

NHRC - JSA REGIONAL PUBLIC HEARINGS ON HEALTH RIGHTS

Related to Public and Private Healthcare sectors

I. Background and broad structure of the programme

A. Overview

The proposed series of public hearings on Health rights across India during 2015-16 will be collaboratively organized by the National Human Rights Commission (NHRC) and Jan Swasthya Abhiyan (JSA). These hearings will focus on reviewing human rights violations in context of the public and private health care services in India, with a view to drawing attention to key systemic and policy related issues, along with issuing a range of related recommendations comprehensively. Series of public hearings on Health rights would be organised in various regions, followed by a National public hearing. This would provide a much-needed platform to share and discuss key issues today related to violation of Health rights of people in various parts of India, and would lead to issuing of a series of recommendations, would result in certain serious violations being taken up as human rights violations by NHRC, and would help build a climate for adoption of various measures required to ensure protection of health rights.

B. Methodology and broad structure of public hearings

Each regional public hearing would be a two-day event and would consist of series of sessions. In most of the sessions, the modalities used will include-

1. **Testimonies by** individuals or groups that have suffered health rights violations (as illustrations of policy and systemic issues).
2. **Case studies** of institutions or services or programmes (e.g. specific CHCs, District Hospitals or Public health institutions, Hospitals involved in schemes like RSBY, Sterilisation camps, etc).
3. **Reports of surveys or studies** concerning shortfall of facilities, services, human power, medicines etc. in the public health system, and similarly relevant data / surveys and studies concerning the private medical sector and PPP arrangements.
4. **Presentations by persons from the Health sector with broad based experience.** Presentations would be made by activists from the JSA network, and senior Health sector experts, including members of the NHRC Core group on Health.

Responding to these testimonies and presentations, concerned public officials (such as State Health Secretaries / Mission Directors / Directors of Health Services / State and National medical councils) will be invited to respond. A panel led by NHRC members and officials will

comment upon the issues, and finally discussion towards recommendations ensuring corrective actions would be conducted in each session.

C. Sessions in Regional Public Hearings

The programme for regional hearings would include following broad themes:

Day I: Promoting Health rights in the context of Public Health Systems

Session 1: Review of delivery of quality guaranteed public health services, to ensure people's health rights—State wise testimonies and case studies on people's critical experiences of Public health services, with focus on more general and frequently encountered issues. Individual testimonies should be accompanied by case studies or survey reports which would demonstrate that the problem being presented is not just an individual incident, but is of a more general or systemic nature. (See suggested themes for this session in the section on information collection related to Public health services). This would be followed by response from State Health officials on the issues raised, and discussion.

Session 2: Emerging Systemic and Policy Issues related to Public health services (this will be based on the testimonies and case studies in session 1, linking these to systemic analysis and policy recommendations regarding Health budgets, infrastructure strengthening, availability of Human power, procurement of medicines, capacity building trainings to healthcare providers, monitoring and supervision, clinical trials and Health rights aspects of major Health programmes, etc.

Session 3: Community accountability, Peoples' participation and Governance issues in Public health system (including status of Community based monitoring (CBM), grievance redressal mechanisms, people's participation in functioning of Rogi Kalyan Samiti (Patient Welfare Committee) and health planning processes, issues related to appropriate utilisation of flexible funds at various levels etc).

Day II: Ensuring Patients' Rights in context of Private Medical Care providers

Session 4: State wise testimonies on violations of Patients' rights and Human rights violations in Private hospitals (e.g. denials of right to medical records, right to emergency medical care, right to free medical treatment to survivors of sexual violence and acid attack, right to second opinion, refusal to hand over body of patient until entire hospital fees have been paid, insisting that medicines must be purchased from Hospital's own medical store, non-provision of free beds to poor patients in Trust / Charitable hospitals etc.)

Session 5: Patients' Rights violations in context of publicly supported Health insurance schemes and Public Private Partnerships (including RSBY, other State specific schemes such as

insurance schemes involving private providers, and fulfillment of public obligations by private hospitals which have received public subsidies)

Session 6: Ensuring effective regulation of Private medical sector for protection of Patients’ rights (dealing with regulation of costs of services in context of high out-of-pocket expenditures, status of implementation of Clinical Establishment Act (CEA) or similar law in each state, role being played by Medical Council in ensuring protection of Patients in context of Code of Medical Ethics, violation of code by certain doctors etc)

During the regional hearings, we understand that there would also be a window / desk run by NHRC to receive individual complaints / grievances, which would be acted upon by NHRC appropriately.

D. Tentative schedule of hearings and suggested timeline for preparatory activities

It may be noted that discussion with NHRC is underway to push ahead the hearing dates in some regions, considering the delay on behalf of NHRC in giving final approval to the process; hence some of the dates for hearings are likely to change, but this would be based on approval by NHRC of the revised dates proposed by JSA.

