A Review of Data Quality Protocols in Administrative Data

NANDITA SAIKIA
KRISHNA KUMAR
BANDITA BORO
JAYANTA KUMAR BORA

Suggested citation

Saikia N., Kumar, K. Boro, B and Bora, J.K. (2021). A report on the review of the Data Quality Assurance Protocol of Program and Administrative Data in India.

For additional information about the study, please contact:

Dr Nandita Saikia, Professor, Department of Public Health and Mortality Studies, International Institute for Population Sciences, Mumbai
Email: nanditasaikia@iipsindia.ac.in

Abbreviations:

AAP	Annual Action Plan
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activists
AWW	Anganwadi worker
BCC	Behaviour Change Communication
CAPI	Computer Assisted Personal Interviewing
CHC	Community Health Centre
CMO	Chief Medical Officer
COD	Classification of Diseases
COMEDEC	Electronic Data Exchange of Civil Status Data
CRVS	Civil Registration and Vital Statistics
CST	Care, Support & Treatment
CSU	Central Surveillance Unit
DACO	District AIDS Control Officer
DADU	Data Analysis & Dissemination Unit
DAPCU	District AIDS Prevention and Control Unit
DCO	Directorates of Census Operation
DEO	Data Entry Operator
DMC	Designated Microscopy Centre
DQA	Data quality assessment
DQP	Data Quality Protocols
DSU	District Surveillance Units
EMTCT	Elimination of Mother to Child Transmission of HIV
EQAS	External Quality Assurance Scheme
EUS	Employment and Unemployment Survey
FSWs	Female Sex Workers
GDP	Gross Domestic Product
HMIS	Health Management Information System
HRGs	High-Risk Groups
HWC	Health and Wellness centres

HYS	Half Yearly Survey
ICD	International Classification of Diseases
ICMR	Indian Council of Medical Research
ICT	Information Communication Technology
ICTC	Integrated Counselling and Testing Centre
ID	Identity Card
IDSP	Integrated Disease Surveillance Programme
IDU	Injecting Drug Users
IEC	Information Education Communication
ILO	International Labour Organisation
IMS	Inventory Management System
IRL	Intermediate Reference Laboratory
IVF	In Vitro Fertilization
JSY	Janani Suraksha Yojana
LHV	Lady Health Visitor
LQAS	Lot Quality Assurance Sampling
MCCD	Medical Certification of Cause of Death
MCH	Maternal and Child Health
MCTS	Maternal and Child Tracking System
MO	Medical Officer
MoHFW	Ministry of Health and Family Welfare
MoSPI	Ministry of Statistics and Program Implementation
MPCE	Monthly Per-capita Consumption Expenditure
MSM	Men Having Sex with Men
MTA	Mid-Term Appraisal
NACO	National AIDS Control Organization
NACP	National AIDS Control Program
NDAP	National Data Analysis Plan
NDSS	National Diabetes Surveillance System

NFHS	National Family Health Survey
NIMS	National Institute of Medical Statistics
NRL	National Reference Laboratory
NRS	National Routing System
NSC	National Statistical Commission
NSO	National Statistics Organisation
NSP	National Strategic Plan
NSSO	National Sample Survey Organisation
NTEP	National Tuberculosis Elimination Program (NTEP) (formerly knowns as Revised National Tuberculosis Program)
ORGI	Office of the Registrar General of India
ORW	Outreach Worker
OST	Opioid Substitution Therapy
PHC	Public Health Centre
PHC	Primary Health Centre
PLFS	Periodic Labour Force Survey
PLHIV	People Living with HIV
POA	Power of Attorney
RCH	Reproductive and Child Health
RDQA	Routine Data Quality Assessment
RNTCP	Revised National Tuberculosis Control Program
RPC	Rural Price Collection
RRT	Rapid Response Teams
SACS	State / UT AIDS Control Societies
SDGs	Sustainable Development Goals
SIMS	Strategic Information Management System
SMS	Short Message Service
SRS	Sample Registration System
SSU	State Surveillance Units
STDC	State Tuberculosis Training & Demonstration Centre

TB	Tuberculosis	**TU**	Tuberculosis unit
TG	Transgenders	**UIC**	Unique Identity Code
TI	Targeted Interventions	**VA**	Verbal Autopsy
TSU	Technical Support Units		

Table of Content

List of tables and figures:

Executive Summary

The detailed report presented below discusses at length the Data Quality Assurance Protocols (DQPs) in several government disease control programmes and administrative data. Broadly speaking, there are six main data quality parameters that have been used to assess the DQPs thoroughly. These parameters are-

- accuracy
- validity
- reliability
- timeliness
- completeness
- relevance

This study focuses on how the various government disease control programmes meet the fixed standards of for data collection, recording, and reporting along with their essential features and limitations. In this report, we have reviewed the Data Quality Assurance Protocols for Civil Registration Systems (CRS), Sample Registration System (SRS), Health Management Information System (HMIS), National Sample Survey Organisation (NSSO), Mother and Child Tracking System (MCTS), National Tuberculosis Elimination Program (NTEP) {formerly knowns as Revised National Tuberculosis Program (RNTP)}, National AIDS Control Organisation (NACO), and Integrated Disease Surveillance Program (IDSP). This study also highlights some of the best practices adopted by the different data sets.

The CRS collects data on vital events such as births, deaths, and marriage registers on a real-time basis and is later verified by registrars. It is essential to ensure that uniform law and standard definitions are followed at all registration units. The registration is majorly done online in most of the states through the ORGI uniform CRS software. However, it also brings to light the lack of a uniform online registration system across the states, which again is major a limitation of this system. Pre-search is also done frequently to avoid any duplication of registered events. It is interesting to note that the CRS lacks completeness and timeliness as records of death by age and sex are not adequately available. Furthermore, data on adult

and maternal mortality, in addition to information on the cause of death is also not available at the district level and every year, respectively.

In the absence of reliable and accurate CRS estimates, SRS data becomes an excellent source for estimating vital events at the national and state level. The census data is used to rectify SRS's estimates, and periodically, every ten years, to be precise, the sample units are revised. In fact, the RGI uses the SRS data for developing abridged life tables, though it cannot be used as a substitute for CRS. The system has also adopted a paperless process that cuts down invalid entries and missing data fields. Such an automated process does not allow records to be submitted without sex or any other such relevant details. This system's dual recording feature is one of the most important characteristics that ensures the data quality. The verification of records by the two agencies is also essential for the generation of accurate data. Additionally, 10 per cent of total households are resampled for quality control purposes. In case of verbal autopsies completed by the supervisor, the review is done by two individually trained physicians.

SRS is considered to be much more diligent in terms of timeliness. At the end of each year, the state annual report is published by the ORGI. It is known that data on the infant mortality rate is an essential indicator of the availability and quality of child healthcare services. This data is pertinent to the calculation of life tables. However, the small sample size may sometimes give a distorted figure, hence it is not applicable to represent the whole population.

HMIS is a data collection system specifically designed to support planning, management, and decision making in healthcare facilities and organisations. The HMIS portal captures data that is to be collected as per the revised formats on a web-based system at the district level. It ensures that primary data is easily aggregated, and the information/reports flow in a prompt manner to the ministry directly from the districts.

A major drawback of this system is that it suffers from incompleteness, inefficient utilisation of resources, and low quality of data. Some of the common errors in the HMIS portal are missing data, duplicate data, thumb suck (when data collection tool is not routinely used, the staff fills in a likely looking number), unlikely values for a variable, contradiction between variables, calculations errors, typing errors and capturing in the wrong box. Errors also often

occur due to multiple registers or poorly designed registers. An earlier study even documented how there are no explicit delegation of powers to approve or confirm data (NRHM-HMIS, 2012). Consequently, this system puts to use two unique techniques to ensure data accuracy—LQAS and RDQA, in addition to standard definitions and norms. There are as many as 22 validation rules for checking internal consistency. HMIS has also adopted a median-based criterion to identify any possible outliers. Data for the previous month is also accessible through the portal for further comparison with the current data. Timeliness is an essential component in HMIS. District level officers check writing for every facility and find out when all facilities say in the district. Hence, maintaining a quality HMIS is essential for an effective healthcare system worldwide.

The NSSO data has continued to play a significant role in improving the various socio-economic parameters. The survey has managed to maintain data accuracy by using international standard definitions for the different indicators used. For this purpose, a high-level steering committee periodically reviews and refines the national indicator framework. The system uses computer-assisted personal interviews (CAPI) for data collection, which substantially reduces the chances of error. Besides, monitoring and supervision are done using an MIS dashboard. The data submission process undergoes a three-level validation process, making it one of the world's best practices. Furthermore, a periodic review meeting is done at the headquarters, wherein the data is published within the prescribed time. Based on the subjects, the data is published monthly, quarterly, and annually. Many organisations worldwide, including International Labour Organisation (ILO), the World Bank, and India's planning commission, have extensively used the NSSO data. The NSSO data is central to policy making in India as it happens to be an official source of key socio-economic indicators (consumption, employment, etc.) and is collected via large-scale sample surveys. The NSSO data, however, is limited to the state level only, although there is a high demand for district-level data for decentralised planning.

The Integrated Disease Surveillance Programme (IDSP) detects early signs of an impending disease outbreak and aids in initiating mitigation measures on time. Under this programme, the sub-centres form an integral part in the network of reporting units from where weekly surveillance data is collected in "S" (syndromic) surveillance format using standard case definitions. At the sub-centre level, the responsibility for the effective implementation of

IDSP lies primarily with the healthcare workers. The objective is to detect if there is a clustering of cases, a sudden increase in the number of instances of a specific syndrome over the past few weeks, or any unusual events/deaths. However, this surveillance system is not as efficient as one would expect it to be. Most of the cases are likely to be detected when the disease has already caused significant damage and before any control measures could be initiated. The main function of this system is to develop standard case definitions, laboratory manuals, and adequate outbreak response. But the lack of clear understanding of standard case definitions limits the functioning of the system and prevents effective case detection and registration. Also, as mentioned earlier, the lack of data on mortality rate is a major limitation of this surveillance system. Studies have in fact found that while data management and analysis were weak at all levels, support functions (laboratory, transport and communication equipment, training, supervision, human and other resources) are weak at the district level. The responsibility for effective implementation of IDSP at the sub-centre level lies with the health workers. District and sub-district levels are pivotal to the IDSP. District level epidemiology needs further strengthening with improved data collection tools and analysis, and analytical and predictive epidemiology training.

NACO, through its NACP, aims to completely eradicate the HIV epidemic in India. NACO has targeted its preventive efforts towards sub-groups that have been identified as 'at high risk' of contracting the HIV infection. Some reports have concluded that the programme has significantly reduced the number of newly infected cases in recent years. The programme not only produces estimations of prevalence of HIV among adults, and annual new infections (HIV incidence), but also, AIDS-related mortality, and prevention of mother-to-child transmission (PMTCT). However, the programme also suffers from certain issues like insufficient human resources, lack of proper training, redundancy in the data collection process, and lack of adequate information technology infrastructure, which inadvertently hampers the data quality.

Data Quality Assurance Protocols (DQPs) ensure data accuracy, validity, completeness, timeliness, and reliability. An absence of these protocols results in the low quality of data. Hence, we strongly suggest well-framed DQPs for each of the systems mentioned above.

Section 1: Background

This study aims to document the data quality assurance protocols in administrative and program data to maintain data quality. We review the Data Quality Assurance protocols for several programs and administrative data such as Civil Registration and Vital Statistics (CRVS), Sample Registration System (SRS), Health Management Information System (HMIS), National Sample Survey Organisation (NSSO), Mother and Child Tracking System (MCTS), National Tuberculosis Elimination Program (NTEP) (formerly knowns as Revised National Tuberculosis Program (RNTP), and National AIDS Control Organisation (NACO), Integrated Disease Surveillance Program (IDSP)

In this study, we answer the following questions:

1. What are the data quality assurance protocols used in registered, program and administrative data systems worldwide, with emphasis on vital and health statistics?
2. What are that drawbacks and limitations that exist in these protocols that prevent the generation of high-quality demographic and health data in these systems?
3. What are the possible ways to minimise those limitations? What modifications are necessary to develop the best data quality assurance protocols?

1. Method

1.1 Following are the steps undertaken to ensure data quality

This section is divided into two parts:

a) We systematically review the existing registered, program and administrative data systems to assess the current strategies and processes of their implementation. Additionally, we review the government and the affiliate's records and reports from other review sources. For these purposes, we also reviewed manuals, guidelines, and published journal studies.

b) We review data protocols of the administrative and program data in various countries of the world. Here we choose only those countries, which generate high-quality vital and health statistics through such systems.

