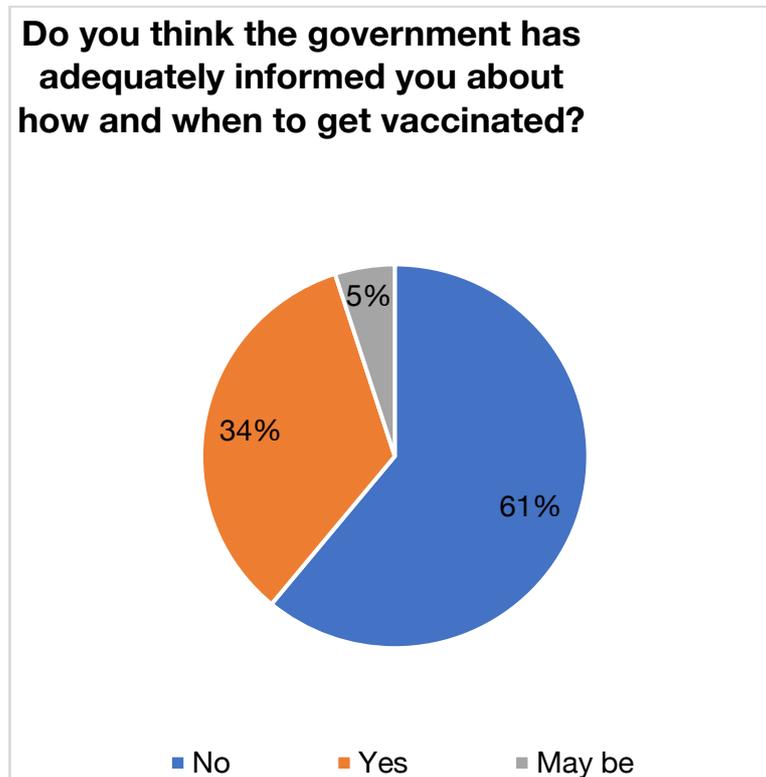
Around 95% respondents from all age categories (18 to 60 and above) felt that vaccination must be brought closer to the elderly, persons with disabilities and informal sector workers by making use of mobile vans, vaccination camps and home-based vaccination. 88% believed that the government must ensure that marginalized groups such as street dwellers, migrant workers, immigrants, refugees and asylum-seekers are given access to vaccination without having to furnish documentation. 90% said that the government must make teachers, domestic workers and those working in medical and grocery stores eligible for priority vaccination by adding them to the list of frontline workers.



These findings echo the lack of prioritisation/consideration and planning of the government on vaccine administration, based on real field-level facts. For instance, in the initial period of COVID-19 pandemic, the policy of the union government was to cover frontline health workers and medical staff but in reality apart from those in the medical field there were other professionals too who were involved in providing Covid-related care in the communities. It is clear that the presence and contribution of workers and professionals (other than medical staff) had not been recognised and addressed by the government. Many state governments had initiated positive measures to address many of these challenges. There is much to be learned from how different states' vaccination drives evolved to address local challenges.

e) Improve transparency and strengthen communication around the vaccine—Over 60% respondents felt that they were not adequately informed about how and when to get vaccinated

61% of respondents felt that the government has failed in informing them about how and when to get vaccinated. There were significant differences across income groups — 74% of those earning less than INR 10,000 per month reported they were inadequately informed, as compared to 27% of those earning over INR 100,000 per month. The government communication around vaccination appears to have failed to reach the poorest and most marginalised people of the country.



Furthermore, 8 in 10 people felt that the government changed its COVID-19 vaccine policy too frequently, especially at the early stages of the vaccination drive. The government failed to maintain transparency in development and implementation of vaccine policy. In April 2021, [Oxfam India and the Forum for Medical Ethics Society \(FMES\)](#)¹⁰⁷ released a [policy brief](#)¹⁰⁸ highlighting the importance of transparency in COVID-19 vaccine policy and demanding the need to consult the state governments and involve the people of India (Taneja, 2021). The COVID-19 pandemic has highlighted how lack of clear information, frequent change in vaccine policy without effective communication of the rationale behind it, and failure to engage with people can foster mistrust among the citizens of the country. Improving transparency can enhance public trust in vaccination policy of the country.

f) Ramp up vaccine production, especially through public sector companies

89% of the respondents said that the government must use all available domestic manufacturing capacity, especially through public sector companies. India has almost [two dozen vaccine production](#)

¹⁰⁷ https://fmesinstitute.org/blog-25-heal-institute-ijme-covid-19-insights-may-24-2021/#.YXa_aJ5BzIU