Region and states	Venue	Proposed time of Public Hearing (tentative)
Western Maharashtra, Gujarat, Rajasthan, Goa	Mumbai	Third week of November
Central Uttar Pradesh and Madhya Pradesh	Lucknow	End of February or early March
Southern Tamil Nadu, Andhra Pradesh, Telangana, Karnataka, Kerala, Puducherry	Chennai	Third week of December
Eastern Bihar, Jharkhand, West Bengal, Odisha, Chhattisgarh	Raipur	Second half of January
Northern Jammu & Kashmir, Punjab, Haryana, Himachal Pradesh, Uttarakhand, Delhi	Chandigarh	Second week of February
North eastern Assam, Meghalaya, Tripura, Mizoram,	Guwahati	Late March

Manipur, Nagaland, Arunachal Pradesh and Sikkim		
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II. General points to be observed while collecting data, recording testimonies and scrutinizing cases

Points to keep in mind while collecting information and screening testimonies

1. The cases to be selected for presentation should be of **serious nature, involving grievous hurt, long term injury (in the context of clinical trials), loss of life, major economic consequences, discrimination** on the basis of caste, class, sexuality/gender, religion, HIV or health status etc. Please also refer to the list of issues for which there are currently legal protections, or entitlements under schemes and programmes.
2. Attempt should be made to collect at least half of the case studies concerning **women** being denied health care.
3. Any case papers / prescriptions or other **relevant documents** should be collected as supportive documents.
4. Oral **consent (written consent wherever possible)** of the person from whom the information will be elicited should be taken.
5. Attempt should be made to ensure that if a documented case is to be presented at a public hearing, the **person affected** or somebody close to the patient (relative or friend) **would present** the case in her/his words. This should, however, not be an absolute necessity – i.e. some testimonies may be presented on behalf of the patient by the organisation involved in documenting the case.
6. **Some internal verification** should be done before accepting the case even though we take complaints at face value. This may require attempting to triangulate information with other parties. It is damaging to be found in some indefensible position because some counter evidence is presented at the event that we did not consider.
7. **Cases without any evidence should be avoided**; however the lack of documentary evidence can be offset by supporting testimonies of more than one person. For example – many people testifying about demand of bribes at a particular facility.
8. The **testimonies presented should reflect diversity as well as commonality**. They should not seem like exceptions.
9. The testimonies should **attempt to capture special vulnerability** due to geography (hilly areas, deep forest areas, flood prone areas, small spread out habitations), age (very young, very old), gender, caste, religion and other factors that either cause difficulty in access and / or discrimination like disability and HIV positivity.
10. **Systemic issues need to be covered**. These would include – distances, physical infrastructure, timings, availability of doctors/staff /labs/ambulances, corruption, attitudes, coverage of emergencies, drugs etc
11. **Some testimonies should clearly highlight the existing costs of care even within the public health care system**, and its impact upon the family. These should range from costs of a normal delivery to costs of a life saving exercise, say in the case of a malignancy (chemo /

radiotherapy + operation + antibiotics + investigations etc.) or major operations like bowel resection and anastomosis etc.

The testimonies should be thoroughly detailed, verifiable and verified. It should be accompanied with corroborating documents as well as observations and evidence of the investigating team. It should be factually in line with the accepted clinical practice. Therefore, it is preferable to have a doctor on the panel or to consult relevant specialists before presenting the case. The denial should be unambiguous and should not fall into a gray area, it should be clear that the testimony represents serious denial and is not just a statistically possible variation of standard management.

Some important points

- It is expected that NHRC will provide a letter to JSA, which will formally authorise JSA activists to collect relevant information from public and private hospitals.
- While documenting any case of denial for giving a complaint to NHRC, we should keep in mind that the incidence of denial should have taken place in the last one year before the date of the public hearing. NHRC accepts only such cases for investigation.
- While a large number of testimonies may be collected, not all of these may be suitable for presentation in the public hearing for a variety of reasons. Hence after collecting testimonies, a period of around a month should be reserved for screening, cross-checking and selecting the cases which are to be presented in the public hearing.
- Intimation about all selected cases which will be presented, should be given to the related District Health Official / CMHO / Civil surgeon or other concerned health official, one month before the actual hearing. This will ensure that District health officials will come to the hearing with all the required information, and may even take corrective action in some cases. This condition has been put forward by NHRC.
- Keeping the above two points in mind, it will be most desirable for JSA state networks to plan documentation of testimonies in such a manner that this is completed two months before the date of the actual hearing – subsequently one month would be required for screening, cross-checking and final selection, and one further month notice would need to be given to health officials who are expected to respond during the hearing.
- We will be communicating with NHRC that all selected persons presenting testimonies should be protected from threats / intimidation by concerned health officials or private providers, during the one month before the actual hearing. We will need to be in contact with such persons presenting testimonies, and may need to support them to ensure that they firmly present their testimony in factual manner without coming under any sort of pressure.