It is worth mentioning that while some systems (such as SRS, HMIS, MCTS, NSSO, IDSP, NACO, and NTEP etc) have an explicit mention of data quality assurance protocols in their manuals or report, other methods don't mention DQPs directly. In case of latter, we carefully scrutinise the different steps followed in the systems to ensure data quality.

Section 2: Study Framework

(i) Six key characteristics of data quality

1. **Accuracy:** Data accuracy indicates the capability to provide the correct value or measurement**.** Data should be sufficiently accurate for the intended purposes, representing clearly and in sufficient detail, the interaction provided at the activity point. It is essential to ensure that data should be captured once only. Accuracy is most likely to be achieved if data is captured close to the activity point. Only if the reported information is based on accurate data, will a fair picture of performance be generated. The need for accuracy must also be balanced with the importance of the data and the collection costs and effort (relevance, timeliness, and cost efficiency). For example, in some cases, a certain degree of inaccuracy is acceptable, where timeliness is essential. The users should know the limitations in case of any compromises on the accuracy.

2. **Validity:** Data should be recorded and used in compliance with the relevant requirements, including the correct application of any rules or definitions. This ensures consistency between periods, space, and similar organisations. In case proxy data is being used to compensate for the absence of actual data, then organisations must consider if this data will serve the intended purpose.

3. **Reliability:** Data should reflect the stable and consistent collection processes, be it manual, computer-based systems or even a combination of both. Managers and stakeholders should be confident that the progress towards performance targets reflects the real changes rather than variations in the data collection approaches or methods.

4. **Timeliness:** Data should be collected at the earliest after the event or activity and must be available for the intended use within a reasonable period of time. It should also be frequently accessible to support information needs and influence the appropriate level of service or management decisions.

5. **Relevance:** The data collected should be relevant to the intended purposes. This entails a periodic review of all the requirements to reflect the changing needs. It may be necessary to capture data at the point of activity relevant only for other purposes, rather than for the current intervention. Quality assurance and feedback processes are also needed to ensure the quality of such data.

6. **Completeness:** Data requirements should be specified based on the organisation's information needs and the data collection process should match to these requirements. Monitoring missing, incomplete, or invalid records can indicate data quality and highlight the problems in recording specific data.

(ii) Protocols on guidance: What kind of training does the field staff get to perform on their Act?

1. **Awareness**: Relevant staff is made aware of the need for data quality and how they can contribute.
2. **Definitions**: Relevant staff is made aware of the purposes of the outcome produced through data collection.

3. **Input**: There are certain controls over information, evident within the services responsible for entering and submitting data. Staff should have a clear understanding of the guidelines and procedures for operating systems. As a general rule, data should be entered onto one system in order to reduce the chances of error and this be done regularly rather than at the end of a period.

4. **Verification**: There are verification procedures in place, for example, a review of recent data against expectations; a reconciliation of systems-produced data with manual records; data cleaning (to remove duplicate records or to fill in missing information); sample checks to eliminate reoccurrence of a specific error (e.g., checking one field of data that is pivotal to a Performance Indicator/data return against documentation); for a some cases, a test run of report output to check the integrity of the query being used to extract data is necessary, along with spot checks (e.g., on external contractor information).

5. **Systems**: The staff needs to be trained and equipped in a manner that they have the expertise to get the best out of the system. It is their responsibility to maintain a robust control environment for information systems.

6. **Output**: It is integral to ensure that output data is extracted regularly, efficiently, and communicated quickly. Performance information should be subjected to scrutiny before it's further sent for management action and approval.

7. **Presentation**: Data and information needs to be presented in such a manner that it provides an accurate picture to external bodies, inspectorates, and the public. The managers are responsible for the accuracy of the data produced within their sections.

(iii) Protocols on roles and responsibilities

The senior officials, the audit section, and the officers involved in inputting, extracting, analysing, reporting, submitting, and managing data are mainly responsible for ensuring that processes and protocols are followed thoroughly.

(iv) Protocols on monitoring

What kind of monitoring is done during field visits, while developing check tables, and during data entry, and processing? What are the steps undertaken to check the data validity post collection? Once estimates are ready, are those compared with previous data or any other sources of data?

Section 3: Findings

Steps undertaken for assuring quality dimensions in various administrative and registered data on vital and health statistics

3.1 Civil Registration System

Accuracy- Vital events are registered continuously and on a real-time basis. This is done to avoid the event's duplicity. Confidentiality of information is guaranteed during registration in order to collect accurate and detailed information. Registrars are required to fill all the mandatory fields such as registration number, date, name, sex, age, place, and cause of death, in case of death. In areas where the Medical Certification of Cause of Death (MCCD) scheme is operational, all institutional death reports must be accompanied by a medical certificate, clearly stating the cause of death to generate accurate data on the same. The computerisation of the system at all levels has significantly cut down missing data fields, invalid entries, and irrelevant information.

Also, capacity building programmes are organised regularly to ensure accuracy in the registration and final monthly or annual reports. Regular supervision is done at the registration units, and registers are checked kept therein. During the inspection, the numbers of registered events are verified along with those reported by the health institutions, ANMs, AWWs registers. In case of false reporting and negligence of duty, penalties are imposed as well. For example, in Andhra Pradesh, show cause notices were issued to the Registrars by the District Registrars, where births and deaths were registered fraudulently without proper field verification. Studies are also organised in areas where data are found to be inaccurate.

The accuracy of cause of death statistics is highly questionable, given the poor compliance with guidelines.

The CRS has been attempting to bring out more detailed and accurate vital statistics. Steps are being taken to digitise old records. All local bodies are being computerised, which will result in precise registration and, finally, accurate vital statistics. Frequent inspections of registration offices and records within a regular time frame have been proposed to improve registered events' accuracy. Software is used for the identification of missing data.

Validity: Uniform law has been implemented, and standard definitions are being used in all states and UTs. The civil authority can only register events after verification of all the details provided by the informants or notifiers. Registrars generally adhere to this protocol. However, in the case of online registration, uploading of digitalised identity documents beforehand is mandatory. Late registration can be done after submitting an affidavit with the magistrate's notarisation or approval. Chief registrar and district registrars do regular supervision to bring uniformity in the system. The validity of online registration is ensured through ORGI uniform CRS software in most states and UTs. For example, the registration unit generates an electronic report after verification, and the certificate is issued through the hospital. The medical certificate of death must comply with the ICD guidelines. Recently, Aadhar linkage of newborns has also been started in Haryana, making certificates generated by the system more valid. In Gujarat, state level summary reports have been compiled to validate data entry of births and deaths registered at all registration unit. Registrars are required to fill forms legibly and without any errors. Guidelines and protocols have been implemented to ensure similar procedures are followed in every state and UTs.

Inspections of registration centres are **irregular** and too **deficient** in most of the states. The intensity of supervision and constant monitoring may increase the validity of results. Validation of data through triangulation can be useful to minimise the potential of misreporting.

Reliability: CRVS is permanent data, and no change is allowed as per the Act. However, in case of correction of errors or any new name additions, it must be informed to the state government or officers delegated for this purpose. Birth registration of a child can only be done after the verification of identity proof of parents. In case of death registration, identity proof of the deceased or an affidavit by the deceased's relative must be provided. The registrar may even reject applications for registration, which does not satisfy him/her. Legal actions can be taken on informants in case entries are made fraudulently or improperly. Systematic and uniform processes have been implemented in every registration unit. ORGI uniform CRS portal has been launched in many government and private hospitals for consistent procedures and continuous registration. For example, in Punjab, a state-wide

rollout was established during 2015, which has brought uniformity throughout the state. Regular monitoring and supervision are also done to generate reliable statistics.

Furthermore, registrars are required to maintain accurate records of birth and death to ensure registrations are done as per the provisions of the Act. Monthly reports must be sent to the state headquarters, where verification of documents is carried out before making the final monthly report. Additionally, interdepartmental committee meetings have also been proposed to generate a reliable estimate.

However, despite the Registrar General's office's consistent persuasion of the state governments, interdepartmental committee meetings have not been convened regularly in most states/UTs. The CRS functionaries involved in registering births and deaths at various levels in most states/UTs belong to different departments and **almost all these functionaries consider and carry out the registration work as an additional responsibility.** Moreover, the frequent transfer of these officials from one department to another causes further hindrance. Therefore, there is a strong need to impart training at regular intervals, which will result in the system's adequate functioning and reliable data generation.

Completeness: Registrars must request adequate details such as name, age, sex, place, religion, etc., from informants or notifiers to record complete information of birth or death. In the areas where MCCD schemes are implemented, the registrar must register all institutional deaths and submit medical certificates for the cause of death along with death reporting forms. Registration can be done by the informant/ notifier or even a suo moto can be initiated by the registrar, which increases the registration level. Latest updates on the registration stauts are now available via SMS and birth and death certificates can be accessed via email. Periodic field inspections are carried out by district registrars or by officers from the chief registrar's office to identify unreported births and deaths, and penalties are imposed on registrars for not registering.

In most cases, records of death by age and sex are not adequately available because some states either do not or partially submit data by the deceased's age and sex. Records on infant and stillbirths are inadequate. Data on adult and maternal mortality, and sex ratio are missing

at the district and lower levels. Data on sex ratio is missing for some states. And many states have not submitted the data on registration within the prescribed time limit (21 days). It has also been observed that most of the states/UTs do not furnish the desired information on certificate issuance.

The number of registered events can be matched with the records of beneficiaries registered under government schemes that are focused on institutional births, postnatal care, immunisation, etc. Regular interdepartmental meetings could also prove to be helpful in the identification of unregistered events. Making birth registration mandatory to avail other schemes may create demand for more registration. For example, a birth certificate is required for the Ladli scheme, postnatal care benefits, etc. A death certificate is mandatory for seeking family pension, insurance claims, etc. The system carries out IEC activities to create awareness of the benefits of birth and death registration.

Timeliness: The Births and Death registration Act mandates registration of all births and deaths within 21 days of the event. This should be done in accordance to guidelines which includes time intervals and fines for late registration. Registrars must also submit a monthly report to the district office or the state headquarters within the first five days of the following month. District registrars are required to submit the statistical parts of the reporting forms to the Chief Registrar within the first ten days of the month. The Chief Registrar further prepares and submits the final report to the state government by 31st July of the following year. It is mandatory that the final report has is published within five months of submitting it to the government by chief registrars.

However, some states do not submit statistical reports within the stipulated time, which delays the publication of the corresponding national report. For example, the latest report does not present Manipur’s data due to the delayed submission of the state government statistics.

Lately, efforts have been made for timely updates on data. For example, in Haryana, Aadhar linked birth registration of newborns has ensured a more efficient system. In Kerala, efforts

have been made to issue birth certificates before the mother and the new-born are discharged. For this purpose, many states have even started online registrations.

Relevance: CRS generates data that has legal, administrative, as well as policy importance. Birth registration has been made mandatory for a number of purposes including school enrolment, governmental schemes, passport, driving license, and even voter ID. Moreover, this certificate is conclusive proof of age, which has many legal advantages. Similarly, records of deaths, especially by age and sex at lower administrative levels, are useful for health officers to prescribe specific health interventions when needed. Maintaining records of infant deaths by place and sex is the most crucial statistic for monitoring healthcare developments.

As mentioned earlier, death certificates are essential for seeking family pensions, insurance claims, and property transfer. The system also provides information on any medical attention received at birth and death which is relevant for policymaking. In this context, the CRVS is an important data source that provides vital statistics at the district or lower administrative levels. It can be used for monitoring and evaluation of different schemes. Birth and death registrations are also essential to generate a cost effectiveness analysis.

However, the system has its own share of drawbacks. The extent and variation of data availability by age in CRS does not allow for meaningful use of this data. Moreover, it is not seen as a priority among policymakers,

Box 1: CRS: FAQs

Civil Registration System: At a Glance

1. What is the field monitoring process?

Answer: It is the block and district level officers who are responsible for regular supervision at the registration units and check the registers kept therein. They verify the events recorded in the system with those registered by the ANMs, AWWs, and health institutions to confirm the complete and accurate recording of events. Additionally, senior officers also periodically participate in field inspections and suggest any corrections, if necessary.