¹⁰⁸ https://d1ns4ht6ytuzzo.cloudfront.net/oxfamdata/oxfamdatapublic/2021-05/India%2520vaccine%2520brief%2520-%25208%2520May-final.pdf?a2yLvayAVVrnyh_AIA9ihnuyzQ2_gzt

[units](#)¹⁰⁹ and both the public and private sector have units that can potentially contribute to the expansion of local vaccine production. In the beginning of 2000s, [80% of India's vaccines](#)¹¹⁰ for the Universal Immunisation Programme were sourced from the public sector. Today, 90% are sourced from the private sector at a higher cost. The pandemic could, therefore, serve as an opportunity to strengthen India's public sector manufacturing capacity. This would entail sharing the intellectual property (IP) of the existing set of vaccine manufacturers thus augmenting supplies and reducing prices. [Brazil's senate](#)¹¹¹ recently voted to approve a temporary breach of patents for COVID-19 vaccines, tests, and medicines for the duration of the pandemic. India has been at the forefront of the global fight for lifting intellectual property rights on the COVID-19 vaccine. It could show the way for other vaccine manufacturers by sharing the recipe for Covaxin for which [ICMR claims royalty](#)¹¹²

¹⁰⁹ <https://thewire.in/government/realistically-how-can-india-expand-covid-vaccine-production-quickly>

¹¹⁰ https://www.business-standard.com/article/opinion/who-destroyed-india-s-vaccine-self-sufficiency-121051700112_1.html

¹¹¹ <https://brazilian.report/liveblog/2021/04/30/brazilian-senate-approves-lifting-of-patents-covid-vaccines/>

¹¹² <https://www.hindustantimes.com/india-news/no-funds-granted-for-vaccine-research-development-govt-101620675320843.html>

Status of access to vaccine — question of equity

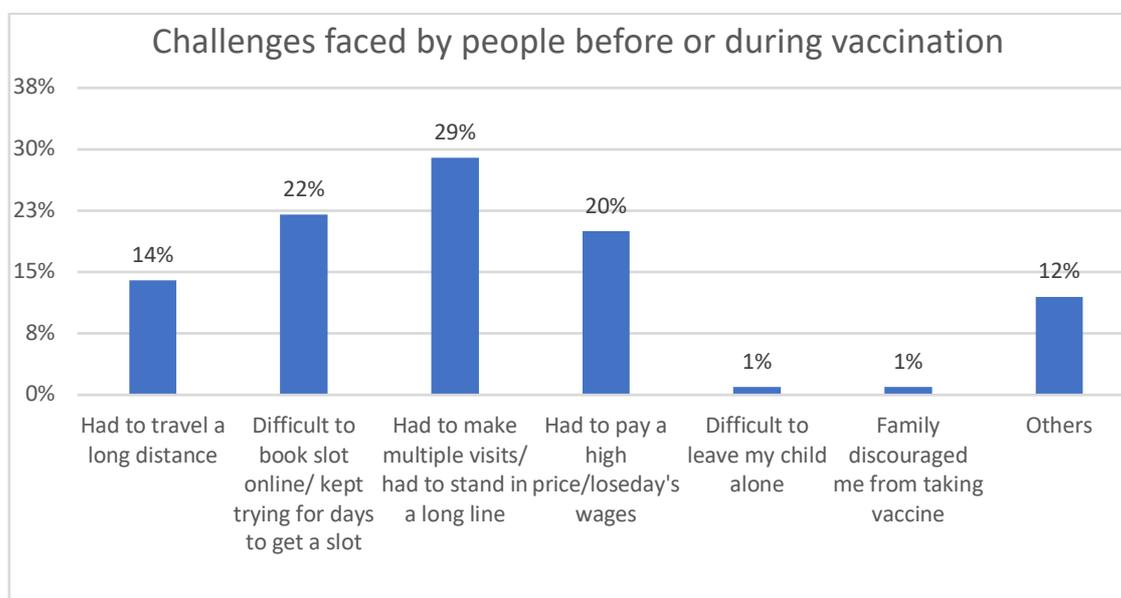
India does not maintain disaggregated information of vaccination based on wealth. While some surveys have been undertaken to look at the extent of vaccination based on caste and religion, information on wealth inequalities is lacking. The experience of the COVID-19 vaccination drive has been largely rigged in [favour of the rich](#)¹¹³ and the relatively more tech-savvy. This rapid survey offers some evidence in this regard.