Cautions to minimize risk / discomfort / disappointment to the persons testifying

1. The testimonies should preferably be drawn from **areas where we have field presence** so that follow up can be done and any negative fallout of the public hearing upon the witness be addressed.
2. The person testifying should be fully aware of the entire process and what it entails. **Each person also would sign a consent form, if they are comfortable with giving their testimony, which explains the purpose of the public hearing and takes consent for the disclosure of the person's identity and story.** (wherever possible, we should try and get consent in writing)
3. It should be possible for testimonies to be taken / heard in camera behind a screen at the public hearing itself if the person so desires and the testimony is powerful. However, the person must at least be willing to register the case with the NHRC which will maintain confidentiality. If this is not done we may be accused of manufacturing cases.
4. The persons should be made aware that they are testifying in the larger interests of people like themselves and that there is **no guarantee of recourse for their particular matter**. This is much easier if they are part of some group (positive persons network etc). This is very important, otherwise we build expectations for compensation, redressal or for punitive action against concerned authorities, so we should make this very clear.
5. Facilitation will be needed to prepare the testimonies and the **documents that provide evidence**. The identifying group must plan for this kind of effort around each case. It may involve putting in **RTIs, accessing medical records, tracing bills etc.** the facilitators should be prepared for incisive questions from the Jury / Bench and should assist the testifier to prove her / his case.
6. It can be made clear that the aggrieved can also on their own approach parallel legal redressal mechanism if they want to take their issue forward individually.

III. Framework for documenting rights violations in Public Health System

The purpose of documenting the case studies of denial of health care is to demonstrate how specific persons have been denied basic health care that is expected from Public health services. The idea is to capture events where obvious and major violations have taken place, leading to loss of life, disability, serious health or economic consequences. We should focus on availability of those services, regarding which the responsibility of the public health system is clear. However the basic idea is to document structural deficiencies, and not to target individual public health care providers. We want to document the existing structural deficiencies that exist, which need to be corrected by major strengthening of the public health system. In a public hearing, even if the focus is intended to be systemic and policy related, *the testimonies form a critical element as they act to highlight the larger issues of significance*. They also elicit

the most attention by the panelists and the media etc, since general issues are often largely known and discussed time and time again in various ways.

Stepwise approach for documentation

Step 1: Collecting/identifying individual cases of violation of health care rights, through enquiring in family-social circles-neighbourhood-in place of work-among people who work with us, members and contacts of social organisation etc; and the responses to the advertisements that will be put out shortly. For action to be taken by NHRC, the violation should have taken place within the past one year.

Step 2: Once some cases have been brought to your notice, then collecting all relevant information from each person using the protocol given. While taking information, informed consent needs to be obtained.

Step 3: Screening/verifying/short-listing some cases for submission to NHRC.

Step 4: All significant cases identified in a state should be submitted to NHRC. However out of the cases shortlisted in Step 3 above, only some will be selected for making oral presentation at the actual regional public hearing (maybe not more than 10 per state, in session related to public health services).

Step 5: Orientation of the affected person and his/her family who would make presentation at the hearing, confirmation about sharing information and presenting before others, possible outcomes, assurance of confidentiality, etc

A protocol to collect the relevant information in the case of denial of health care is given separately. Besides the points mentioned in the protocol, additional points or information may be added as relevant to the particular testimony

Some of the major types of cases of this kind are outlined below, however any other similar cases, which come to the attention of activists, can be documented.

Suggested common themes for data collection and testimonies/case studies:

A wide range of gaps, deficiencies and issues would be observed while documenting people's testimonies related to the public health system. However, we should keep in mind that our objective is to highlight certain structural and systemic issues that need to be addressed, for strengthening public health services and ensuring that people receive quality health care from the public system. Hence we are proposing that some major themes should be taken up during the hearings, and some proportion of testimonies should definitely be related with these themes:

Theme A: Lack of adequate Health sector human power (insufficient specialist doctors, general medical officers, ANMs, MPWs, Laboratory technicians, pharmacists, counsellors etc.) leading to deficiencies in health services and denial of health rights, insufficient numbers of trained counsellors at health facilities to respond to issues like survivors of domestic violence, child sexual abuse and sexual violence; issues of adolescents, insufficient presence of doctors during night hours to respond to cases of violence etc.

Example: Due to lack of gynaecologist / anaesthetist at the CHC, cesarean sections are not performed; a woman with difficult delivery cannot be managed at the local CHC and has to be taken to a far off next level public hospital (like district hospital) leading to further complications, or to a private hospital, leading to massive expenditure and inconvenience.

As part of this theme, certain serious problems being faced by public health staff due to work overload linked with widespread staff shortages etc. may also be shared.

Theme B: Lack of functional Health care facilities in sufficient number (e.g. insufficient numbers of functioning sub centres / PHCs / CHCs / urban health facilities to cover the required population; inadequate functionality of facilities since staff have been assigned to multiple responsibilities, or their presence is inadequate; lack of functioning indoor services or ambulance services etc.)

Insufficient availability of medicines and diagnostics (including laboratory facilities, x-ray, sonography and screening facilities such as PAP smear, viral load in HIV case etc) in public health care facilities could be included in this theme, or if this is perceived to be a widespread and serious issue, then availability of medicines could be taken as an independent theme. This would include range of medicines as well as quantities of medicines, which are available free of cost to patients in public facilities.