2. **What are the steps undertaken to ensure the validity post data collection?**

Answer: There are uniform guidelines and standard definitions that are followed at all registration units. In most state and Union Territories, the validity of online registration is ensured through ORGI uniform CRS software in. For example, an e-report is generated after verification, and the certificate is issued through the hospital. Pre-search is also compulsorily done before registering births and deaths to avoid duplicity. It is mandatory to comply with the ICD guidelines while generating medical certificates of death. Registrars are required to fill forms legibly, without any errors. It is essential to ensure that protocols are being followed strictly at all levels of the system.

3. **Once estimates are ready, are those compared with previous data or any other sources of data?**

Answer: The CRS annual report presents tables and charts as per the CRS estimates and makes a clear comparison with the SRS estimates. The annual report also presents the estimates of vital events (births and deaths) and sex ratio over the last ten years However, 2014 onwards, the report did not publish any such comparison tables or graphs. Previous studies can still be referred for comparison of SRS and CRS data. According to one such study, that included data from Odisha, Rajasthan and Kerala, it was found that CRS suffers from under-reporting in Rajasthan and Odisha. (James, 2013)

Protocols followed in CRS

1. Registration can only be completed through online uniform CRS software or similar software in registration units where computerisation has been done.
2. It is mandatory to use standard definitions at all registration unit. For example, the cause of death must comply with the ICD guidelines.
3. The registrar must have an office in the local area where births and deaths can be registered. Also, there should be a board in the local language, at the entrance, bearing their name, designation, the duration of their availability.
4. The registrar must take cognizance of the births and deaths in their jurisdiction and register them.
5. The registrar is required to maintain records of births and deaths and ensure their accuracy
6. It is compulsory to pre-check before registration of any event. If the event is not registered earlier, a non-availability certificate may be provided on demand.
7. It is mandatory to obtain a certificate stating the cause of death where the schemes of MCCD are applicable.
8. All events must be registered as per the place of occurrence.
9. In case of births, stillbirths, or deaths in hospitals, health centres, or other institutions, the Medical Officer-in-Charge or an officer delegated by them for this purpose must report it to the concerned Registrar.
10. In case such an event takes place in institutions like jail, hotels, boarding houses, or public resorts, the official in charge is required to relay the information to the concerned Registrar. If the event takes place in a public place, then the police officer in-charge must also be informed. In case of a moving vehicle, the owner is bound to report the incident to the concerned registrar.
11. Similarly, if the event occurs in a plantation, it is the responsibility of the plantation superintendent to inform the registrar.

Protocols followed in CRS continued.

12. ANM, ASHAs, and Anganwadi Workers must obtain the household's signature on the respective reporting form.
13. In case the applicants do not receive the certificate within 30 days of reporting, the registrar is required to transmit the same to the concerned family, by post, within 15 days prior to the expiry of the said period. Additional copies of the certificates can be issued on the payment of a prescribed fee per document.
14. Late registration can only be done after paying the fee and verification of details provided by the applicant.
15. The registrar is authorised to make necessary corrections in spelling of the child's name without any alteration to the original entry.
16. The registrar can make other corrections as well to the entry, if the applicant produces a declaration stating the error. Further, a declaration from two persons with complete knowledge of the facts of the matter is required. The register is required to communicate the same to the state government or an officer delegated for this purpose.
17. In the death certificate, the particulars regarding the cause of death must not be disclosed to the public.
18. In case of registration of children born outside India, whose parents are Indian, the process must be completed within 60 days of the arrival. Late registration can be done after the verification of the details provided and payment of a late fee.
19. In case of violent deaths and other medico-legal cases, the certificate can be issued only by the medical examiner after the verification of the evidence provided
20. In case of adoption, registration can only be done on the orders of the magistrate who has jurisdiction over the area. Moreover, the birth certificate should not reflect the child who is adopted.
21. In case of an IVF birth, the name of the father need not be mentioned in the registration form
22. A death certificate for a missing person can be procured only after seven years from the date of missing and on providing a formal court order.

Protocols followed in CRS, continued

23. It is required that births, stillbirths, and events registered with a registration centre are reported to the authority in-charge on a regular and timely basis. The officer so delegated for this purpose at the district office must relay all the statistical parts of the reporting forms to the chief registrar within the prescribed time limit.
24. The district registrar must inspect the registration office and check the registers at regular intervals of time.
25. The district registrar can also impose a penalty on denial to provide information, providing false information, refusal to write names, and submit returns monthly.
26. Regular training must be organised for all registrars at lower administrative levels at a fixed time interval.
27. The chief registrars must submit all statistical forms to the state government and publish the annual report within the stipulated time limit.

Protocol or guidance on roles and responsibilities

As per the Act, the central government may, by notification in the Official Gazette, appoint an official to be known as the Registrar General of India.

Role of the Registrar General, India: He/she is the central authority with the power to issue general guidelines regarding the registration of births and deaths in the territories where the Act is applicable. He/she is responsible for coordinating and unifying the activities of Chief Registrars. Additionally, he/she is required to an annual report to the central government with details on the working of this Act.

Roles of Additional Registrar General/ Deputy Registrar General (CRS)/ Joint Registrar General (Director of Census Operations): The roles of Additional Registrar, Deputy Registrar, and Joint Registrar General have not been discussed in great detail in the CRS manual published by ORGI. The central government appoints these officers as it thinks fit for discharge under the Registration General's superintendence and direction, such functions of the Registrar General under this Act as he may, from time to time, authorize them to deliver.

Role of Chief Registrar/Additional Chief Registrar/Deputy Chief Registrar: The state government may, by notification in the Official Gazette, appoint a Chief Registrar for the state. Under section 4(2) of the Act, an Additional Chief Registrar or Deputy Chief Registrar can also be appointed in all states and Union Territories. The Chief Registrar is the chief executive authority in the state responsible for implementing the provisions of this Act. He/she coordinates, unifies, and supervises the registration in the country to ensure an effective system. Furthermore, he/she is responsible for preparing and submitting an annual report on the working of this Act in the State and the statistical report. The state government can also appoint an Additional Chief Registrar/Deputy Chief Registrar under the superintendence and directions of Registrar General of India. Details regarding the roles of these officers are not presented in the CRS manual published by ORGI.

Role of District Registrar/ Additional District Registrar: The District Registrar/ Additional District Registrar is subject to the Chief Registrar's direction. They are responsible for carrying into execution in the district the provision of this Act and the Chief Registrar's

orders from time to time for this Act's purpose. They are required to inspect the registration offices and examine the registers kept there. Additionally, they often instruct and guide other registrars and organise periodic training courses for them. They also ensure a timely flow of returns from the registrars to state headquarters. They monitor the registration unit at a definite time interval and identify excellent and lousy registration areas. Furthermore, they have the power to impose a penalty on denial to provide information, false information, refusal to write the name, and submit returns every month. Also, they ensure custody, production, and transfer of the registrars and other records kept with registrars.

Registrar/Sub-Registrar: The state government appoints a registrar for each local area within the jurisdiction of a municipality, panchayat or any other local authority, under this Act's provision, the Registrar may appoint Sub Registrars with prior approval from the Chief Registrar and assign him any or all his power and duties with regard to the specified areas within his jurisdiction.

Role of Registrar/ Sub-Registrar: They must collect information on every birth and death, within the jurisdiction, and ascertain and register the particulars of the event. They are required to have an office in the local area to report all the births and deaths. It is also their responsibility to take cognizance of births or deaths in the area that have not been reported for registration. They are required to maintain a register, verify the records of births and deaths, and ensure their accuracy. Registrar and Sub-registrar are also required to have an office, with a board placed outside stating the registrar's name, designation, the areas for which they have been appointed, and the duration of their availability, in the local language.

3.2: Sample Registration System

Accuracy: The respondents are generally given assurance that the information provided by them will be kept confidential and only used for policymaking and research purposes. The introduction of a paperless system has helped in reducing missing data fields, illegible information, and invalid entries. The automated process also does not allow records to be submitted without relevant details like gender, etc. Also, for accurate measurement of events, the SRS sampling frame is revised every ten years based on the census results. Updated samples represent the real change in the population and remove limitations observed in the previous sample. The investigator updates the household population list during the biannual survey to get the correct community member. The records collected by the enumerator and an independent supervisor are verified to determine any omissions, corrections, and errors. Corrective steps such as revisiting the households, verifying the data with the enumerators` register, and regular training of staff are undertaken in units where the results are unsatisfactory. Furthermore, a yearly training was proposed and has even been conducted in many states to increase their efficiency in terms of data collection.

Validity: The efficiency and intensity of supervision in SRS is a critical factor for producing valid data. Events are not recorded till the enumerator is satisfied with the data's credibility. Every six months, the supervisor visits each and every household in the sample units and administers an independent survey. The supervisor does not have any record from the field during the survey, ensuring that it is independent of continuous enumeration. The matching and joint re-verification of a partially matched event are generally done by third parties to avoid the chance of enumerator and supervisor collusion in making out corrections in records without informing the State headquarter.

It has also been observed that 10 per cent of the households are resampled for quality control purposes and the supervisor and the investigator are required to submit a report in the prescribed format. Well-defined boundaries of the sample and a permanent house numbering system have been designed to ensure an accurate estimate of the population at risk. The assignment of a cause of death must comply with ICD-10 to bring valid results.

Each individual in the SRS has a unique ID, linked with the COD record to the individual's record and its associated information to verify documents.

Reliability: In addition to the dual recording system, the department officials also pay periodic visits to the sample units to supervise enumerators' work and provide necessary guidance and clarifications. The officers check the completeness and accuracy of the birth and death registrations and enquire about roughly 10 per cent of records. Furthermore, enumerators are required to maintain a record as well as verify the documents. In case of verbal autopsies completed by the supervisor, the review is done by two separate trained physicians. and the COD (Cause of Death) certification is assigned on the basis of ICD-10. If the two physicians do not agree on the COD, then reports are for further discussion and reconciliation on the cause of death. If both the parties do not agree on the matter, a third physician is introduced to adjudicate. The whole process results in a more reliable recording of COD. Monthly reports are withdrawn from sample units before the biannual survey.

Furthermore, the supervisor investigates 10 per cent of the sample units and conducts a biannual survey in another 10 sample units. Uniformity in the system is maintained through the the four manuals prescribed for enumerators, supervisors, and the headquarter staff. Officers are sometimes assigned field checks in units where the performance of enumerators is unsatisfactory. A comparison of the data collected by the two agencies (enumerator and supervisor) minimises the chance of misreporting.

A review of COD is generally only done in urban hospitals. Its application is not consistent, which can affect the data's quality (ORGI, 2015). It is unclear whether the unmatched death records will be verified in the field or records collected during a half-yearly survey are considered for verbal autopsies. If the latter is the case, the exclusion of documents collected during continuous enumeration will produce a biased COD statistic.

Timeliness: Enumeration work generally starts in all sample units from a fixed date to provide estimates for a particular period. Enumerators must visit all the rural households in the sample unit once in three months and all the urban households once in a month. All enumerators must share a monthly report with the state headquarters on the first day of every following month. It is essential to ensure that monthly reports from all sample units are received by the 25^{th} of the succeeding months. Moreover, monthly reports for all six months are required to be dispatched at the end of the first week of the seventh month. It is mandatory to send half-yearly reports to ORGI within five months of the close of the six

months. Supervisors are required to send a report immediately after the completion of the inspection. At the end of each year, the state annual report is published by ORGI. A specific server is installed at all the Directorates of Census Operation (DCO), enabling fast file creation, downloading, and uploading files, and generating forms, so that SRS can timely disseminate the data.

However, there is no clear documentation on how often or how the coded COD data is transmitted to the RGI for analysis and publication purposes.

Completeness: To ensure all births and deaths are recorded in the sample units, a dual recording system are introduced in SRS. Part-time enumerators must visit each household in rural areas quarterly, and each household in the urban areas monthly to record missing events, if any. The enumerator is required to maintain contact with the informants and notifiers on a regular basis and keep a list of pregnant women to record all births, stillbirths or infant deaths in the area, if any. A retrospective survey for the previous year is carried out along with a six-month biannual survey to record any missed events. The enumerator must fill all possible details specified in the forms clearly for an individual's complete information. Periodic inspection by a departmental official at the field level is done to ensure no events are missed. The agencies' technical personnel are inclined to pay more attention to the departments' regular work and do not see SRS work as a priority.

Coordination between multiple departments and centralised monitoring is needed to cover important events in the sample units. Information on the number of events matched between the half-yearly surveys and continuous enumeration is currently not published. Still, disseminating such data would be essential to monitor and evaluate the system's completeness (Mahapatra P, 2007).

