

## **Format - I**

### **Documentation of individual testimonies of denial of Health rights in Public health facilities**

Step 1: Collecting/identifying individual cases of some kind of violation of patient rights: through enquiring in family-social circles-neighbourhood-in place of work-among people who work for us, doctor friends, etc; and the responses to the advertisements that will be put out shortly. For action to be taken on a complaint by NHRC, the perceived 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 using the protocol given.

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

Step 4: Selecting from cases shortlisted in Step 3 above to be presented at the actual hearing in the region.

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

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### **Protocol for collecting information from individuals related to denial in Public health facilities**

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

A copy of the Informed Consent Form (see below) 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.

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, shall not be revealed in public reports, except to the NHRC. If you wish to, and if your testimony is selected for presentation, 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 can 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:

**QUESTIONS TO BE ASKED FROM PERSON(S) GIVING TESTIMONY REGARDING DENIAL OF HEALTH RIGHTS IN PUBLIC HEALTH FACILITY**

*(These questions provide a broad outline for documentation of the testimony of denial. However the interviewer will also have to probe further and get additional specific details depending upon the answers given, such as - were you made to wait for a long time in emergency; or were you not examined by doctor; or did the doctor or staff behave improperly or rudely with you; or were you made to go to a private facility for purchasing medicines or get tests, etc....)*

1. Affected Person: Self / Family member:
  
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 relative giving information:

4. Age of affected person/patient: ..... years
  
5. Gender of affected person:
  
6. Whether the family has BPL card:
  
  
7. Address for correspondence:
  
  
  
8. Name of health centre/hospital and location (city/village, town, Tehsil, District and State):
  
  
  
9. Date of incident: ..... (at least month, year)
  
  
  
10. Date of Interview:.....

**Experience in hospital : Details of care received at PHC / CHC / Rural Hospital / Sub-Divisional Hospital (SDH) / District Hospital (DH) / Urban Health facility**

- Location and type of Health centre / Hospital –
  
- Illness / complaints for which PHC / Hospital was visited (emergency such as accident / delivery / acute illness / chronic illness / follow-up / routine check (in pregnancy etc.), immunization of child, etc)
  
- Total Number of visits to PHC / CHC/ Hospital for this illness; also specify whether visits were for OPD or IPD?
  
- Date of visit / period of stay when denial took place –

**1. History of last visit in the patient's / attendant's words –**

(Here we want to collect information regarding the main symptoms of the patient, who gave care at the hospital, and what kind of examination, investigation and treatment were given)

General description of main symptoms and health problem for which the patient sought care:

- What treatment were you given? (including whether examination was done, if directly sent to other hospital without any care, if health centre/hospital was closed and hence had to go to other hospital/centre)

(If affected patient was referred to another hospital after examination and some immediate care, then **go to Section 5 directly and fill it up**. In case the patient was directly sent to another hospital without giving any care, or the health centre/hospital was closed and hence affected patient had to go to other hospital/centre then go to **section 6 directly and fill it up**.)

- What were the perceived shortcomings or deficiencies in care? (As perceived by the patient or attendants)
  
- According to patient, was there any **adverse outcome** because of deficient or negligent care? (Death, disability, continued or chronic health problem, severe financial loss e.g. major loan taken or sale of assets)

## **2. Medical attention received:**

- Name of the doctor who attended to you –
  
- How long after you reached the PHC / Hospital did the Medical Officer / Doctor attend to you?
  
- If the doctor was not available at that time, then who attended to you and *after how much time?*
  1. Nurse / ANM-
  2. MPW-
  3. Pharmacist-
  4. Any other person, specify-
  - After how much time were you attended?
  
- Were examination / treatment / operation delayed or denied because of non-availability of a nurse, 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, medicines 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?

**Diagnosis-** (as told by the doctor – get a copy of the case paper / discharge card if available)

### **3. Medicines and diagnostics:**

- Did you get all the required medicines at the PHC / Hospital?
- Did you have to go to any private medical shop to buy some medicines?
- If so, which medicines you had to buy from private medical shop?
- How much did it cost?

- Do you have the prescription? (If yes, obtain a Xerox of the same and attach)
- Did you get all the required investigations at the PHC / Hospital?
- Did you have to go to any private diagnostic centre (Lab, X-ray or Sonography centre etc.)?
- If so, which investigations had to be done from outside? How much did this cost? (attach referral slip and bills / receipts)

#### **4. Expenditure:**

- Case paper fee / indoor fees charged
- Did you receive a receipt for the payment made?
- Were you charged excess money at the PHC / Hospital (more than specified rates)?
- If yes, how much excess was charged? To whom was the payment made?
- Did your family have to sell any assets (land, cattle, jewelry etc.) or take loans to make payments related to treatment in the Govt. hospital?

#### **5. In case the patient was examined and then very soon referred to next level hospital / health centre for treatment, then ask:**

What was the reason given for referral? (Patient cannot be treated here, Treatment not available at this hospital so referred to a higher level public hospital, or sent to a non-public hospital with which there is a partnership)

In case there is a partnership with a non-public hospital to which patient was referred, then what is the name of this scheme / partnership?

Were you given a proper referral form with details written on it? (Take a copy of the referral slip if it was given)

Was arrangement made for vehicle?

- Vehicle arranged without asking for money
- Vehicle arranged after taking money
- Vehicle not arranged

**6. In case the facility was closed, or the patient was simply sent away without being examined, and the patient had to go to another hospital,** then ask where the person went – name of facility, place, whether public or private hospital, how far it was, what happened there, and the total expenses in that hospital.

7. Due to gaps in treatment given, or not being attended to in emergency, was there any serious impact on the patients' health? (Due to lack of medicine & emergency services there was risk to patient's life, or health problem worsened, or patient became disabled, or patient died.)

8. If there was a violation then did you seek some redressal? Yes/No

If yes, then what/whom did you approach?

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

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

10.

11. Are there any other relevant facts or aspects of this instance of denial that you would like to share?

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**Take photocopies of discharge card / discharge summary, investigation reports, hospital receipts and bills and any other relevant documents**



**Analysis (to be filled by health activists or panel who screen the cases):**

**A. What are the main forms of denial of care that the patient had to suffer in this case?**

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

**C. Which official / officials are likely to be answerable for these denials?**

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

**E. What are the structural / systemic issues that emerge from this case?**