In the survey, 12% people who earned less than INR 10,000 per month had not received even a single dose of vaccine, while only 5% people who earned between INR 60,000 and above did not receive a single dose.

¹¹³ <https://www.ft.com/content/538bc0a3-d3e0-45ef-8f19-1d14b1365f9f>

Challenges faced by people before/during vaccination

Challenges faced in vaccination were fairly similar irrespective of the socio-economic profile of respondents or the site of vaccination. These included the need to make multiple visits to vaccination centres, economic consequences of doing so (either in terms of loss of wages or high cost of vaccination) and the need to travel long distances to obtain the vaccine.



29% report making multiple visits or standing in long queues

Around 29% of respondents said that they either had to make multiple visits to the vaccination centre or stand in long queues at public vaccination camps (31%) or public vaccination centres (29%). Long queues outside vaccination centres have been [reported¹¹⁴](#) across India in the early months of the vaccination drive. 36% of respondents belonging to Economically Backward Class (EBC) followed by 30% of people from OBC and general categories reported that they had to make multiple visits to the vaccination centre/stand in a long queue at the centre. However, long waiting time was the biggest challenge reported for private vaccinations as well.

Over 22% people report challenges in booking a slot online

Over 22% people reported facing issues in booking the slot online, and having to try for multiple days to get a slot in all vaccination camps/centres. This challenge was particularly prevalent in the initial days of vaccination when booking through the CoWIN portal was compulsory to get a slot.

Travelling long distances and loss of wages—9% respondents lost wages to get vaccinated

16% said that they had to travel long distances to reach private vaccination centres, contrasted with 10% who had to travel to access a public vaccination camp. According to public health [experts¹¹⁵](#), the long distance is a deterrent for women to get vaccinated, particularly if there is no male member to accompany them. 9% respondents who visited vaccination centres or camps reported losing a day's wage to get themselves vaccinated or had to pay a high price for the vaccine. There are multiple

¹¹⁴ <https://www.news18.com/news/india/covid-norms-go-for-a-toss-as-hundreds-queue-up-outside-vaccination-center-in-mumbais-dharavi-4004969.html>

¹¹⁵ <https://www.indiaspend.com/covid-19/1-billion-vaccine-doses-but-women-tribals-lag-785262>

[reports](#)¹¹⁶ showing that the risk of wage loss is a huge deterrent for daily wage workers such as domestic workers, agricultural workers, and construction workers from getting vaccinated. 18% of OBCs and 16% of Dalits reporting having lost a day's wage to get the vaccine, compared with 12% of respondents from the general category.

The experiences were fairly similar for people across income groups. The group of highest earners were slightly more likely to have travelled long distances (16% vs 12%) and have persevered to obtain a vaccine slot online. In contrast, the economic barriers were higher for those who are poorest (high price/lost wage).

¹¹⁶ <https://abcnews.go.com/Health/wireStory/vaccine-inequality-india-sends-falling-gaps-77909315>

Barriers faced by people in getting vaccinated

While our vaccination rates have improved in the past couple of months, only 1 in 4 Indians are fully vaccinated. While the previous section showed challenges that people faced while getting vaccinated, this section details barriers faced by people who couldn't get a single dose of the COVID-19 vaccine.

43% couldn't get vaccinated because no vaccines were available in the centre

After the second wave, when people were desperate to get vaccinated, there were multiple reports of vaccine centres shutting [down](#)¹¹⁷ due to a lack of vaccines. Consistent with these reports, this study found that of those respondents who couldn't get a single dose of the vaccine, 40% could not get vaccinated because the vaccination center had run out of vaccines when they visited the center. While the country celebrates reaching the 1 billion dosage mark, it must remember that the vaccination drive has been plagued with supply issues that have prevented people from taking the vaccine when they wanted to.

20% respondents couldn't travel on their own

Traveling independently to get vaccinated was a huge barrier; 1 in 5 respondents reported that they couldn't get vaccinated because of this barrier. The biggest challenge faced by the elderly has been their inability to travel on their own; 33% people above the age of 60 years said that it was not possible for them to travel to the vaccination centre compared with 11% of the rest of the sample. This suggests that India is missing out on vaccination of the most vulnerable sections of the society including persons with disabilities and the elderly. The current government at the centre has historically been opposed to [doorstep vaccination](#)¹¹⁸ until November when the PM finally endorsed it during a call with the [group of CMs](#)¹¹⁹. We hope that this policy move would play a significant role in increasing vaccination rates.