Relevance: Data is extremely essential for policy and program formulation, especially in the health sectors. The system's infant mortality rate is an essential indicator of the quality and availability of child health services. The distribution of deaths by age is crucial in identifying the vulnerable age groups, in order to provide health services. SRS data is often used for the calculation of life tables. SRS frame has been adopted in many evaluation studies, such as census evaluation study. Fertility and mortality indicators from SRS data are usually used for

evaluation of the impact of reproductive health programs. Moreover, SRS data is commonly used to determine CRS's completeness, the validity of NFHS, and fills a critical data gap.

Box 2: SRS: Questions to be answered

Sample Registration System: Questions to be answered

1. **What is the field monitoring process?**

Answer: Officers from the state headquarters conduct inspections on regular intervals. The supervisor does spot-checking for the births and deaths recorded. Besides, he verifies from the informants whether the enumerator regularly contacts them to know about the births and deaths that take place, visits each household in urban areas and rural areas once a month, and once in three months, respectively. Sometimes, officers are assigned field checks in units where the performance of enumerators is unsatisfactory.

2. **What are the steps undertaken to ensure the validity post data collection?**

Answer: The events recorded by the enumerators and the supervisors are often verified and a third party carries out the re-verification of the non-matched and partially matched events. In case the third party finds out that an event has been missed by both the enumerator and the supervisor, a necessary update in the respective forms is made. Inspection of nearly 10 per cent of the records is done by a supervisor or department official. In case of verbal autopsies (VA), the papers are reviewed by two separate trained physicians. They assign the COD based on ICD-10, information provided in the VA, and other medical records. If the two physicians do not agree on the COD, then reports are returned for further discussion and reconciliation. However, if no decision is made, a third physician is introduced to adjudicate. Each individual in the SRS has a unique ID, which can link the COD record to the individual's record and its associated information to verify records. (Jha et al., 2006)

3. **Once estimates are ready, are those compared with previous data or other sources of data?**

Answer: It is not clear whether SRS estimates are verified with other data sources. There has not been any systematic evaluation of SRS in the recent years. However, indirect estimates

from 1990 and onwards have shown that registration completeness has worsened over time and the quality and completeness vary from state to state. (Mahapatra et al., 2010). Additionally, more than 10 per cent of the causes are coded as ill-defined (12.4% in 2010–2013 for all ages, and much higher for adults aged 70 and older (29%), indicating that additional training in medical certification of death may be needed (ORGI, 2019)

Protocols followed in SRS

1. Individuals' details are kept confidential, and only statistical information is used for analysis.
2. Events must be recorded as soon as they occur.
3. A dual system of recording has been introduced. A continuous survey by a part-time enumerator and an independent half-yearly survey by the supervisor is done.
4. Events recorded by the enumerators are to be withdrawn from the state headquarters before the half-yearly survey is started by the supervisor.
5. Before the commencement of the survey, a mandatory training is imparted to the enumerator and supervisor to understand their roles and responsibilities.
6. Instruction/ operating manual must be given to the enumerator and supervisor.
7. The supervisor must carry a handheld device for data collection.
8. The enumerator must take the respondent's signature or thumb impression in the box above his/her name.
9. Enumeration work starts in all sample units from a fixed date to provide estimates for a particular period.
10. Enumerators must visit all rural households in a sample unit once in three months, and all urban households once a month.
11. Officers must check the accuracy of births and deaths at fixed intervals and enquire about 10% of the records.
12. The findings of the continuous enumeration and half-yearly survey are verified. Unmatched and partially matched events are re-verified by a third party
13. The verification must be done at state/region/ district headquarters and not in a sample unit.
14. If the enumerator or supervisor reports events inaccurately, then such entries have to be cancelled with suitable remarks.

15. A monthly report must be sent by the enumerator to the state headquarter within the prescribed time limit.
16. After finalising the data, the Directorate of Census Operation (DCO) uploads it to the central server
17. The Cause of death (COD) recording must include compliance with ICD-10
18. In verbal autopsies completed by the supervisor, the review is done by two separate trained physicians.
19. A retrospective survey for the previous year is also carried out along with a six-month biannual survey.
20. If no events are recorded, the enumerator is required to send a NIL report to the state headquarters.
21. The validation process is undertaken at the state headquarter before preparing the critical events.

Protocol or guidance on roles and responsibilities

Roles of enumerator: It is the responsibility of the enumerator to record every detail of the births and deaths that take place in their area. They enumerator is required to aid the supervisor in conducting a baseline survey for the area under their jurisdiction. He/she must visit each household in urban and rural areas, once a month and once in three months, respectively. Furthermore, he/she must prepare a monthly report and send it to the state headquarter within the stipulated time limit. They are also required to meet and enquire the informants and notifiers at regular intervals.

Roles of supervisor: The supervisor conducts a baseline survey in the sample unit, including preparing layout maps and filling in different schedules. He/she conducts Half Yearly Surveys (HYS) in about 12 units as assigned by the state headquarters. During this survey, they must visit each household, check the entries, and ensure its up to date. They are also responsible for informing any discrepancies detected in the field and ensuring missing monthly returns. They are required to compile the results of the HYS in a prescribed format and submit the status report to the state headquarter. He/she also assists the investigator in carrying out analytical studies, undertaking fieldwork as may deemed necessary, and carrying out re-verification work in the units assigned by the state headquarters.

Furthermore, the supervisor also carries out inspections and spot-checking to verify the accuracy of the events. They must regularly contact the informants and enumerator and ensure timely submission of returns.

Role of officers from state headquarters: The department officials pay periodic visits to the sample units and supervise enumerators' work and provide necessary guidance and clarifications. They are also responsible for providing training to enumerators and supervisors. They carry out random checks and inspections in a few households to detect any possible omissions by the enumerators. They are required to maintain control sheets, quality control charts, study trends in vital rates and probe into the reasons for abnormal variations. They also conduct inquiries into aberrant units and sends the results of extra/spurious events detected by ORGI. The officer is required to send an inspection report to the state headquarters. Monthly reports are thoroughly scrutinized in a state headquarter by officers at state headquarters.

Role of Registrar General of India: The Registrar General ensures the smooth implementation of protocols and guidelines for the successful completion of the survey. He is also responsible for publishing an annual national report based on the survey.

3.3: National Sample Survey Organisation (NSSO)

NSSO: The National Sample Survey Organisation (NSSO) was established in 1970 to rectify data gaps in socio-economic planning and policymaking through sample surveys. The NSSO conducts surveys on all essential variables required for policy formulation. The areas covered under this survey include consumption expenditure of individuals, the job market, employment in the informal sector, migration, education, nutrition, disability, time use pattern, and healthcare. The organisation functions under the supervision of Ministry of Statistics and Programme Implementation (MOSPI). In this study, we have presented the data quality issues in NSSO data. We have used the following parameters to check the quality of NSSO data**.**

Accuracy: The system for data collection in NSSO has been completely digitised. Computer-Assisted Personal Interviewing (CAPI) is now used for data collection, which considerably reduces the chances of error as compared to the manual system. There are two levels of supervision during the data collection phase. The level 1 supervisor verifies all the data recorded by the enumerator and rectifies it if found erroneous. The level 2 supervisor verifies 10 per cent of the data and provides his/her feedback on the same. Monitoring and supervision are generally done using an MIS dashboard. Furthermore, an independent body, called the National Statistical Commission (NSC), approves the result for further data use.

The NSSO inspects whether there are issues and concerns regarding the accuracy of information provided by the respondent. Characteristics of the respondents and their ability to provide required data has a significant impact on the accuracy of data. The data is usually not completely free of identification, enumeration, and tabulation errors. There have been occasions where discrepancies were found in the codes recorded against sample observations/individuals for the status of employment/industrial classifications/occupational classifications" (Mitra S, 2018).

Validity: The NSSO provides consistent and uniform training to all the survey personnel. Data validation is done in real-time. The data submission process undergoes a three-level validation process. These three stages are as follows.

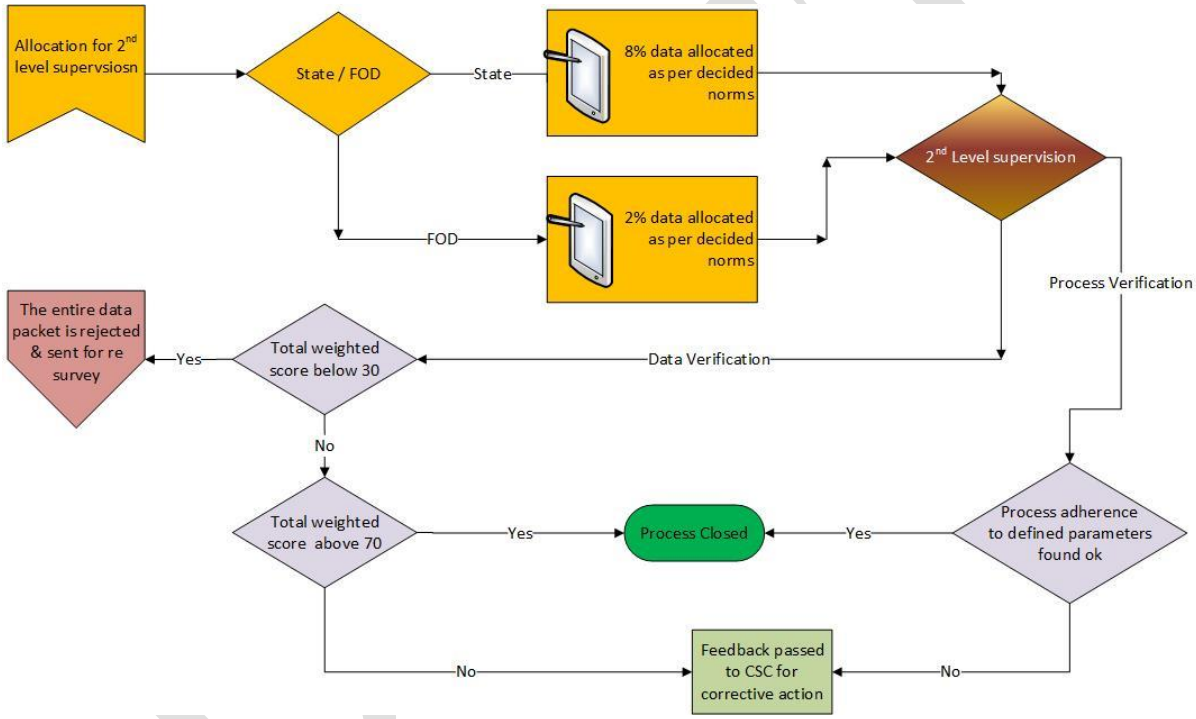
First stage: content check

Second stage: coverage check

Third stage: Howler check (detecting abnormally high or low values in the data).

In addition to this, there are two other methods of data verification. The first method is process based, and the second method is quality based. The process based verification is based on five critical parameters. It is used to inspect the process of enumeration anywhere between 5 to 20 days of the survey's commencement.

Figure 1: Data Verification process of NSSO data



Source- MoSPI, GOI

In quality-based verification 30 per cent of the enumerator's work is verified by the level 1 supervisor. Quality check is done for the supervision of the survey quality. Weighted quality score is generated by the system; if the score is less than 30, the entire data packet is rejected and sent for re-survey. Figure 1 shows the whole process of data verification.

The NSSO checks for evidence of systematic differences in the quality of fieldwork carried out by both centre and state-level organisations. Reasons for such differences have not investigated and corrected yet.

For example, Pandey A et al. (2010) documented that data collected during the 58th round lacks precise definition of mental disability. Another study by Thorat A (2004) documented cases with reference period and consistency of concept used. Therefore, there may be issues around the quality of information.

Reliability: The NSSO data is based on high standards of planning and designing. Adequate and effective probing is done for error-free data collection process. A high-level steering committee periodically reviews and refines the national indicator framework. Furthermore, a periodic review meeting is conducted at the headquarters regularly. Besides, there are active collaborations among all stakeholders, and regular training is provided to the field staff on the before the commencement of each round. The fieldwork is carried out by teams consisting of experienced and highly trained investigators from the Field Operations Division (FOD) of the NSSO. Measures have been undertaken to create a brand name for National Statistics Organisation (NSO) and increase cooperation from respondents to improve the quality of data. It has been observed that there are differences between NSS estimates and those obtained from other sources.

It was believed that staff constraints had prevented the NSSO from increasing the sample size. The higher the number of people observed, the lower is the margin of error and the more reliable the data is. Understaffing seems to have had an adverse impact in the western zone, with 41% of senior statistical officer positions and 34% of junior statistical officer positions lying vacant (Samarth B, 2017).

