

# DATA SHARING GUIDELINES

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National AIDS Control Organisation,  
Ministry of Health & Family Welfare,  
Government of India, New Delhi



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**National AIDS Control Organisation**  
**India's Voice against AIDS**  
Ministry of Health & Family Welfare, Government of India  
[www.naco.gov.in](http://www.naco.gov.in)

## Data Sharing Guidelines

### **Background**

National AIDS Control Organisation, Department of Health & Family Welfare, GOI collects data on components related to HIV/AIDS through various mechanisms including routine monitoring, sentinel surveillance systems, Behavioral Surveillance surveys and other evaluations / operations research studies. The main objectives of this information collection through integrated M&E system are to track the progress of HIV/AIDS epidemic in the country and to track performance of National AIDS Control Program.

The data collected through these mechanisms is used for various purposes including program management, resource allocation and taking corrective decisions.

### **Purpose of Data Sharing Policy**

The data collected varies from inventory information to patient disease details. With web-enablement, the data can be made available through internet at all levels and to all partners who are involved. The data transfer is gradually shifting from sequential (RU→District→State→National) transfer to direct web transfer so that information is available to all simultaneously. Adequate measures for data security are in place for restricting access by giving various levels of permission. However, due to stigma associated with HIV/AIDS, maintenance of confidentiality is crucial for security and confidence of HIV patients.

Involvement of large number of organizations ranging from government, semi-government, private, civil society, and many more in fighting against HIV/AIDS and interest and support of large number of donors and stakeholders emphasizes need of transparency and availability of data to all those who are involved in the program related to HIV/AIDS. Post graduate and PhD student/scholar, who want to do research in HIV/AIDS field, also give request for data access. The approaches and implementation strategies being adopted by programme pose several operations research questions and researchers in constant need to add to the existing knowledge or create new knowledge require information. The information needs thus vary according to levels and area of work. Looking at the stigma and discrimination faced by HIV infected person and keeping the confidentiality at forefront, there is need to use this data with utmost caution and maturity. Considering the above, this Guideline has been developed.

Following matrix gives broad guidelines of data sharing:

| Type of Information   | Level of security | Availability   | Approving Authority   | Process  |
|---|-------------------|--|---|--|
| <b>Data that can be shared without a review</b>   |                   |  |   |  |
| Information on location of service facilities (BB, STI Clinic, ART Center, ICTC, F-ICTC, TI etc);<br>Published Reports and documents of studies, evaluations, surveys, surveillance or any other programme activities   | Low               | On Website<br><br>Programme Divisions of NACO/SACS                   | Approval not required, if available on website, if not available on website, than respective HODs | Undertaking not required                                       |
| <b>Data that can be shared after review</b>   |                   |  |   |  |
| <b>Data up to State level (including all facilities and district level under it) requires approval by SACS</b>  |                   |  |   |  |
| District/ RU level aggregated data on no. of centres, uptake of services & positivity rates etc. from programme data;<br>Disaggregated data (i.e. break up by age, gender, demographic variables, programmatic variables, etc.) beneficiaries of various components under NACP under one state                        | Moderate          | Programme Division of SACS   | Project Director, SACS  | Undertaking required.<br><br>Request will be processed by SACS |
| Individual level data (Without personal identifier) of beneficiaries of various components under NACP under one state<br><br>Financial information – total budget sanctioned under various schemes, utilization rates, etc.<br><br>Information on procurement & utilization of kits, drugs and other consumables etc. | High              | Programme divisions of SACS  | Project Director, SACS  | Undertaking required.<br><br>Request will be processed by SACS |
| <b>National level Data ( including State level; two or more states ) requires approval by NACO</b>  |                   |  |   |  |
| Multiple State level only of aggregated data on no. of centres, uptake of services & positivity rates etc. from programme data;<br>Disaggregated data (i.e. break up by age, gender, demographic variables, programmatic variables, etc.) beneficiaries of various components under NACP                              | Moderate          | SIMU Divisions of NACO after review by concerned programme division  | HODs /Competent authority   | Undertaking required.<br><br>Request will be processed by NACO |
| Individual level data (Without personal identifier) of beneficiaries of various components under NACP for more than two states  | High              | SIMU Divisions of NACO, after review by concerned programme division | Competent authority after review by Data Sharing Committee  | Undertaking required.<br>Request will be processed by NACO     |
| Individual level data (raw data) from HSS, BSS, IBBS and other studies/ surveys conducted by NACO   | High              | SIMU Divisions of NACO, after review by concerned programme division | Competent authority after review by Data Sharing Committee  | Undertaking required.<br><br>Request will be processed by NACO |
| Information on procurement & utilization of kits, drugs and other consumables etc.  | High              | Procurement Division, NACO   | Competent authority after review by Data Sharing Committee  | Undertaking required.<br><br>Request will be processed by NACO |
| Financial information – total budget sanctioned under various schemes, utilization rates, etc.  | High              | Finance Division, NACO   | Competent authority after review by Data Sharing Committee  | Undertaking required.<br><br>Request will be processed by NACO |
| Approval for Publication  | High              |  | Competent authority after review by Data Sharing Committee  | Undertaking required.<br><br>Request will be processed by NACO |
| <b>Individual level data (With personal identifier) of beneficiaries of various components under NACP cannot be shared , thus in this regard no proposal will be accepted</b>   |                   |  |   |  |