(This is not an exhaustive list but rather outlines certain broad categories with examples)

Examples:

- *There is **no functioning Sub-centre** to serve a cluster of villages with combined population of over 5000, leading to denial of immunization, antenatal care and other services.*
- ***At various levels this may include non-availability of services as in following examples:***
 - ***In a PHC** - Non-availability of treatment for snakebite or Anti-rabies vaccine; Non-availability of treatment for a child with pneumonia or severe dehydration due to diarrhoea resulting in death*
 - ***In a CHC / Rural hospital:** The above deficits or Lack of blood transfusion for a bleeding patient due to accident or bleeding related to pregnancy; Non-availability of emergency drugs leading to serious delay in treatment and death or disability of the patient*
 - ***In a Sub-divisional / District Hospital:** The above deficits or Non – availability of emergency surgery leading to death or disability of the patient; non-availability of essential or emergency drugs*

Theme C: Denial of Women's Health rights, including reproductive health rights: This would include women not receiving essential health care from public health facilities – inadequate reproductive health services such as delivery care, antenatal care, abortions etc.; inadequate referral transport; denial of care to women for general health problems, and other gender related issues like health care and medico-legal process in cases of domestic, sexual and other forms of gender based violence; denial of health care services to adolescents, including for sexual and reproductive health needs and concerns; poor implementation of initiatives such as the Rashtriya Kishor Swasthya Karyakram (RKSK) for young people.

Examples:

- *The PHC in the area does not function after 5 pm, so women in labour requiring care have to go the far off CHC or to a private facility.*
- *Abortion services are not available in most of the PHCs in the area, leading to denial of abortion care to women.*
- *Maternal Health Care: Lack of facility or performance of a normal delivery in a PHC or higher facility; lack of facilities for necessary cesarean operation in Rural hospital or higher facility; unavailability of blood transfusion service to a woman before, during or after delivery; lack of abortion facility leading to septic abortion or other adverse consequences*
- *Care for burns: A woman reporting with burns in a CHC or higher facility and not receiving care for burns*

Additional possible themes that may be taken up by states may include:

- **Denial of health rights of unorganized and organized workers – this may include inadequate ESI services, serious occupational health problems etc.** Case studies may be presented on denial of medical services for occupational/work-place injuries to workers by employers and other concerned authorities.
- **Children and adolescent health rights** - children's health rights, deaths of children due to vaccine and IMR MMR can also be documented and presented here. The Rashtriya Bal Swasthya Karyakram is an ambitious comprehensive programme which is supposed to offering full and free health services to children upto the age of 18 but its implementation needs to be assessed and denial of services needs to be documented.
- **Denial of health rights to marginalized communities** such as Dalits, Adivasis, Muslim communities, sex workers, persons belonging to sexual minorities, HIV infected and affected people, persons with disability. Case Studies can be prepared on denial due to discrimination against one or more of these sections.
- **Denial of health rights in urban situations**, especially related to the urban poor
- **Major inequities / disparities within a state leading to denial of health rights** to large numbers of people in less developed, hilly or remote areas
- Lack of adequate Health care facilities **in areas where people are facing displacement due to projects such as dam construction or mining etc.**
- Lack of adequate health services **in conflict areas, such as in Bastar region of Chhattisgarh, in Kashmir valley and in some of the North-eastern states (case studies).**
- Denial of rights of patients/ subjects enrolled in **clinical trials/ other research.**

While documenting testimonies the following points may be kept in mind:

- ❑ Each State should work out a minimum number of testimonies of denial that would be documented, even if all these testimonies are not going to be presented in detail at the public hearing. It is suggested that depending on the size of the state, each state starts with a target of say **25 to 50 testimonies**, which should be spread across several Districts in the state.
- ❑ The attempt should be to document testimonies where denial of health care has resulted in **significant loss to the patient**, either in physical or financial terms, to strengthen the case for a human rights violation
- ❑ Document case studies only where incidence of denial has taken place in the **last one year** (NHRC only accepts such cases for investigation).
- ❑ Attempt should be made to collect at least half of the case studies concerning **women** being denied health care.
- ❑ Any case papers / prescriptions or other relevant documents should be collected as supportive documents.
- ❑ Oral **consent (written consent wherever possible)** of the person from whom the information will be elicited should be taken. The involved person should be given basic information about the campaign. While documenting the case it should be made explicit to the person that there may not be any direct personal gain of presenting the testimony in a public hearing. The difference between grievance redressal forum and public hearing should be explained clearly to all the participants -- otherwise, there is a fear of disappointment later. The person should be given the idea that the case may be presented in the public hearing in the presence of Government officers and the panel members. There is a possibility that these testimonies would be submitted to NHRC. In that case, NHRC may investigate these cases. However, we cannot guarantee the outcome of the investigation.
- ❑ Attempt should be made to ensure that if a documented case is to be presented at a public hearing, the **person affected** or somebody close to the patient (relative or friend) **would present** the case in her/his words. This should, however, not be an absolute necessity – i.e. some testimonies may be presented on behalf of the patient by the organisation involved in documenting the case.

IV. Framework to document rights violations in Private medical sector

The second day of each public hearing will be focused on Patients' Rights in context of Private Healthcare providers. This is a relatively new area for many of us health activists in JSA, and obtaining information on this may be more difficult. So there is need to be innovative and to explore different sources of information/data regarding violation of patient's rights related to private healthcare providers. Barring the exception of Charter of Patient's rights in the Rules of Chhattisgarh Nursing Home Act, no other state / central law has yet clearly laid down patient's rights in a legal format. However there are many entitlements that emerge from various

Supreme Court judgments, judgments by Chief Information Commissioner and Code of Ethics of Medical Council of India etc, which can be used to make a strong case for patient's rights.