Completeness- The NSSO generates pan-India as well as state-level estimates and reports based on the samples covered under its integrated framework. However, NSSO does not generate district-level estimates due to inadequate sample size, although there is a high demand for such data for decentralised planning. The pooling of central and state sample data is under considerations for increasing sample size and robust estimates.

A study by Mohan Kumar S (2013) documented the issues with NSSO sampling design coverage. Sampling design for a state like Kerala should have had adequate coverage and sample size to generate estimates of Monthly Per-capita Consumption Expenditure (MPCE) by districts. However, since 2011-2012, there is no comparable information on the status of the country's labour force, workforce, and unemployment rates (Mitra, S, 2018).

Timeliness: Data needs to be published within the prescribed time period. Based on the subject, data is published either, monthly, quarterly, or annually. For example, the Wholesale Price Index (WPI) data is published monthly, the RPC bulletin called the 'Prices and Wages in Rural India' is published quarterly, and specific annual survey data is published annually. Monthly data must be posted on the 25th of the month or prior to that if it happens to be a public day.

Given the data quality issues, the Ministry decided not to release the Consumer Expenditure Survey results of 2017-2018.

"It felt that lack of timely and periodic estimates on the number and types of jobs in the country, level of unemployment, and employment opportunities created by government schemes, along with lack of plausible definition of formal employment, were the major challenges before policymakers" (Sharma Y, 2017).

Coherence: NSSO data is comparable over time. Most of the indicators generated using NSSO data are used in showing trend analysis. The NSSO also conducts quinquennial surveys like Employment Unemployment Survey. There exists a continuity as well as comparability across these employment-unemployment data at several general and disaggregated levels. This data is also internationally comparable (Mitra S, 2018). Besides, annual growth in Gross Domestic Product (GDP) is also compared with previous years.

The current Periodic Labour Force Survey (PLFS) by MoSPI provides annual employment-unemployment figures for rural areas and similar quarterly statistics for urban areas. The methodology adopted for the PLFS also indicates departures from the earlier EUS rounds and, therefore, is not fully comparable with the previous rounds of NSSO-EUS(MitraS,2018).

Relevance: Organisations worldwide, including ILO, the World Bank, and India's planning commission, have always been using the NSSO data extensively. Academic and private

institutions use this data for research purposes. In addition to the data published in its reports, the NSSO also provides unit-level (household and individual) data, which consists of a vast source of information on several aspects of individual households at detailed disaggregated levels. Data from NSSO is integral to policymaking in India as it happens to be an official source of key socio-economic indicators (consumption, employment, etc.) collected via large-scale sample surveys. For example, NSSO-Employment and Unemployment Survey (EUS) helped immensely in analysing trends and evaluating the impact of government interventions, thus playing an essential role in influencing the country's overall macro policy framework. (Mitra S, 2018).

Box 3: NSSO: Questions to be answered...

NSSO: Questions to be answered

1. What is the field monitoring process?

Answer: NSSO systematically monitors the quality of data at the field level. There are two levels of supervision during data collection. The Level 1 supervisor checks 100 per cent of the data recorded by the enumerator and corrects it if found erroneous. Then, the level 2 supervisor verifies 10 per cent of the data and provides his/her feedback. Additionally, real-time monitoring is done using an MIS dashboard.

2. What are the steps undertaken to check the data validity after post collection?

Answer The data submission process further undergoes a three-level validation process--First stage: Content Check, Second Stage: Coverage Check, and Third Stage: Howler Check (detecting abnormally high or low values in the data). Data verification is also done through two other methods. The first method is process based and the second method is quality based. Process-based verification is used to check the enumeration process between 5-20 days of the survey's commencement. Quality check is done for the supervision of the survey quality. Weighted quality score is generated by the system; if the score is less than 30, the entire data packet is rejected and sent for re-survey.

Once estimates are ready, are those compared with previous data or other sources of data?

Answer: NSSO estimates are generally compared with forecasts of the previous round. Most report presents trend analysis of the forecast. For example - the NSSO report on health (75th round) also showed estimates of the previous round (52nd round, 60th round, 71st round) for presenting trends. A previous study showed that there are differences in NSSO estimates and estimates from other sources. The density of doctors, nurses, and midwives per 10,000 people is 20.6 according to the NSS and 26.7 based on the registry data (Karan et al., 2019)

3.4: Integrated Disease Surveillance Program (IDSP)

Integrated Disease Surveillance Program is a decentralised, state-based surveillance program in India aimed at detecting early warning signals and signs of impending outbreaks and help initiate an effective response on time, thereby preventing plenty of cases. IDSP is also expected to provide essential data in order to monitor ongoing disease control programmes' progress and help allocate health resources more efficiently.

The Integrated Disease Surveillance Project was launched by the Ministry of Health and Family Welfare (MoHFW) along with the World Bank, in 2004. It continued as the Integrated Disease Surveillance Programme (IDSP) during the 12th Plan (2012–17) under the National Health Mission with a domestic budget. Under the IDSP, a Central Surveillance Unit (CSU) in Delhi, State Surveillance Units (SSU) in all State/Union Territories (UTs) headquarters, and District Surveillance Units (DSU) in all districts have been established.

Objectives of IDSP:

1) To strengthen/maintain decentralised, laboratory-based, and IT-enabled disease surveillance systems for epidemic prone diseases

2) To detect and respond to outbreaks in the initial phase through trained Rapid Response Teams (RRTs).

The IDSP includes a total of 13 diseases, both communicable and non-communicable, for surveillance. These are Acute Diarrheal Disease, dysentery, hepatitis, enteric fever, malaria,

dengue, chikungunya, Acute Encephalitis Syndrome, diphtheria, pertussis, chickenpox, pyrexia of unknown origin, acute respiratory illness, pneumonia, leptospirosis, Acute Flaccid Paralysis, and snakebite. As part of IDSP, data is collected in a phased manner throughout the country, right from the block level.

Accuracy: Under IDSP, data is collected right from the District Surveillance Unit level and is then transferred to the state and central levels through the IDSP portal and via email. The information is collected in three specified reporting forms- The healthcare, workers, village volunteers, and nonformal practitioners fill Form S, to report on suspected cases/syndromes. Form P is meant for presumptive cases, or probable/clinically suspected cases. In this regard, pharmacists collect information from the OPD and nurses, which is then entered in the daily tally sheet. There is also Form L, for laboratory-confirmed cases, filled by laboratory staff. Standard case definitions are used for specific disease conditions while reporting. The syndrome and the written symptoms are clearly defined in the manual for the health workers and are followed accordingly. The syndromes are noted in Form S when the health workers go for routine visits to the village and urban wards or sub-centres

The syndrome, patient's name, age, sex, address, and date of onset of the syndrome are all recorded in the register. The Syndrome Reporting Form (Form S) is filled throughout the week from Monday to Sunday. In case of specific symptoms, healthcare workers send the specimens for laboratory tests. When the health workers refer patients for further check-up and diagnosis, the referral's outcome is confirmed by the Medical Officer at the PHC.

The validity of data: The IDSP checks the data's validity electronically as the software has inbuilt provisions. Once the information is entered and verified in the software, the reports are finally generated. These reports are produced on a weekly basis for diseases that have outbreak potential and on monthly basis for the other communicable diseases. The data entered enables comparison of the incidence rates and case fatality ratios for a particular month between the various reporting units. If there is a sudden rise or fall in the incidence rates, the data is rechecked to see if any error has occurred. The healthcare workers carry out a preliminary analysis of syndromic surveillance data in the register to look for any unusual patterns such as a sudden increase in cases of a particular syndrome in time or an area or among a specific population/group. Specific attention is given to see if there is a clustering of

cases, a sudden increase in the number of cases of any particular syndrome over the past few weeks, any unusual event/deaths.

Relevant aspects of data collection include:

- The response fraction having valid and reliable instruments for collecting data (including sphygmomanometers, questionnaires, etc.) and
- Attention to the calibration of instruments and training of staff and monitor the quality of measurements themselves.

Completeness of data: The Medical Officers monitor the reporting units to check the complete reporting of the cases on time. The reporting units are the sub-centres of PHC and urban health centres. The register, which contains the verifiable information, is counter-checked by the supervisory staff under IDSP at PHC/CHC and district levels to ensure the data's completeness. A report is complete only when all the reporting units within the area have submitted the information on time. If only 8 out of 10 units have submitted, then the remains incomplete. The District Surveillance Officer maps and pursues all possible hospitals in the districts that generate data for IDSP. In the hospital, the superintendent, with nodal officers, maps out all potential data sources to collate in the P form and L form. The Data Entry Operator posted at the Medical College under IDSP ensures that proper and complete (P & L forms) information is collected, collated, and shared with the surveillance authorities.

Timeliness of data: Under the IDSP, timeliness is defined as reports that are obtained within one week post the reporting week's last date. A report is said to be on time if it reaches the designated level within the prescribed time period. If it reaches later than the stipulated time, then the report is considered late (and of lesser public health use). The reports are generated every week by monitoring the weekly forms (S/P/L). The information collected by the healthcare workers is translated into a summary sheet (form S) and given to the medical officer in charge of the PHC / Urban Health Centre (reporting units) every Monday, which is then immediately forwarded to the District Surveillance Officer. The sentinel private practitioners who are also part of the reporting system submit the S forms to the healthcare workers. They then submit it to the PHC without any further delay. Each PHC chooses an optimal method of reporting cases that is suitable according to the situation. The appropriate method is adopted for sending the report to each unit so that if there is a delay in reporting, it can be quickly

addressed. The methods used for sending the reports are 1) Telephone followed by the mailing of IDSP format by hard copy 2) Fax or email to DSO 3) Courier 4) Direct contact with healthcare worker. The Medical Officer of the PHC retains one copy of the form S. The remaining copy is then forwarded to the District Surveillance Officer immediately on Monday or latest by Tuesday. All the reporting units' data and reports consisting of graphs and maps are compiled to publish a weekly or a monthly report.

Consistency: The minimum expectation under IDSP is that each reporting unit reports for at least 40 weeks (or 80% of the week at any given time under consideration) in a year However, for programme purpose, the following definition of consistency is followed:

1) A reporting unit is consistent if it has been reported for at least 40 weeks (or >= 80% of the week at any given time).

2) A district is consistent for a week if at least 80% of the reporting units under the district report for a particular week.

3) A state is consistent for a week if at least 80% of the district (having consistent RUs) report for a particular week.

Box 4: IDSP: Questions to be answered.

Integrated Disease Surveillance Program (IDSP)

1. **What is the field monitoring process?**

The Medical Officers monitor the reporting units to check for the complete reporting of the cases on time. The register, which contains the verifiable information, is counter-checked by the supervisory staff under IDSP at PHC/CHC and t district levels to ensure the data's completeness. The Data Entry Operator posted at Medical College under IDSP guarantees that proper and complete weekly (P & L forms) information is collected, collated, and shared with the surveillance authorities. It is the responsibility of the healthcare workers to maintain the IDSP Surveillance Register.

2. **What are the steps undertaken to check the data validity post collection?**

Checking the validity of the data reported is done electronically, as the software has inbuilt provisions. The data entered enables comparison the Incidence rates and Case Fatality Ratios for a particular month between the various reporting units. If there is a sudden rise or fall in the incidence rates, then the data is rechecked to see if any error has occurred. The healthcare workers carry out preliminary analysis of syndromic surveillance data in the register to look for any unusual patterns such as a sudden increase in cases of a particular syndrome in a certain population/group. This ensures that valid data, and thereby valid conclusions are produced, and protocols are followed at all stages of the process.

3. **Once estimates are ready, are those compared with previous data or other sources of data?**

The current data is compared with the previous year's report/data. The Monthly Surveillance Report (June 2020) documented how the fatality rates for H1N1 were 0%, 9.21% and 0% in June 2018, 2019 & 2020 respectively. Similar comparisons study have been made for other indicators as well.

Protocol or guidance on roles and responsibilities

The functions of the State Surveillance Unit include-

- Collation and analysis of data received from the districts and transmitting the same to Central Surveillance Unit.
- Coordinating activities of Rapid Response Teams and deputing them to the field.
- Monitoring and reviewing the District Surveillance Units' activities, including checks on the validity of data, responsiveness, and laboratories' functioning.
- Coordinating the activities of the state public health laboratories, medical colleges, and other state-level institutions.
- Sending regular feedback to the district units on the trend analysis of data.
- Coordinating all training activities under the project.
- Organising meetings of the State Surveillance Committee.

