

Format - II

Documentation of individual testimonies of denial of Health rights in Private medical facility

Although denial of patients' rights in the private medical sector is widespread, it is more challenging to document these violations, because a legal framework of rights related to private health care providers is not yet well established in India. The following steps would need to be taken while documenting such violations:

Step 1: Preliminary identification of individual cases of violation of patient rights: by making enquiries in family - social circles - neighbourhood - in place of work - social organisations - among people who work with us, doctor friends, etc; and through the responses to the NHRC advertisements that will be published in newspapers. (NHRC would admit complaints only related to incidents that have taken place in last one year).

Step 2: Once some cases of possible denial have been brought to your notice, then collecting all relevant information using the protocol given below. This should be preceded by obtaining informed consent and explaining the context, what to expect and not to expect from the public hearing.

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

Step 4: Orientation of the affected person and his/her family who would make presentation at the hearing, Briefing about speaking before a bench, possible outcomes, assurance of confidentiality, etc

Protocol for collecting information from individuals, who sought care from a private health care facility

If an individual has been denied any health service in a private health facility, then the following information should be collected. Before proceeding with the information collection, the person should be told about the purpose behind information collection, namely about the NHRC-JSA hearings, about the possible outcomes, and should be asked for informed consent to the whole process.

A copy of the Informed Consent Form has to be given to the respondent and another copy kept with the interviewer, with signatures of both parties.

INFORMED CONSENT FORM

A series of public hearings on rights of patients is being held across India by the National Human Rights Commission (NHRC) and Jan Swasthya Abhiyan (JSA). These hearings will focus on denial of health services to individuals and other kinds of patients' rights violations in the public and private health care services in India. The purpose of these hearings is to draw attention to key systemic and policy related issues that are giving rise to such denial of services and violations. These hearings would provide a much-needed platform to present and discuss key issues related to violation of Health rights of people in various parts of India, and would lead to issuing of a series of recommendations, and would help build a climate for adoption of various measures required to ensure protection of health rights. A list of the range of denials and violations that often take place is appended with this Form.

An important component of these hearings is presentation of individual testimonies by persons (or family members) who have suffered some serious denials of services in a hospital or some other healthcare facility. Hence, on behalf of NHRC-JSA we request you to share your experience(s) of the problems and denials that you or your family member faced while trying to get medical care.

Participation in this process is completely voluntary and may not necessarily lead to any personal compensation or benefits for you. The idea of collecting such information is to focus attention, through such individual cases, to the widespread problems in both government and private health services in India today; and through this to initiate improvements in them in the overall public interest and for public welfare.

We assure you that all the information that you share shall be kept confidential and personal information, such as name and contact details etc, would only be given to the NHRC and concerned JSA representatives, and shall not be revealed in other public form without your permission. If you wish to, you can be present at the public hearing and present your case before the group of officials from NHRC, health department and other eminent citizens.

So, you have to decide whether or not you wish to participate in this process. There is no pressure on you for this. If you do not wish to answer some question during the course of the interview, you have the full right to do so. Similarly, for any reason, if you wish to stop the interview in the middle, we will stop there and then. There will be no negative impact of this. If you have any queries about this process, please feel free to ask questions. If you wish to participate in the interview, please give your permission/consent about the same.

If you decide to participate then you will be asked to share information as per the given questionnaire. You will also have to give copies of relevant case papers and receipts, etc. All this information will be also submitted to the NHRC.

I, declare that I have received detailed information about the public hearings on denial of services and rights of patients in public and private healthcare facilities, being held by NHRC-JSA in different regions of the country.
I am ready to participate in this process.

Signature/Thumb impression/Oral consent of respondent: _____

Name and address of the respondent

Signature of Interviewer: _____

Date: _____

There are two scenarios related to patients approaching the Private medical sector – either the patient may be without any medical insurance, or patient may have cover of some government health insurance scheme like RSBY or state health insurance scheme.

Therefore two different formats are being given below, to be used accordingly.

Format IIA is to be used for those patients who do not have any health insurance.

Format IIB is to be used for those patients who are covered by some health insurance scheme.

Format II A – for documenting denial of individual patient’s rights in private facilities (patient not covered by any insurance scheme)

QUESTIONS TO BE ASKED, after explaining and getting the Informed Consent Form signed

1. Who is the affected Person: Self / Family member or friend

2. If family member, then relation to the person giving the information: Mother/father, spouse, sibling, son/daughter, friend, other

3. Name of affected person/patient:
Name of related person giving information:

4. Age of affected person/patient: years

5. Gender of affected person:

6. Address for correspondence:

7. Name of private hospital / health care facility where violation has been experienced with address (city, town):

8. Which kind of facility - is it a Private Hospital / Private nursing Home / Specialty Hospital / Individual doctor’s clinic?