What is our objective while presenting cases from the private sector in NHRC hearings?

Today, due to the highly commercialised and unregulated nature of the private medical sector in India, a very wide scale of violations of patients rights are taking place on a frequent basis. We need clearly defined, legally protected patients rights, an effective regulatory system, and patient-friendly redressal mechanisms to check these widespread violations – all of which currently do not exist. As one step to build a climate for such provisions, we will be presenting testimonies of violations of patients' rights in the private sector during NHRC-JSA hearings. It is foreseen that in a desirable scenario (assuming that NHRC is positive and is willing to take appropriate action), we can attempt to achieve the following objectives related to the private medical sector through the NHRC hearings:

- a. In some cases, where clear violation of patients rights has taken place, NHRC may order or recommend that the concerned regulatory body (e.g. State Medical Council) should take action against a particular doctor or hospital
- b. If there are a large number of instances of a similar nature (e.g. non-display of rates by many hospitals and doctors), it can be argued that State Medical Councils should have special drives to ensure compliance with the Code of Ethics. Given widespread violations of the MCI Code of Ethics linked with violation of patients' rights, NHRC could recommend that State Medical Councils set up special cells or other mechanisms to deal with patients complaints in timely and proactive manner.
- c. Based on our documentation of widespread violations of patients' rights, it can be strongly argued with State governments that they should include provisions to protect patients' rights in their state level CEA / Rules, or if they have adopted the National CEA then they should adopt the state level rules, and accelerate implementation of CEA in the state.
- d. Keeping in mind the evidence of large scale and recurrent violation of patients rights that would be generated through the entire series of hearings, we can think of convincing NHRC to give a complaint to the Central government to intervene in the functioning of MCI to protect patient rights. There is even possibility of filing a PIL, presenting the large number of instances of patient rights violations and asking that MCI and State Medical Councils must take proactive steps to ensure protection of various patients rights that are linked with the MCI Code of Ethics.

Here we need to keep in mind that out of the wide diversity of violations that patients are facing, today due to inadequate legal provisions, only in certain kinds of cases we can claim with some legal justification that rights violations have taken place. For example, the Medical Council of India, which is supposed to regulate the conduct of doctors in India, has a '**Code of Medical Ethics Regulations**'. This code specifies the ethical guidelines to be observed by doctors during their dealings with patients, with each other, with the general public, and with the pharmaceutical industry. If any doctor violates this code of conduct which may be related to

violation of the rights of a patient, then that doctor is legally liable to punishment by the council. Similarly, the Supreme court of India and National Consumer Redressal Commission have made certain judgments in favour of patients who have suffered from serious problems in private hospitals. There are also some obligations that 'charitable' or 'Trust' hospitals are supposed to fulfill related to patients from economically weaker sections. Based on these considerations, we have compiled below a list of possible areas of violations, especially where some legal justification exists to claim that in these kinds of cases, it should be considered a legal violation (B.1 below). During the NHRC hearings, we will need to focus on these kinds of cases, since NHRC may not be willing to consider taking action on problems, where no concrete legal justification exists today to claim that these are rights violations.

What kind of issues could be presented related to private medical sector, during NHRC hearings?

Three broad types of issues may be considered, related to violation of Patients rights in the private medical sector.

I. Possible types of direct denial of patients rights in the private medical sector, which have some legal justification today

- 1) Denial of Emergency medical care in hospital, on the grounds that emergency treatment would be started only after payment is made by patient / caregivers
- 2) Patient / caregivers not provided basic information related to nature of treatment and related costs in a private hospital
- 3) Patient is not given records / reports on demand during period of hospitalization
- 4) Denial of right to second opinion – patient or caregivers not allowed to consult another doctor / specialist during period of hospitalisation
- 5) Denial of right to informed consent – proper information not provided before operation or other invasive procedure
- 6) Not respecting patient's privacy, or not keeping confidential the identity of the patient.
- 7) The dead body of a deceased patient is not handed over to the relatives, until the full payment of all expenses has been made to the hospital. Similarly, newborn baby is not handed over to the mother, until the full hospital expenses have been paid.
- 8) Patient is coerced into buying medicines from a specific medical store in the hospital premises
- 9) Patients rights denied during a clinical trial – proper informed consent not taken, full information about trial not provided, treatment for trial side effects not given, insurance coverage related to trial not provided, obtaining consent from the poor patients by providing them other benefits or threatening of losing benefits, etc.
- 10) Patient from economically weaker section denied treatment in a 'Charitable' / Trust hospital which is supposed to reserve certain proportion of beds for such patients (this provision is applicable only in some states like Delhi, Maharashtra)

We propose that collection of individual testimonies related to the private medical sector should be focused on these areas of denial.