The functions of the District Surveillance Unit:

- Collation and analysis of data received from districts and transmitting to the State Surveillance Unit.
- Assembling Rapid Response Reams and deputing them to the field whenever needed.
- Implementing and monitoring all project activities.
- Coordinating with public health laboratories, medical colleges, NGOs, and private sectors.
- Sending regular feedback to the reporting units on the analysis of data.
- Coordinating training and IEC activities within the district.
- Organising meetings of the district surveillance committee

3.5: Health Management Information System (HMIS)

HMIS can be defined as a tool that helps gather, aggregate, analyse, and then use the information generated to improve the performance of the healthcare system (GOI, 2008). Ministry of Health and Family Welfare (MoHFW) launched the HMIS web portal on 21 October 2008. The HMIS portal enables collection of public health data from public and private institutions in rural and urban areas. The portal has been envisioned as a single window for all public health data under MoHFW. It helps in understanding the population's health needs, and monitoring effectiveness and coverage of health programs. It facilitates the evaluation and assessment of data and focuses on designing appropriate remedial strategies as long as the data is of high quality. One of the key initiatives in HMIS has been undertaken by the National Health Systems Resource Centre (NHSRC). It is focused on developing a technical redesign of the HMIS to make architectural corrections in the health systems, on the customisation of a free and open-source HMIS software to meet the states' needs and training requirements, and on capacity building for effective use of information, in order to take action. HMIS has introduced 21 indicators for routine monitoring of the key aspects of the healthcare system's performance. These indicators are further based on five broad categories- Reproductive health, Immunisation, Disease Prevention and control, Resource utilisation, and Data Quality.

Data Entry Process

Data on service delivery, training, and infrastructure are entered on a monthly, quarterly, and annual basis. Data elements are recorded in a primary register by the service prevents of similar nature that occur in a single month are aggregated and reported in specified reporting formats. There are three types of data elements in HMIS- simple, disaggregated, and calculated. Some essential indicators are computed by converting data into information/indicators using statistical methods.

Quality Issues of HMIS

Accuracy: Small errors at the facility level often get accumulated into more significant miscalculations when multiple facilities are aggregated. This low data accuracy could be due to the following four factors- ambiguity regarding data elements, data entry errors, systematic errors, and fraudulent reporting. The HMIS has repeatedly been said to be riddled with many

problems. Not only have the records suffered from incompleteness and low quality, but there is also a tendency to over report the outcomes. Irregularities in report generation, data duplication, and data inconsistencies are some common observations.

There is usually some standard error in the HMIS report, which needs to be corrected. The These could be missing data, duplicate data, thumb suck (when data collection tool is not routinely used, the staff fills in a likely looking number), unlikely values for a variable, contradiction between variables, calculation errors, typing errors and capturing in the wrong box. Errors also occur due to multiple registers or poorly designed registers. Often, recording of information in various forms and formats becomes monotonous, which adds to data weariness.

By visually scanning the data, one can detect missing data values. In order to examine unexpected fluctuations beyond the maximum and minimum values, inconsistencies between linked data elements, and mathematical errors, the HMIS uses two unique techniques—LQAS and RDQA.

Data accuracy is verified using Lot Quality Assurance Sampling (LQAS) methodology at the health facility level. It is a technique mainly used to assess whether the desired level of data accuracy has been achieved by comparing data in relevant record forms and HMIS reports. All health facilities maintain a registry to record data accuracy and verify results. Furthermore, HMIS personnel also use this technique for data accuracy check during supportive supervision visits.

Routine Data Quality Assessment (RDQA) is a tool is used for checking data accuracy. Under this technique, the administrative level's accuracy is checked by a quantitative comparison of the recounted data and reported data., This method is adopted for the assessment of intermediate aggregation sites and to check whether data has been collected and reported accurately, by providing a ‘Verification Factor’,(level of under or over-reporting) for the data under observation. Generally, to study the HMIS data accuracy level in a given administrative area, a sample of 12 health facilities is selected. Each of these chosen health facilities is visited regularly to complete the RDQA. In this technique, data duplication is a serious problem, which hampers the data quality, leads to false coverage of services, and inaccurate decision making. In many cases, ANM reports services delivered by PHC, CHC, or hospital facilities

There is no clear delegation of powers for approving or confirming data, which is particularly required for late reporting facilities, non-reporting facilitates, cumulative data coming in,and error management. (NRHM-HMIS, 2012).

An earlier study shows how study variables were mostly over-reported for cases where high coverage levels were desired but not achieved. Khandade et al., in 2013, in their research focused on Bihar, reported that accuracy of HMIS for various indicators varied from 65% to 80%. The figures in Haryana ranged between 55% and 90% for multiple indicators (Sharma et al., 2016). The overall quality of HMIS in Haryana was far better, when compared to other states which could be attributed to the state government's efforts towards improving the quality of the same (Sharma et al., 2016). With regard to ANC check-ups by pregnant women and PNC home visits by ANMs, figures were lower than others, and ranged between 20% and 50%. Khandade et al. (2013) also reported 100% incompleteness of HMIS records for contraceptive usage. In an earlier study undertaken in Uttarakhand in 2012, 24.6% of the entries were reported missing for various indicators (Husain et al., 2012).

Validity: In HMIS, a validation check is carried out by comparing two values of two or more data elements. Standardised definitions and norms are used in every health facility. MoHFW has defined 22 validation rules for checking internal consistency. It has also adopted a median-based criterion to identify possible outliers, which is uniformly used at all levels. For example, HMIS stores the medical records in standard formats so that it is possible to link it with other EMR (Electronic Medical Record) systems. It back and forth exchange of data with third-party networks and along referral channels will also increase security to prevent sensitive information. Moreover, all mandatory details and approvals from district administration and state administration are required for healthcare facility users to enter data in the HMIS portal. Guidelines for monthly service delivery and infrastructure data has been made available to all ANMs to ensure data validity by standardizing data definitions.

Data entry errors can be corrected through visual scanning and performing validation checks by comparing values. Some standard validation rules are also available for different indicators- ANC, blindness control, deliveries, immunisation, JSY, new-borns, post-natal care, etc. It is important to note that violation of a validation rule due to- management issues like availability of vaccines or medicines in stock, disease outbreak, the actual improvement due to a good BCC program. Systemic errors also occur due to poorly designed primary registers, computation problems in the register, misinterpretation of data elements,

consistency of terms used, issues in data aggregation, confirmation and error management procedures, logistical issues, duplication, wrong choice of indicators /denominators, inability to create indicators- or too many data elements for one indicator, and errors in death reports. However, HMIS has data collection & reporting guidelines to handle all these issues.

Hussain Z et al. (2012) presented how the wrong definition of abortion was being followed at District Headquarter/Sub-district Headquarter. He also observed the existence of outliers in many variables and how too many validity rules were being flouted. Another study documented that although there was information available on the provider's details for delivery, there was no mention of the referral centre, in case of a complicated delivery. Underreporting and discrepant reporting have also taken place occasionally, which have not been verified by HMIS (Dehury RK et al., 2018).

Reliability: Data is often checked for quality and consistency at the block, district, and state levels. Feedback is taken from the facilities and periodically, a national level meeting is conducted, where states' performance is reviewed (Hussain Z et al., 2012). Systematic errors such as poorly designed primary registrars, misinterpretation of data elements, consistency of terms used, data aggregation, logistical issues, etc., are eliminated for quality and reliable results. It is mandatory to follow strict guidelines during data entry and report generation. The HMIS portal notifies one regarding the accuracy of data before the final submission on the portal. Data for the previous month is also accessible through the portal for further comparison with current data. For example, in Uttarakhand, district and block programme managers evaluate the data, followed by the state programme unit, who later share their feedback with the districts. Another study by Sharma A et al., 2016 showed a comparison of ANM records with monthly reports which were sent to higher facilities and documented over-reporting from 1.4% to 6%. Another study based in Odisha by Bhojani et al. showed how inadequate supervision and accountability of data and preliminary data review before transmission to the next level was a significant challenge that adversely impacted thedata quality. Most processes and data under HMIS are a result of program reporting, carried out by programme officers independently.

HMIS has been built to facilitate the delivery of protocolized care. For example- for a nurse documenting a patient's visit, the HMIS supports an interface that closely mimics the SOAP protocol. SOAP is an acronym comprising of the four stages: 'Subjective' captures the patient's condition in their own words; 'Objective' consists of notes from, physical

examination and tests; ‘Assessment’ consists of a summary and differential diagnosis and finally ‘Plan’ recommends a course of action including prescriptions and referrals (Rajanna& Kapila, 2016).

Completeness: Under HMIS, there are 11 common data elements in the recordings registers– breastfeeding within the first hour, new cases of hypertension, complication and death due to sterilisation, severe side effects following immunisation, IUD removals, Hb test for ANC, midnight headcount, total number of times ambulance was used for transporting patients, adolescent counselling services, JSY registration at the time of ANC, and the total number of 9-11 months old fully immunised children.

Completeness of the reported data is assessed using the following formula—firstly, the number of facilities reported against the total facilities is checked. Secondly, the number of data elements reported against the total data elements in the reporting form is checked. All the fields under specific indicators must be filled by the health facility and submitted to the HMIS portal. During the assessment, one must check for zero and blank fields as the inclusion of zero increases completeness by a large margin. The reasons for such occurrence could be unavailability of services in these health facilities, unavailability of recording registers for these events, or simple ignorance. Therefore, the zero/blank values in various data elements groups are checked.

In Uttarakhand, data capturing was observed to be weak as all departments did not report data. Also, missing data was higher in two districts (Udham Singh Nagar or Rudraprayag) as compared to the whole state. Additionally, 24.6% of the entries were reported missing for various indicators (Hussain Z et al., 2012). A study undertaken by Hari Kumar in 2013 found that the limit of completeness of data in Kerala is 29%. In Haryana, the completeness of ANM records ranged from 73% for the DPT1 vaccination date to 94.6% for the delivery date.

Timeliness: It is mandatory to submit data on service delivery, training, and infrastructure on a monthly, quarterly, and annual basis. It is required for district level officers to check for reporting for every facility and find out when all facilities report in the district. Reporting data on time is an essential component in HMIS. For example, during monthly review meetings, if 5 out of 10 sub centres do not submit the report on time, it becomes difficult for the MO to assess the performance and develop a plan for PHC in particular or even the sub-centre in general.

In Uttarakhand, the reporting period is either 19th or 20th of each month. However, there is no calendar month followed in other states. ANMs at the sub-centre level and at the Primary Health Centre fill in the monthly HMIS forms during the last week of the month. Data from SC and PHC are forwarded to CHC between 26th and 28th of every month.

Many states have also implemented the Mother & Child Tracking System (MCTS), with special focus on timely updates.

Relevance: HMIS is an integral tool to ensure the continuous flow of quality data on public health and healthcare services to assist in local planning, programming, implementation, management, monitoring, and evaluation. It provides access to micro-level data that is uploaded frequently. HMIS is also essential for the maintenance of health-related data and increases the effectiveness and coverage of healthcare facilities. HMIS allows for evaluation, assessment, and designing of appropriate remedial strategies. It is particularly integral to the evaluation of progress made in SDG. Moreover, HMIS is extremely important in India, where donors are increasingly linking the release of funds to performance, based on the indicators.

Box 5: HMIS: Questions to be answered…

Health Management Information System

1. What is the field monitoring process?

Data definition guidelines for monthly service delivery and infrastructure data are made available to all ANMs to ensure data accuracy by standardising data definitions. Verification of the MCTS work plan with the RCH Register and visiting the house of at least two pregnant women in the area have been made mandatory for all monitoring officials. Visual scanning, LQAS, and RDQA are used to correct data at the facility and administrative levels, respectively.

2. What are the steps undertaken to check the data validity post collection?

Data validation is performed by comparing two values of two or more data elements.The Ministry of Health and Family Welfare (MoFHW) has developed 22 validation techniques that are used for examining internal inconsistencies in data. It has adopted a median-based criterion to identify possible outliers, which is uniformly used at all levels. Additionally, the statistical outliers are identified, and systemic errors in the data are checked. Independently supervision is done at the facility level, and then data is matched with those collected by the facility provider or any other officer authorized to do so. A study showed that the date of the DPT1 vaccine administration mentioned in HMIS records matched with the one reported by the households in 65.8% cases for a ± ten days' period window and 77.5% cases for a ± 30 days' period window. (Sharma et al., 2016).