9. Date of admission / visit to hospital: (at least month and year)

10. Reason for going to hospital: (emergency / accident/delivery/acute illness/ chronic illness / planned operation or procedure / routine checkup / other)

11. In the hospital was there any display board, showing the rates for services provided by doctors? Yes/ No

Experience in the hospital

1. What happened, describe sequence of events -

○ Illness / complaints for which you visited the hospital (emergency – accident / delivery / acute illness / chronic illness / follow-up / routine check (in pregnancy etc.) / other

○ Total Number of visits to the hospital for this illness; also specify whether visits were for OPD or IPD

○ Date of visit / period of stay when denial took place –

○ During hospital stay, regarding conditions that required prompt care, was the doctor available on call to attend to the patient? Were nurses or hospital staff available to attend to the patient as and when required?

2. **What kind of patient's rights violations occurred? Give details about any of the following which may be applicable: (Mark any of the following which are applicable, for those points which are applicable, take further details)**

- In case of accidental emergency, were you made to deposit some money before being attended to, or were you asked to pay the complete amount before starting treatment;
- Did the doctor / hospital provide information in advance about expected cost of treatment and diagnosis, broad line of treatment;
- Was an attendant or female nurse present during examination of female patient
- Did any doctor /staff/hospital authority discriminate against you in course of providing treatment on basis of HIV status or other issue;
- Did hospital perform any surgery without taking your informed written consent; was proper information not provided before operation or other invasive procedure?
- Were you denied access to your medical reports and results of tests when these were demanded;
- Were you allowed to seek second opinion or was this discouraged / prevented; were patient or caregivers not allowed to consult another doctor / specialist during period of hospitalisation?
- Were you instructed to purchase medicines or get tests only from a particular store or centre;
- In case of charitable trust hospitals, were you given information about free or subsidized treatment as per rules of hospital;
- In case of charitable trust hospitals, were you given free or subsidized treatment as per rules;
- Were you included in a clinical trial, without being given proper and complete information about the trial, or did you experience other significant problems as a result of this trial (if yes then refer to question 7 below);
- Did hospital keep patient/ new born baby/ body of deceased patient as hostage, and made their release dependent on payment of full bill;

3. Do you feel that any procedure/operation performed on you/affected person was unnecessary? Do you have the opinion of any doctor or comparison with similar case to support your impression?

Expenses in hospital

4. Were the doctor's fees displayed in the hospital? Did the hospital provide you an estimate of expenditure at the beginning? If yes, was final bill within 10% range of this estimate? If not, did you contest the final bill? Was there any bargaining with the hospital? If Yes, did hospital reduce the bill? By how much?
5. Total Expenses at the hospital – for consultation, diagnostics, medicines, transport, room and other charges in case of indoor patients?
6. Based on your experience and comparison with similar cases, do you feel that you were grossly overcharged and forced to pay excessive sums of money for treatment without appropriate justification? Please state the logic or justification for your impression.
7. How did your family pay for these expenses - Did your family have to sell any assets (land, cattle, jewelry etc.) or take loans to make these payments?
8. Did you get a receipt for all the payments you made – for consultation, for test if any, for medicines if purchased from shop within hospital, any other? Yes / No
9. Due to gaps in treatment given, or not being attended to in emergency, was there any serious impact on the patients' health? (Due to denial of emergency services or other forms of denial, there was risk to patient's life, or health problem worsened, or patient became disabled, or patient died.)
10. If patient was enrolled in a clinical trial, then describe what happened, and which rights were denied. In case of clinical trial patient, did any of the following happen with the patient?
 - 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 poor patients by promising them other benefits, or threatening that they would lose benefits if they did not participate in trial
 - any other relevant violation

11. If there was any perceived violation then did you seek some redressal? If yes, then what/whom did you approach?

12. Was your complaint/grievance addressed? How? Do you have copies of the complaint, etc?

13. Do you know of any other such cases of violation in the same hospital? Or in any other hospital? Can you give contact of details this person?

Collect copies of discharge card, investigation reports, hospital receipts and bills and any other relevant documents

14. ANY OTHER RELEVANT INFORMATION GIVEN BY PATIENT/RELATIVE

Format IIB – for documenting denial of individual patient’s rights in private medical facility (patient is covered by some government funded health insurance scheme like Rashtriya Swasthya Bima Yojana, Arogyasri Yojana etc)

There could be two possibilities when a patient with cover by government supported health insurance scheme goes to a hospital:

Scenario 1- The patient is enrolled in the scheme and the hospital is empanelled, however, *the hospital refuses to utilize the insurance scheme and asks the patient to pay for the entire treatment*, or the patient is made to go to another hospital.