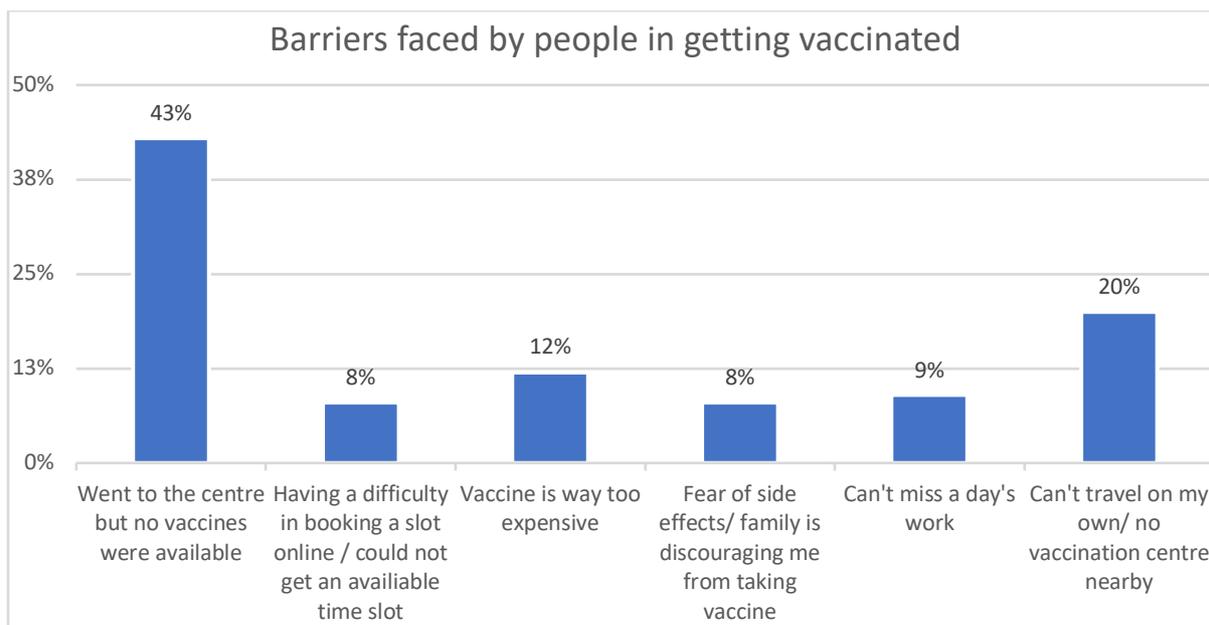
12% did not get vaccinated because of the high prices of the vaccine

One of the key differences between the COVID-19 vaccination drive and previous vaccination drives, such as polio, is that the current vaccination drive is being delivered by government and private health providers. Thus, 12% of those who couldn't get vaccinated, reported that they could not afford the high prices of the vaccine, presumably in the private sector. This could be a combination of two challenges — the perceived unavailability of vaccines in public health facilities and the lack of clear communication from the government on how to access free vaccines.

¹¹⁷ <https://www.ndtv.com/india-news/delhi-runs-out-of-covishield-many-covid-19-vaccine-centres-to-be-shut-tomorrow-2485145>

¹¹⁸ <https://www.thehindu.com/news/cities/mumbai/door-to-door-vaccination-not-possible-centre-to-bombay-high-court/article34377035.ece>

¹¹⁹ <https://www.telegraphindia.com/india/pm-reiterates-need-for-doorstep-vaccination-to-a-group-of-cms/cid/1837182>



9% said they can't miss a day's work to get vaccinated

Allowing walk-ins at vaccination centres has been a step in the right direction to enable those without access to technology, to get themselves vaccinated. There have also been positive measures by various state governments, such as setting up vaccination camps in remote areas and running door to door vaccination drives through ASHA workers. However, these measures have not been universal in nature and people still need to travel to a vaccination centre during their working hours to get vaccinated. This is a deterrent for daily wage earners and informal sector workers, as evidenced by the survey as well, where 9% said they couldn't get vaccinated because they can't afford to forgo a day's wage.

Furthermore, the experience of vaccination has varied based on place of residence. Rural respondents found it harder to obtain vaccines either in terms of booking a slot or going to the vaccination centre or going to the vaccine centre without obtaining the vaccine. In contrast, expensive private vaccines and failing to have necessary documentation was a greater challenge for urban areas.

Conclusion and Recommendations

This survey makes some suggestions for improving COVID-19 delivery, particularly from perspective of vaccine equity. People from all income groups and all strata of society faced common challenges and barriers in both public and private health facilities while availing the COVID-19 vaccines. They also made fairly similar recommendations for enhancing vaccination.