3.Once estimates are ready, are those compared with previous data or other sources of data?

In HMIS, the current data is compared with the previous month's data to examine the change in trends or the accuracy of a particular indicator. The Health Program Manager Manual presents how data triangulation has been done for Orissa with sources like DLHS and NFHS, to assess the quality of HMIS. The current report is also matched with the previous year's report to check any variations. For example, the Manager Manual shows the sex ratio in Sikkim at two different time periods for quality check. Also, a comparison of RGI data with HMIS data is made to assess the accuracy of COD.

There are many independent studies that have been undertaken in different states which examine the quality issues of HMIS; The following can be used for a comprehensive assessment of HMIS.

Table 1.1: Steps followed in HMIS for improving the quality of data

Quality Indicator	Yes/No	Steps followed
Accuracy	No	LQAS and RDQA techniques are applied to check the accuracy of the data. **Previous studies have showed that data has not been accurately uploaded.**
Validity	NO	MoHFW has defined 22 validation rules for examining data inconsistencies. Data validation is performed by comparing two values of two or more data elements that are comparable. Data definition guidelines for monthly service delivery and infrastructure data are usually made available to all ANMs to ensure data validity by standardising data definitions. **Previous studies show the existence of outliers and how many validity rules are flouted**
Reliability	Yes	Periodically, a national level meeting is conducted, where the performance of states is reviewed. (Hussain Z et al., 2012) Systematic errors such as poorly designed primary registrars, misinterpretation of data elements, consistency of terms used, data aggregation, logistical issues, etc., are eliminated for reliable results. An independent supervisor also carries out supervision
Completeness	No	Completeness is assessed using the following formula—first, the number of facilities is reported against total facilities. Second, the number of data elements is reported against total data elements in a reporting form. All boxes corresponding to the given indicators must be filled by the health facility and submitted to the HMIS portal. **Completeness of data highly varies state to state and from district to district.**

Timeliness	Yes	It is mandatory to submit data on service delivery, training, and infrastructure monthly, quarterly, and annually. District level officers check to report for every facility and find out when all facilities report in the district.
Relevance	Yes	HMIS is an essential tool to ensure the continuous flow of quality data on public health and healthcare services to assist in local planning, programming, implementation, management, monitoring, and evaluation. It provides access to micro-level data that is uploaded frequently. It is also essential for the maintenance of health-related data and increases the effectiveness and coverage of health facilities. HMIS allows for the evaluation, assessment, and designing of appropriate remedial strategies.

The protocol followed in HMIS:

- It is mandatory to ensure that visits documented by the nurse are approved by a doctor.
- For every patient, the healthcare provider can access their records of all the visits.
- Follow-ups can be done when patients seek care at a higher level.
- Periodic training must be conducted for officers and staff at lower administrative levels.
- It is also essential to assess data before uploading it on HMIS every month.
- ANMs and PHC/CHC level doctors and pharmacists must check for accuracy and prepare a report before uploading it on the portal.

Hierarchies of officers and their roles and responsibilities

- ANM- ANM works at the sub-centre level. ANM maintains registers and records data in the authorized fields. They are also responsible for preparing monthly reports and uploading them on the HMIS portal, which needs to be verified by LHV.
- Doctors or pharmacists at PHC and CHC must record all data elements provided at their facility centre. They are also responsible for preparing a monthly report in the

prescribed format and uploading it to the HMIS portal. Also, they verify the data reported by ANC's and LHV's.

- District Statistical officer-health, family welfare department and TB, Malaria, and Leprosy officer – These officers collect data from different programmes independently and prepare a report and upload it on the HMIS portal within the prescribed time limit.
- Dy/Joint Director Statistics-Family welfare, Dy/Joint director-vital statistics, a team of surveillance units and officers from Sample Registration System coordinate HMIS at the state level. It provides training and guidelines to the staff at lower administrative levels.
- Officers from the Central Bureau of Health Intelligence, Officers, Department of Family Welfare (Statistics, Medical officers from CGHS, Statistics Division, Department of Health and officers from Sample Registration System- These officers are involved in managing, coordinating, facilitating, and providing required logistics and training at lower administrative and facility levels.

Table 2.1: Organization/Official responsible for HMIS Matrix

Location/hospital	**Person responsible**
Sub-centre	ANM
PHC/Hospital	Pharmacist (designation of a statistical assistant)
District	District statistical officer- health, family welfare Dt. TB, Malaria, Leprosy officers
State	Dy/Joint director (Statistics) Dy/Joint director(Vital Statistics) Surveillance Unit Sample Registration system
Central Government	Central Bureau of Health Intelligence Statistics Division, MoHFW CGHS Statistics Division Department of Health ;Sample registration System

Source- Bodavala, R., (1998).

3.6: Maternal and Child Tracking System (MCTS)

MCTS is an innovative, web-based, name-based, tracking system which enables healthcare workers and officials to ensure timely delivery of complete maternal and child healthcare services to pregnant women and children up to the age of five.. Launched in 2009, by MoHFW, it was further initiated at the Mission Mode Project (MMP) in 2011. The MCTS captures data such as location and identification of beneficiaries, details of the healthcare providers, details on ANC, pregnancy outcome, and PNC, along with the infant's details. The system also collects information on children's immunisation details and concerned health providers. MCTS is the primary source for reporting and review of MCH services. Due to Reproductive and Child Health (RCH) programmers' changing data requirements, the ministry has designed an RCH portal. The RCH portal transfers the data to the MCTS portal in a phased manner (MoHFW, 2015). We aim to assess the quality of MCTS using the following quality parameter.

Accuracy: In MCTS data is not entered in real-time. The data entry operator enters the data into the portal from the RCH register. Reports are prepared by compiling data from various registers, which is a time-consuming error and prone to errors. The system provides a standard manual, including a proper definition of the terms used in the RCH register. A unique ID number is generated by the system for adequate tracking of the beneficiary and, consequently, accurate reporting of the data in the system. An SMS is sent in regional language to avoid misinterpretation of the services provided.

The previous study shows that MCTS work plans (Gera et al.,2015). A recent study also found out that there is no dedicated DEO under MCTS (Nagarajan et al., 2016).

Validity: The system uses uniform and standard manual to maintain uniformity in the system. The data entered into the portal is regularly monitored by the supervisor. MCTS follows a robust protocol and guidelines. The dashboard is also established for viewing health status on a single screen. The system also organizes periodic training of all the staff.

A study documented MCTS training among service delivery, supervisory, and data entry staff was inconsistent (Nagarajan et al., 2016).

Reliability: SMS facilities are provided to beneficiaries and healthcare workers for the confirmation of services scheduled or provided. Mobile phones are widely used and have

proven to be an effective medium to reach out to the beneficiaries. MCTS has resulted in increased accountability and improved supervision of healthcare workers. As the MCTS is solely dedicated to government health operations, its data is password protected and is not openly available. Moreover, data is also verified by a supervisor at regular intervals.

A previous study shows that the DQA's (Data Quality Assessment) overall performance results were 34 % for sampled pregnant women and 33 % for sampled children in Rajasthan. (Gera et al., 2015).

Completeness: One of the major drawbacks of MCTS is incomplete data. The completeness of data, especially in India, varies from state to state. For example, in Uttar Pradesh 21 % of the sampled pregnant women and 43 % of the tested children were found not to have MCTS profiles. The study also found that an incomplete MCTS portal data reflects the incompleteness of the primary data source (Gera et al., 2015).

Timeliness: In MCTS, the report is generated on a real-time basis. The system generates a monthly report, which further facilitates the timely delivery of services and better interaction with healthcare providers.

Relevance: The system helps in the identification of poor performing districts and gaps in the healthcare facilities. It also facilitates the deployment of healthcare workers and planning of supplementary antenatal and immunisation activities.

Box 6: MCTS: Questions to be answered

1. **What is the field monitoring process?**

The supervisor monitors the ANM work and checks the RCH register during field inspection. Besides, a standard manual is also provided to ANM for accurate data collection.

2. **What are the understeps taken to ensure data validity post collection?**

Data is checked by the supervisor or CMO at the block/district level before preparing the monthly report. They also match the data entered into the portal with the ANM register to verify the accuracy.

3. **Once estimates are prepared, are those compared with previous data or another source of data?**

Data is always compared with the previous month's report. These reports also showcase the trend analysis. However, there is no confirmation or clarity on whether the same data is compared with other sources as well.

Table 3.1: Steps followed in MCTS for improving the quality of data

Quality Indicator	**Yes/No**	**Steps followed**
Accuracy	No	Data is not entered on a real-time basis. Previous studies have even shown how inaccurate data are entered into the portal.
Validity	Yes	Standard and uniform manuals are followed in all the units.
Reliability	Yes	The supervisor checks the data entered into the portal regularly.
Completeness	No	In many states data has been found to be incomplete.
Timeliness	Yes	A timely monthly report is published regularly.
Relevance	Yes	Data plays an essential role in identifying the demand and supply gaps in health facilities. It also facilitates the deployment of healthcare workers and planning of supplementary antenatal and immunisation activities.

3.7 National AIDS Control Organization (NACO)

National AIDS Control Organisation (NACO) is the MoHFW's central agency for National AIDS Response. The National AIDS Management Program is a fully funded central sector system initiated in states / Union Territories (UTs) by State / UT AIDS Control Societies (SACS). It supervises 188 high-priority districts through the District AIDS Prevention and Control Unit (DAPCU). The National AIDS Control Program (NACP)-IV (extension) was introduced for the 2017-2020 period.

The first National AIDS Control Programme (NACP) was launched in 1992, and focused on the national HIV surveillance system, prevention activities among High-Risk Groups (HRGs), including information on HIV, and blood safety programme.

NACP-II launched in 1999, focused on the upscaling of targeted interventions for HRGs, especially prevention, outreach, HIV testing & counselling, and fostered greater involvement of People Living with HIV (PLHIV) and community networks. A treatment program was also launched under NACP II. The institutionalisation of decentralised programme management through the State AIDS Control Society (SACS) was a key thrust in phase II.

NACP-III, launched in 2007, showcased a rapid expansion of prevention, care, support, and treatment efforts across the country, focusing on increasing service access points through institutional upscaling and outreach.

The NACP-IV (2012-2017) focused on consolidating the gains made in NACP-III and accelerating the HIV epidemic's reversal. The critical strategies under NACP-IV included intensifying and reducing prevention services with a focus on HRGs and vulnerable population, increasing access and promoting comprehensive care, support and treatment, expanding IEC services for the general population and high-risk groups with a focus on behavioural change and demand generation, building capacities at national, state and district levels and strengthening the Strategic Information Management System (SIMS).Care, Support & Treatment (CST) are the key pillars of all HIV/AIDS control efforts in India.

There are seven different components in India's NACP—Prevention, Information Education and Communication (IEC), Testing, Treatment, Laboratory Services, Mainstreaming & Partnership, and Social Protection and Strategic Information.

NACO aims to provide every HIV inflicted person living in India, access to quality care and the right to live with dignity. It stands committed to building an environment wherein those infected or affected by HIV play a central role in all responses to the epidemic. NACO has taken measures to ensure that HIV patients have equal access to quality healthcare services. By fostering close collaboration with NGOs, women's self-help groups, faith-based organisations, and other networks, and communities, it aims to improve access and accountability.

NACO undertakes HIV estimations biennially in collaboration with the Indian Council of Medical Research (ICMR -National Institute of Medical Statistics (NIMS). The objective of HIV estimations is to provide updated information on India's HIV epidemic status at the national and State/UT level. Thus, NACO takes measures to ensure that quality data on HIV/AIDS is generated in India.

India's HIV epidemic is considered to be concentrated in nature. NACO has targeted its preventive efforts towards sub-groups identified as at high risk of contracting the infection. These High-Risk Groups (HRGs) include FSW, MSM, Hijra(H)/Transgenders (TG), Injecting Drug Users (IDU), and bridge populations such as migrants and truckers. They are provided with several preventive services through 1,400+ NGO/CBO led Targeted Interventions (TIs), including HIV prevention and screening, treatment, care, and support services. People from high-risk communities are engaged in delivering services and acting as catalysts linking them for services and commodities. TI projects provide a package of prevention, support, and care to HRGs through drop-in centres (DIC) and outreach-based service delivery model. This model includes screening and treating STI, distributing free condoms, and lubricant among core groups. Behaviour Change Communication (BCC), creates a conducive environment with community involvement and participation, integrated counselling and testing centres, care and support services, community mobilisation, ownership building, free distribution of sterile needles and syringes for IDUs, abscess prevention and management, Opioid Substitution Therapy (OST), and detoxification/rehabilitation services. The entire programme is based on a peer-led approach in partnership with NGOs/CBOs, SACS and Technical Support Units (TSU). They mentor and support the TIs for quality service delivery, enhancing the overall program performance.