II. Some issues that have a bearing on patients rights, but information on these needs to be collected from sources besides patient testimonies

There are certain important issues which are related to fulfillment of patient rights, and for which some legal provisions exist. However, we may not get information about these from patient testimonies, if possible evidence on this may be collected in other ways, for example:

- 1) **All doctors are supposed to display their professional rates** (MCI Code of Ethics), however very few doctors do so. This can be documented by visiting some clinics / hospitals.
- 2) **Doctors are not supposed to take gifts or sponsorships from pharmaceutical companies** (MCI Code of Ethics). They are also not supposed to sponsor such products. Naturally, the massive amounts that drug companies spend on doctors are recovered through charging very high drug prices from patients. However information about this could be provided by Medical representative associations or other 'internal' sources.
- 3) **Doctors are not supposed to give or take commissions in any form**, in their relationships with other doctors (MCI Code of Ethics). Again, information on this is difficult to obtain except from certain ethical doctors who may have been offered but have refused such commissions in the past.
- 4) **Doctors are supposed to prescribe medicines by generic names as far as possible**, which would lead to reduction in the cost to patients (MCI Code of Ethics). However, as we know, this does not happen usually. To document that this is not taking place, we could collect say 100 prescriptions by private doctors, which do not mention the generic name of the drug.

III. Some major problems faced by patients in private hospitals, which are not included in the above categories

It will be obvious to Health activists that many important problems faced by patients in private hospitals are not included in the above list, for example:

- 1) **Medical negligence**, where the quality of medical care provided is sub-standard or deficient leading to bodily damage, and in some cases even death of the patient
- 2) **Gross over-charging** and arbitrary charging of patients, forcing patients to pay large sums of money for treatment, but no justification is apparent for the scale of charges
- 3) **Irrational and unnecessary procedures** including medication, investigation, operation or other treatment that is provided by a hospital / doctor, even though it is not indicated according to rational treatment guidelines and medical textbooks

Among these, the first issue i.e. Medical negligence is covered under the Consumer Protection Act. If such cases are presented to NHRC, they would most probably direct such persons to approach the relevant consumer redressal forum. The second and third issues are very serious and widespread, perhaps forming the main basis for popular dissatisfaction related to the

private medical sector today, however until these areas become regulated through Clinical establishments Acts including regulation of rates and standard treatment guidelines, they may not be regarded as legal violations in the current situation. Hence it is doubtful if presenting information on these areas to NHRC would be followed by any specific action from their end, and it may not be productive to ask people to present testimonies on these areas to NHRC. However these issues could be raised in a general manner, demanding for these concerns to be addressed through operationalisation of appropriate CEAs, since they obviously have a major bearing on the protection of patients' rights.

There would be three sessions on Day Two of the session on violations in the private sector:

Session 1 - testimonies on individual cases violations of Patients' rights and Human rights violations in Private hospitals;

Session 2 - Patients' Rights violations in context of publicly supported Health insurance schemes and Public Private Partnerships;

Session 3 - Ensuring effective regulation of Private medical sector for protection of Patients' rights;

Information would need to be collected for all three sessions, but in this set of guidelines we will focus on collection of information for Sessions 1 and 2, which would be the largest sessions on the second day and would involve maximum amount of data collection and analysis of information.

It is expected that around four-five hours would be available **for session 1 and 2**, in which five to six states from the region would need to make their presentations, also there would be responses from health officials, medical council officials, comments by NHRC members / officials.

Keeping in view that there would be two parallel sessions, **each state may get around total 60-80 minutes (depending on the number of states in the region that participate in the hearing) for making their entire set of testimonies and presentation of any other data in session 1 and 2 collectively.**

Main types of information to be collected related to private medical sector

- a. **Individual cases of major violation of patient's rights in private hospitals (last one year)**

Some of the examples of patients' rights, regarding which cases of denial can be collected, are as below-

- *Denial of right to medical records and right to information*

- *Denial of right to emergency medical care, insisting on payment to be made before starting treatment*
- *Denial of right to free medical treatment to survivors of gender related violence including acid attack*
- *Denial of right to second opinion*
- *Denial of right to human dignity*
- *Discrimination related to patient from marginalized sections of society, people living with HIV/AIDS etc*
- *Insisting that medicines must be purchased from Hospital's own medical store*
- *Refusal to hand over dead body of patient until entire hospital fees have been paid*
- *Non-provision of free beds to poor patients in enlisted Trust / Charitable hospitals*
- *Performing clinical trials on patients without proper informed consent; other unethical practices in clinical trials*

Individual testimonies can be collected through our network of contacts, various types of formal and informal networks, through collected responses to NHRC advertisement etc

- b. **Individual cases of major violation of patient's rights in private hospitals, negligence etc which are pending before State Medical Councils for very long time** without any progress or relief; thus showcasing the failure of Medical councils.
- c. **Individual cases of denial of entitled services in publicly funded healthcare insurance schemes like RSBY, Arogyasri or PPPs.** This may include various levels of denial including non-provision of cards to deserving families, non-provision of care to person approaching an empanelled hospital, extra charging by the hospital despite the patient having coverage under the scheme, and gross deficiencies in provision of care through such schemes. *(see section V below)*
- d. **Testimonies from selected rational doctors about instances of gross irrationalities in healthcare** including unnecessary tests, unnecessary procedures, commission practices etc.
- e. **Testimonies by representatives of associations of Medical Representatives about Pharma companies –doctor / hospital nexus,** involving unethical gifts, sponsorships, trips etc., which is linked with denial of access to affordable medicines.
- f. **Surveys of private hospitals, trust hospitals, prescription studies, patients undergoing clinical trials etc demonstrating that poor oversight of medical councils and lack of effective participatory regulation** of private healthcare sector without provision of patient's rights leading to large scale violation of patient's rights.