In the event that India opts for booster doses or doses against new variants, it would be critical to have a well thought out policy to ensure vaccines are available free of cost and accessible through the public health system. At the same time, it would be important to learn from this experience for subsequent vaccination drives.

Policy recommendations

Government should ensure that vaccination policies are open to public scrutiny, for that-

- All vaccination should be done completely free of cost through the government, like previous vaccination drives. Ensure delivery of free vaccines through government centres, avoiding the use of private hospitals to deliver vaccination;
- This should be funded through progressive taxation including a one-time tax of 1% on the networth of India"s richest 1000 families. Existing practice of funding taxes on essentials like petrol should be avoided;
- Proactively releasing timely information on vaccination strategies, modalities and accomplishments in disaggregated, user-friendly and open source formats;
- Prioritising the allocation, distribution and administration of vaccines for marginalized, poor, vulnerable, excluded communities first, of course along with for those who are at risk; Extend operational hours of vaccination centres beyond 9 AM-5 PM to allow for vaccination without loss of wages;
- Maintain record and release disaggregated data on vaccination coverage based on social and economic groups including Dalits, Adivasis, Muslims, and Persons with Disabilities (PwD);
- Bring vaccination closer to the vulnerable. For covering all population mainly people from informal sector, elderly and PwD, 'door to door 'vaccination is very effective. For COVID-19 vaccination, there was major delay in taking decision regarding door to door vaccination drive and its execution and this should be avoided in future;
- Improve information about vaccination. Existing technology-based mechanisms (Arogya Setu and CoWin app) for getting information about vaccination centres locations and availability of vaccines is not sufficient. At local level, youth, local elected representatives, SHG members, elected local bodies such as Village Health, Sanitation and Nutrition Committees (VHSNCs) and School Management Committees (SMCs) must be involved in mobilising communities to address the challenges faced during the vaccination drive and will contribute to reducing the burden of work faced by frontline health workers. At the same time, it would be important to build a robust and functional grievance redressal mechanism from national to local level to address emerging challenges. Adequate flexibility must be given to local health administrations to adapt to local circumstances.
- Further ramp-up vaccine production, especially through public sector companies.

OVERALL CONCLUSION

Both surveys have shown the extent of denial of fundamental Health care. The experience of patients' rights violations and inconvenience faced by citizens while obtaining vaccines have faced by all income groups and strata of society. Making the healthcare system more responsive to the needs of its patients is an area where the interests of India's middle class and the poor could potentially coincide.

This state of affairs is not inevitable. The Government of India's letter to the states to notify the Patients' Rights Charter was among the first decisions of then newly re-elected Modi government in June 2019 during its second stint. The fact that it was issued in the first month of the government coming to power, reflects the priority that the government had placed on ensuring that all Indians are respected in the healthcare system. It is time for governments to live up to this commitment.

It is time for governments to take the rights of patients seriously by notifying and implementing the Patients' Rights Charter. This would need to be backed by robust mechanisms to amplify patients' voices in the health system. Fundamentally, India needs to develop a robust grievance redressal mechanism to avoid some of the gross rights violations that the country saw during the course of the second wave of the pandemic.

It is time to also start capturing the differential experiences and challenges of patients who are rich and poor, of men and women, of the privileged and marginalized communities and the unique needs of specific communities like Persons with Disabilities. This should then become the basis of shaping strategies to ensure that the health system becomes responsive to their individual needs and contexts.

The government would need to ensure that patients' rights are protected not just in the public healthcare, but also (and perhaps even more critically) in private hospitals. This calls for more robust process of monitoring and enforcing regulations related to non-discrimination and protecting citizens from commercialisation in these settings.

All of this is, in turn, predicated on building awareness on the rights of patients and citizens in the healthcare system, especially the Patients' Rights Charter. This can be done collaboratively with communities and civil society in order to hold providers responsible.

In the long run, India needs to further strengthen the Public Health system and establish social control over Private Health Sector. It is time for the government of India to enact a justiciable right to health to ensure that every citizen have recourse when their rights are violated.

It is possible for the government to do so. As our Prime Minister said two years back:

“Health does not simply mean freedom from diseases. A healthy life is every persons' right.

The onus for this is on our government to make every possible effort to ensure this”-

Hon'ble Prime Minister Shri [Modi, 2019](#)¹²⁰

¹²⁰ <https://www.thehindu.com/sci-tech/health/indias-experience-in-affordable-healthcare-is-available-for-use-to-all-developing-nations-says-modi/article29493005.ece>