## Key Protocols:

1. For all data collected through National AIDS Control Program (NACP), NACO/SACS is the custodian. Data in all forms, the standard tables, reports as well as raw data will be under the custody of NACO/SACS.
2. All agencies supporting NACO in data generation through various processes including routine monitoring, surveillance or surveys should handover complete data sets to NACO after completion of the process / reports.
3. Individual, agency, Organisation who access to the data of the National AIDS Control Programme, have to submit the data request in the prescribed format (Annex-1) with clearly defined purpose and clear details of the data that is required.
4. The applicant will also have to sign an undertaking (Annex-2) with NACO/SACS, assuring maintenance of data confidentiality, avoiding conflict of interest, acknowledgement of NACO/SACS in the publication.
5. The applicant should submit detailed protocol of the study along with data request form; protocol should give objectives, methods, analysis framework that is proposed to be used in the analysis and implications of the analysis /study for the programme.
6. In order to simplify the procedure for many students who seek data from the programme for their thesis work, the applicants are categorized as below.
  - I. Students seeking data for his/her Graduate/ Post Graduate thesis work
  - II. Doctoral students seeking data for his/her PhD thesis
  - III. All other applicants, other than students
7. If the applicant is seeking data for his/her Graduate/ Post Graduate thesis,
  - I. If the data required (accessing available data/generating fresh data through interviews of beneficiaries) is limited to one or two reporting units/ centres, the student can collect the data from the centre subject to following conditions.
    - i. S/he should have obtained necessary ethical clearance from his/ her institutional review board, for the thesis.
    - ii. S/he should obtain permission from the in-charge of the Reporting Unit/ Centre.
    - iii. S/he should intimate SACS & NACO about the study before starting data collection.
    - iv. S/he should seek permission from NACO before publishing any report or paper using data under National AIDS Control Programme.

In this case, it is also the duty of In-charge of the RU/ centre to inform SACS & NACO about such study along with details of the student and the data being accessed.

- II. If the data required relates to district or higher level (either aggregate data or individual data) that is collected through CMIS/SIMS/PALS or any other data collection /reporting mechanism under NACP, the student should approach SACS/NACO with data request. In such a case, the protocol as given in table above will be followed.
8. If the applicant is seeking data for her/his PhD thesis, s/he should approach SACS/NACO with data request, irrespective of which level of data s/he is seeking (facility level/district /state /national). In such a case, the protocol as given in table above will be followed.
9. All other applicants should also approach SACS/ NACO with data request for obtaining any data from NACP.
10. All the data requests will be examined by Data Analysis & Dissemination Unit, Strategic Information Management Unit at NACO and depending on the category of data requested, it will be referred either to concerned HOD or Data Sharing Committee of NACO, for their review, as per the protocol given in the table above.
11. **Data sharing committee** shall review the data requests based on the following criteria, give its recommendations and submit for approval of Competent Authority, NACO.
  - I. Whether the topic for analysis is in line with the priorities for analysis & research of NACO
  - II. Any possible conflict of interest situation with the applicant, due to his/ her organizational or institutional affiliation
  - III. Whether the applicant has obtained the necessary clearances from required Institutional Review Boards/ Ethics Committees
12. Personal information will be filtered to conceal identity of individuals from any raw data which is to be shared.
13. Data will be shared with the applicant only after the approval of Director General, NACO. Instructions will be given to concerned programme division of NACO/SACS to provide the information.



**Format for Data Request**

1. Name of the Individual/Institute/Agency Requesting Data:

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2. Purpose :

- a. Planning new programme
- b. Program management / evaluation
- c. Research
- d. Others (Please specify) \_\_\_\_\_

3. Whether protocol of the study is enclosed : Yes / No

4. Details of data use (Explain how the requested data would be used):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. Define the data requirement

- a. Component on which information required
- b. Geographical area
- c. Time period
- d. Level of data –Aggregate or individual level
- e. Indicators/Variables required
- f. Any disaggregation required

Date:

Sign:

Name & Designation:

Institution:

**UNDERTAKING**

I/We,.....(Name), working as  
 .....(Designation), in.....  
 .....  
 ..... (Complete Name and Address of  
 Institution/ Organisation), am/are involved in the study/analysis titled  
 “.....  
 .....”  
 from..... to .....(time period).

I hereby declare that the data that I am provided access to, under the above-mentioned study/ analysis will be used only for the purpose of the work mentioned hereinabove and only in the manner that National AIDS Control Organisation (NACO) authorizes and permits. I expressly acknowledge and agree that without prejudice to all the available legal remedies, I am also liable to administrative action in case the data is used for any purpose beyond the scope of this study. I will not share the data with any one, or publish the research data without prior written consent/permission from NACO and shall maintain the confidentiality of all Confidential Information. I shall submit a copy of all the data files, analysis papers and reports generated as a part of this analysis work to NACO at the end of the study/analysis. Any publication out of this analysis will have prior NACO approval. Any publication, document, and/or paper arising out of this analysis will be jointly owned.

.....  
**(Signature)**

Date:.....Place:.....

**Contact Details:**

Mobile & Telephone:-

Email:-

.....  
**(Signature of the Head of Institution/Organisation)**

**Official Seal:**

.....  
 Name of the Head of Institution/Organisation:

Date: ..... Place: .....