Some selected surveys can be undertaken and their findings can be presented.

E.g. MCI Code of Ethics says that "A physician shall clearly display his fees and other charges on the board of his chamber and/or the hospitals he is visiting". Similarly it also says that physician should write preferably generic names of medicines in a prescription.

Hence, a survey of say 5 - 10 private facilities and prescriptions in a geographical area can be done to assess observance of these provisions and this can be presented in the public hearing.

- g. **Secondary data** which supports our arguments about need for effective regulation of private providers along with standardization of healthcare and standardization of costs; and highlights failure of PPPs etc

V. Documenting rights violations related to Govt. funded health insurance schemes and PPPs

a. Documentation of rights violations related to Govt. funded health insurance schemes

Presently patients are experiencing various kinds of denial of health rights, when they seek services in context of Publicly funded health insurance schemes (GFHIS). These schemes may be the centrally organised Rashtriya Swasthya Bima Yojana (RSBY) or state specific schemes. Some examples of state specific schemes are as follows:

Name of scheme	State
Vajpayee Arogyashree Yashaswini	Karnataka
Mukhyamantri Swasthya Bima Yojana	Chhattisgarh
Aarogyasri	Andhra Pradesh & Telengana
Rajiv Gandhi Jeevandayee Arogya Yojana	Maharashtra
Chief Minister's Comprehensive Health Insurance Scheme	Tamil Nadu

It will be important for us to first understand the specific scheme that is functional in our state and its entitlements, and then collect information accordingly. Consent must be taken as per the consent form circulated for patients/families.

The possible common rights violations under these schemes and the broad framework for documenting them, are discussed as follows:

1. **Enrolment and exclusion of eligible families-** All these schemes have their ‘target group’ who are supposed to be enrolled under the scheme. However, we may find that certain ‘eligible’ families/communities/vulnerable groups (eg. dalits, STs, Sexual minority groups, sex workers, , mentally and physically challenged, migrants etc) have not been able to enroll under this scheme and therefore are not able to access this scheme. We may get this formation from

program data, surveys or field experience. In such situations, we need to document the following:

- Who has not been covered? (It may be an individual household, a whole village or a vulnerable group). Why have they not been enrolled?
- What attempts have been made by the government to enroll them? If any attempts have been made by the people to enroll themselves, like writing application to the government, informing the panchayat etc., then this should be noted.
- What kind of expenses and distress did they have to face as a result of not being enrolled in the scheme? Explore financial distress, issues of access, denial of services, negative outcome etc.

2. Out of pocket expenditure despite being enrolled under the insurance scheme- Once a family is enrolled in such a scheme, they are entitled to cash-less (i.e. free) treatment under various packages (depending on the scheme) from empanelled (public or private) hospitals. However, it is found that in many cases, either treatment is denied under the scheme or the patient is made to incur out of pocket expenditure for the treatment.

Scenario 1- The patient is enrolled in the scheme, and the hospital is empanelled, however, the hospital refuses to utilise the insurance scheme and bills the patient for the entire treatment or the patient has to go to another hospital.

Scenario 2- The empanelled hospital bills the patient under the insurance scheme but in addition to that, takes money from the patient on some pretext (like saying that the package cost is not enough or that patient has to pay for bed charges, medicines etc).

(Questions to document the details in such situations are included in the format for individual denial in context of private medical sector).

3. Discriminatory treatment at the hospital - It has been found that often, patients admitted under these insurance schemes are provided a kind of 'second class' treatment. At times there is a separate ward for these patients, separate medicine shop and other discriminatory arrangements. Such instances could be documented.

4. Irrational & unnecessary procedures- A lot of evidence on irrational care and unethical practices have emerged with respect to these insurance schemes; for example, unnecessary hysterectomies & C-sections. We may encounter individual cases or may identify a trend across districts, or across hospitals. This information may be collected using the protocol for documenting rights violations in private medical sector, in addition to details regarding utilization of the insurance scheme for the treatment (out of pocket payment, experience on hospital, attempt for grievance redressal).

5. Documenting violation of right to equal access to health care & right to information- By virtue of it being a 'business model', these insurance schemes adhere to market principles,

thereby excluding the most vulnerable who are both economically & politically powerless. This inequity is reflected both in enrollment, and utilization. The secondary data, if available, can be analysed to detect such underserved pockets and thereby a case made for denial of rights. Analysis of claims to private and public providers could also be done. The issue of non-transparency and non-availability of data of these insurance schemes using public funds could also be documented as a denial of the right to information.

To obtain information about patient experiences in context of GFHIS, we have included some questions in the format to document individual testimonies related to the private medical sector. Those patients who have taken care from a private hospital, and are supposed to be covered by a GFHIS may have suffered from specific types of denial or health rights violations, which can be documented through this format.

b. Documenting cases related to ‘Public-Private Partnerships’ and privatisation of public health services

There are many forms of private sector involvement in providing public health services in India, some of which are very old. There is a tendency to characterize many public-private collaborations as PPPs, although they vary widely in nature. Therefore, we should look at the impact of all forms of privatisation (or private sector involvement). The evidence on the performance and impact of these models should be documented and included for the NHRC hearings. This may be documented in the form of individual cases of denial or by collating the evidence on the performance of a particular model.