Scenario 2- The empanelled hospital admits the patient under the insurance scheme but *in addition to billing the insurance company / deducting charges from the insurance coverage amount, the hospital also takes money from the patient on some pretext* (like saying that the package cost is not enough, or that patient has to pay for certain charges, medicines, procedures etc).

QUESTIONS TO BE ASKED, after explaining to patient and giving Informed Consent Form

1. Who is the affected Person: Self / Family member or friend
2. If family member, then relation to the person giving the information: Mother/father, spouse, sibling, son/daughter, friend, other
3. Name of affected person/patient:
Name of related person giving information:
4. Age of affected person/patient: years
5. Gender of affected person:
6. What government funded insurance scheme does the patient have – name of the scheme:

(Take a copy of the card / papers provided under the scheme).

7. Address for correspondence:

8. Name of concerned hospital / health care facility and address (city, town):

9. Is it a Private Hospital / Private nursing Home / Specialty Hospital / Individual doctor's clinic?

10. Is the hospital empanelled for this government funded insurance scheme? Yes/ No

11. Date of admission / visit to hospital: (at least month and year)

12. Reason for going to hospital: (emergency / accident/delivery/acute illness/ chronic illness / planned operation or procedure / routine checkup, etc)

13. In the hospital was there any display board, showing the charges of services provided?
Yes/ No

14. Did you have balance in your insurance cover or was your insurance limit completely used up?

Yes, had balance / No, did not have balance

If your illness was covered by insurance and if you had balance, then did the hospital utilize the insurance scheme to cover the costs?

If hospital did not use the insurance cover, what was the reason? Were you sent away without treatment or referred to some other hospital?

If the hospital utilised the government funded insurance scheme and treated the patient, then proceed with the following questions.

Experience in hospital

15. What happened, describe sequence of events - (Interviewer will have to probe and get specific details depending upon the answer– such as - were you asked to deposit some money before being attended to, or were you asked to pay the complete amount before starting treatment; did the doctor / hospital provide information in advance about expected cost of treatment and diagnosis, broad line of treatment; were you made to purchase medicines or get tests from only a particular place; were you provided all reports and results of tests on demand; were you allowed to seek second opinion; were you given full information about the procedures under the insurance scheme, etc.)

- General description of main symptoms and problem being faced by patient:

- What treatment were you given? (including whether examination was done, tests prescribed, medicines given etc.) (Take copies of the case paper)

- Were examination / treatment / operation delayed or denied because of non-availability of doctor or specialist?

- During hospital stay, regarding conditions that required prompt care, was the doctor available on call to attend to the patient? Were nurses or hospital staff available to attend to the patient as and when required?

- Was an attendant or female nurse present during examination of female patient?

- Do you think that non-availability of any crucial equipment or supply (oxygen, incubator, anaesthetic equipment, ventilator, blood, emergency drugs etc.) or diagnostics adversely affected the quality of care?

○ Were all the equipments required for the examination and treatment of the patient available in working condition in the hospital?

16. Total Expenses at the hospital – for consultation, diagnostics, medicines, transport, room and other charges in case of indoor patients?

Were these charges covered fully by your government funded insurance scheme?

17. If the hospital used your government funded insurance cover, in addition to that, did they charge extra money from you on some pretext (like saying that the package cost is not enough or that patient has to pay for bed charges, medicines etc). Yes/No

If the hospital charged extra money, above the insurance cover, then for what – at time of admission, for consultation, for treatments or some procedure, for medicine?

How much extra money did you have to pay?

Did you get a receipt for these payments?

How did you raise the money for these extra payments?

18. Do you feel that you were you treated differently from other patients who did not have government funded insurance and who were paying from their pockets? For instance: were you kept in a different ward from the paying patients, or given different kind of food, or any other kind of treatment, or callous behaviour?

19. Any other problems/issues in getting benefits under the government funded insurance scheme?

20. Did the family seek any redressal from the hospital or government? If yes then what happened?

Analysis: (To be done by Health activists involved in screening of cases)

A. What are the major forms of rights denial observed in this case? Is there evidence that any of the Patients' rights (list mentioned in section 2 of IIA on page 5 above) has been denied?

Note: In any case related to the private medical sector, there is likely to be a combination of various issues and problems; in many cases general overcharging and performing unnecessary procedures may be combined with other issues. However an attempt should be made to identify the specific rights denials mentioned on page 5, to the maximum extent possible.

B. What were the major negative consequences – physical, mental, financial – due to these denials?

C. Can any public authority be held answerable for preventing such violations? (like State Medical Council / State Health Department responsible for Private sector regulation / Government authority or body managing the Health insurance scheme / Charity commissioner responsible for ensuring fulfilment of obligations by charitable hospitals)

D. What is the main redressal now being asked for by the complainant(s)?