It is important to note that there is a variety of such arrangements. We would first need to list them for our states. Some examples of privatisation models are laid out in the table below¹:

Sr. No	Name of the PPP model	Type of Engagement	Private Entity / Service provider	Geographical Area
1	Chiranjeevi Scheme, Thayibhagya Scheme, Janani Sahayogi Yojana	The GoG ⁺ contracts-in private facilities to deliver Maternal services for BPL patients. Package is fixed for 100 deliveries irrespective of normal or c-section delivery. Package amount varies from state to state	Empanelled Private practitioners	Gujarat, Karnataka, MP
2	Arogya Raksha Scheme – Voucher based system	A GoAP scheme in which anybody who undergoes sterilization is given a voucher which provides hospitalization and personal accident benefits.	New India Assurance Company and private facilities.	Andhra Pradesh
3	EMRI (108) –	Many state governments have	EMRI	Many states

¹ From Asha Kilaru, Prasanna Saligram, Sudha Nagavarapu, Anna Giske. 'Some health care for some people, some of the time': An exploratory study of public-sector health services and privatisation in Karnataka in the context of Universal Access to Health Care. Working paper 2013

Sr. No	Name of the PPP model	Type of Engagement	Private Entity / Service provider	Geographical Area
	Emergency Medical Services	understanding with EMRI to undertake emergency medical services (ambulance services). A contracting out mechanism. Similar schemes are the Janani Express in MP.		
4	Adoption of PHC by NGO	State governments hand over the PHC to organizations for running them. One more contracting out mechanism	NGO	Karnataka, Orissa, Arunachal Pradesh etc.,
5	Family Planning Services – I	Agreements were signed between NGOs and the central government to provide family planning and outreach services. These agreements are now managed by state governments. In some case, building and equipment is also provided	NGO	Select states in India, including Karnataka
6	Family Planning services - II	Family planning services are contracted out to private facilities, nursing homes and clinics.	Accredited private facilities	Bihar
7	Haryana Urban RCH model	Private service provider is roped in to deliver specific services to urban residents. The provider gets an incentive of Rs. 100 per patient per year.	Private service provider	Haryana
8	Concessions to corporate hospitals	Government provides concessions such as land, tax exemptions etc. to corporate / Trust hospitals in exchange for free treatment (both IPD and OPD) for BPL families.	Corporate or Trust hospitals	Many states
9	Government hospital run by corporate chain	Government constructs hospital and then hands it over to corporate chain in exchange for free treatment (both IP and OPD) for BPL families	Corporate hospitals	Karnataka, Chhattisgarh
10	Radiological services contracted out to private parties	Government contracts out radiological facilities to private parties who will levy user charges to recover their costs. The patient welfare committees (Rogi Kalyan Samiti) will reimburse the BPL patients	Private facilities	West Bengal, attempted elsewhere
11	Contracting out of Non-clinical services to private companies	The hospital contracts out dietary and kitchen services, Cleaning/Scavenging and laundry facilities to private entities. BPL families get diet free of charge and other patients pay 50% of the charges.	Private entities	West Bengal
12	Service delivery for national health programs	Private service providers contracted in for providing OP services on TB, Leprosy and so on	Private facilities	Nationwide
13	Social Marketing	Government provides subsidized contraceptives to selected organizations which piggy back the marketing of these	Hindustan Latex Limited and other such companies	Nationwide

Sr. No	Name of the PPP model	Type of Engagement	Private Entity / Service provider	Geographical Area
		contraceptives along with their products.		
14	Telemedicine and Tele Health project	GoK has entered into a contract with Narayana Hrudayalaya to provide online tele-diagnosis and consultation for coronary care in select district hospitals	Narayana Hrudayalaya	Karnataka
15	Build, Own, Operate and Transfer (BOOT)	The GoAP through the Rajiv Arogyasri Trust has entered into a BOOT agreement with Braun for setting up of Hemodialysis units in government hospitals. BPL and Arogyasri card holders are entitled for free treatment and the government reimburses the costs upto Rs. 10000 per month per patient	Braun Company	Andhra Pradesh
16	Contracting-in of specialists	Contracts signed with specialists or contracting firm for their services. Paid on a case-by-case basis	OB-Gyn's company, individual private practitioners	Karnataka

The following questions could be asked in an analysis of the privatisation model – as a case Study of PPPs in the state.

1. What is the type of service provided by the private sector under the PPP arrangement?
2. For how long is the contract valid?
3. Stated reasons for involving the private sector in this arrangement.
4. What is the private provider being paid for this service? Compare with public provider costs for the same.
5. What are the grievance redressal mechanisms? What are the penalties for the private provider?
6. What negative impact has this model had on the public health system/services (e.g. reduced utilisation).
7. Individual denial cases to be documented keeping in view the expected services to be provided vs. actual experience of patients.

Any study of a PPP arrangement in a state may require developing a more specific framework for the study, based on the exact nature of the PPP. Hence it is advisable that JSA activists could contact one of the following JSA activists for inputs, while developing a framework to study a specific PPP in their state:

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