The National AIDS Control Policy (NACP) aims to effectively control the HIV/AIDS epidemic in the country by restricting its spread from the high-risk groups to the general population and from initial hot spots to new areas in India. The preventive services undertaken in this regard are- awareness generation, condom promotion, prevention of parent to child transmission, increasing ICTC services, promotion of voluntary blood donation, and access to safe blood. The policies also have guidelines on targeted Interventions (TIs) for high-risk groups like injecting drug users (IDUs), men having sex with men (MSM), female sex workers (FSWs), etc. Apart from this, policies have extensive guidelines for managing common opportunistic infections, and malignancies among adult/adolescent PLHA, and ART centres' operational procedures to standardise services. The National Policy on Blood Banks ensures adequate supply of safe blood and blood components.

The Strategic Information Management System (SIMS)

The National AIDS Control Programme (NACP) recognises that rigorous and scientific evidence is integral for an adequate response. Hence, having strong Strategic Information management was a high priority under NACP-IV. Over the past 15 years, the number of data sources has expanded. The Strategic Information Management System (SIMS) is an integrated, web-based reporting, data management & decision support system, with monthly reports from over 30,000 users across the country, covering various HIV/AIDS Control Programme components. The entire SIMS application is managed under the supervision of the M&E unit at NACO. The IT experts work on the maintenance, development, modifications in the input formats, resolution of bugs/errors reported, and on the SIMS application servers continuously.

Data Entry process

At the Targeted Intervention (TI) level, NACO-approved register/forms is used for data collection at three-levels-

1. Outreach level
2. Clinic level and
3. Project level

Table 4.1: Types of three different forms used in NACO

Forms/tools	When is it filled?	By whom it is filled?	Frequency of verification	By whom it is verified and reported?
OUTREACH LEVEL				
HRG (High-risk group) registration format **(FORM A)**	A new contact has been established in a hotspot by the concerned Peer Educator (PE). He/she introduces the new HRG to the Outreach Worker (ORW) in charge.	ORW	Weekly	Weekly to the PM/ MIS Officer
Peer Educator Weekly Planning & Activity Sheet. **(FORM B)**	On the same day, when the PE makes contact at the site/hotspot level, the service details are filed.	PE	Weekly as well as on every visit made to the field by ORW in charge.	ORW
PE wise individual HRG compiled Monthly Sheet. **(FORM C)**	Every month, the ORW will compile it in the right format for each HRG, with details on the contacts made during the month. This format is used to monitor the services provided to each HRG by the PE in a given site.	ORW	Monthly	Programme Manager

Monthly summary Sheet (Form C_1)	It is a summary sheet to track PE performance each week, based on which the next week's planning is done.	ORW	Weekly	Programme Manager
Outreach weekly report. **(FORM D)**	Every week, the ORW visits the field for observation. The findings (qualitative) are noted in the report and shared with the programmes manager. It summarises the visits made, activities conducted, issues addressed, and challenges faced,	ORW	Weekly	Programme Manager
HRG Master Register. **(FORM E)**	Every week information will be taken from the HRG registration form filled in by the ORW, which is used as a line listing.	MIS officer	Weekly	Programme Manager
CLINIC LEVEL				
Patient register format (Form F) including Abscess management format	Every day the doctor fills in the details for each HRG patient visiting the clinic, which includes their illness and medical history. For each patient, one form during every visit to the clinic	Doctor	Daily (on clinic days)	Program Manager

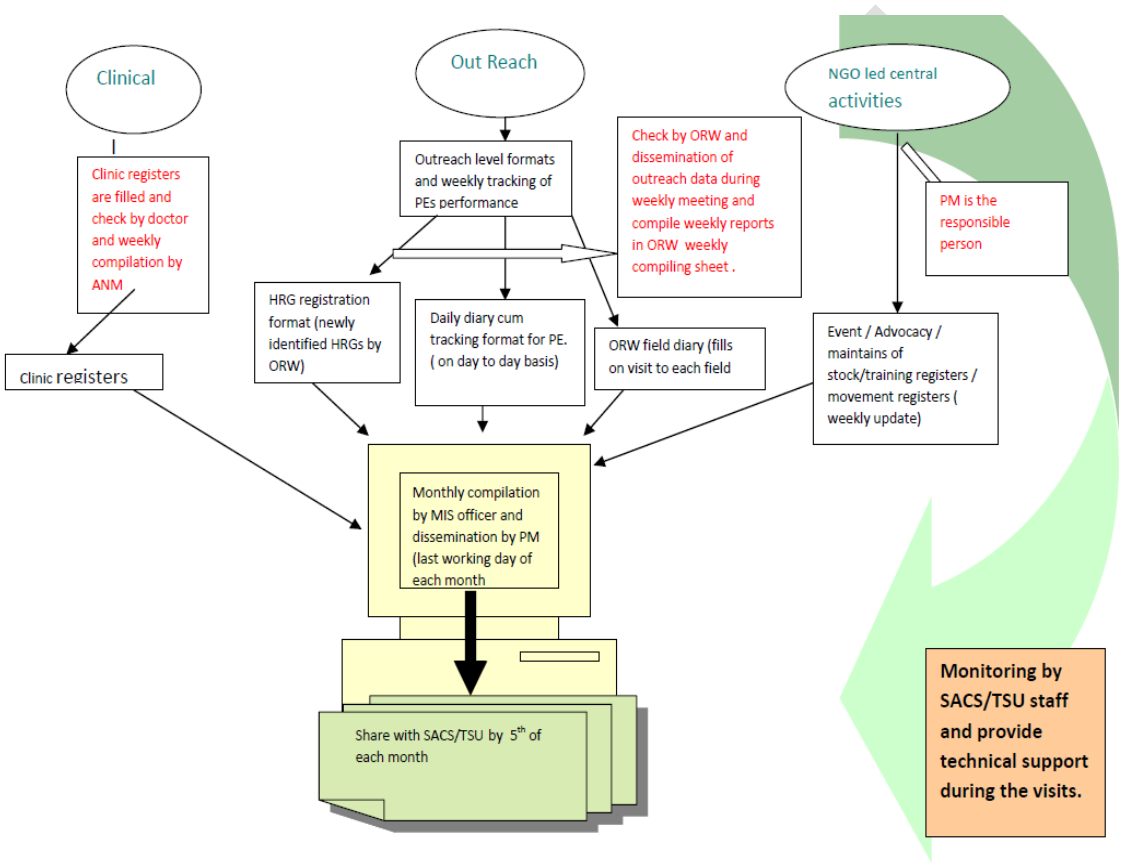
(FORM F_1)				
Clinic Daily summary sheet (FORM FF)	At the end of each clinic day. This register is a summary of the patient who has visited the clinic each day. The information from the filled inpatient register format is transferred here. It gives information on the number of patients who have visited each day and the type of diagnosis and treatment provided.	ANM/Counsellor	Daily (on clinic days)	Doctor
Medicine Stock register. (FORM G)	At the end of each clinic day. The register is maintained at the clinic for tracking medicines – received, issued, and the balance.	ANM/Counsellor	Weekly	Programme Manager
Referral slip and Registers. (FORM H)	When a patient is referred to a referral centre (ICTC, ART, TB /DOT). The slips are in triplicate. The referred details from the slip are noted in the referral register, which further helps track referrals made during a given period.	ANM / Counsellor	Weekly	Programme Manager
Counseling Register. (FORM I)	After every counselling session is conducted. the register gives information on the type of counselling done, the duration of counselling, details of	ANM/ Counsellor	Weekly	Programme Manager

	pre/post counseling, etc. Each row contains information on one counselling session.			
PROJECT LEVEL				
Advocacy activity report. **(FORM J)**	After every advocacy or advocacy-related activities are conducted. It gives details on the activities performed. The advocacy activities could be meeting with police personnel, meeting with government departments., religious leaders, and other stakeholders.	Program Manager	Monthly	Project Director / SACS / TSUs staff
Crisis Management register. **(FORM K)**	As and when violence is reported at the NGO level. Each form is to be used for each set of violence reported.	Programme Manager	Monthly	Project Director / SACS / TSUs staff
Training register. **(FORM L)**	As and when training is conducted for the TI staff. This register is for documenting details of the training conducted for the project TI staff. The activity could be within the NGO or the SACS / TSU or other agencies recommended by the SACS.	Programme Manager	Monthly	Project Director / SACS / TSUs staff

Drop-in Center Register. (FORM M)	Every HRG visiting the drop-in centre needs to fill in their details. This register is available at each and every drop-in centre. If there are two drop-in centres in a given TI, then there needs to be two registers as well.	ANM / Counsellor	Weekly	The Programme Manager
Commodity Stock register. (FORM N)	The register is maintained to track the commodities received (free condoms, social marketing deliverables, lubricants, needles, and syringes) from SACS or the other sources for further distribution through the project HRGs the project services.	Programme Manager	Every month for reconciliation of stock received and issued	Project Director / SACS / TSUs staff
Movement Register. (FORM O)	When a TI project staff at the NGO level is travelling out to carry out project-related activities like field supervision visits, attend a workshop/seminar/conference etc,The register does not apply to PE.	Individual staff members	Daily	Project Director /Programme Manager/SACS/TSU
Community mobilization Activity Register.	When a group/committee is formed in a given site/hotspot, the formation	Programme Manager	Monthly	Project Director / SACS / TSUs staff

(FORM P)	details are recorded. The memberships are updated every month for the record at the TI level.			

Figure 2: The flow chart at the NGO/CBO(TI) level and reporting to SACS/TSU



Source – National AIDS Control Organisation

Accuracy

The SIMS has made real-time data entry and access possible for the users. A checklist is used to review the minimum quality standards at the ICTCs, and the necessary corrective measures are undertaken for Continual Quality Improvement (CQL). This technique has been proven to be useful in periodic self-evaluation, to improve the ICTC (by the ICTC Staff/Medical Officer). Furthermore, the ICTC infrastructure and activities are directly observed and their

compliance with the checklist is verified, followed by a review of records/registers/reports, which must adhere to SOPs and manuals. Sample documents are also reviewed often To extract relevant information.

In order to maintain the quality of services provided under the programme, the CST division has designed a set of Monitoring and Evaluation (M&E) tools, namely Scorecard and Quarterly Feedback Report.

Scorecard

The scorecard is developed to show each ART centre's performance status on pre-decided critical indicators to the programme managers at SACS. The performance quality is colour coded, wherein green denotes good performance, yellow depicts average, and red denotes the performance deficit. These scorecards are to be sent on a quarterly basis to the SACS.

Quarterly Feedback Report

The CST division had developed a report to provide feedback on the state's performance on the indicators critical to achieve India's committed target of 90-90-90 by 2020.

The diagnostic services provided through ICTCs across the country are strictly monitored by a strong Internal and External Quality Assurance Scheme (EQAS). The ORW, when in need of technical support, visit the hotspots regularly, and carry out random checks at the field level, to verify the quality of information that has been captured and entered in the form. An ORW review is also carried out on a monthly basis to check the completeness and accuracy. The program manager conducts a performance assessment based on the data submitted by the ORW for the week.

Validity:

The supportive supervisory visit is made by the officials of NACP facilities to review the on-ground implementation of NACP services.

A supply chain monitoring mechanism for inventory management has been developed to monitor the inventory status for all commodities at the state, district, and facility-level.

NACO has implemented the PLHIV-ART Linkage System (PALS) in India to track and monitor the cascade of services provided to HIV-positive general individuals, pregnant

women, and their children. The PALS allows the tracking of services provided by different healthcare facilities at different periods of time and geo-locations. All states/UTs have implemented the PALS and are required to report data pertaining to it..

Community-Based Screening is also followed in many areas for improving early diagnosis, reaching first-time testers and people who seldom use clinical services. BSD,and NACO conduct review meetings on BSD components at regular intervals at both national and state levels, including review meetings for SACS (ICTC, PPTCT) and STI components. The purpose of the conference is to evaluate the performance of the states/UTs under NACP.

SOPs for CBS and a training manual labelled 'Testing through TT', for community-based HIV testing, under National HIV Counselling and Testing Services Guidelines, 2016 has been shared with all the states.

Data verification is usually done based on certain indicators outlined in the global guidelines pertaining to the criteria and process of unique program verification. For example- NACO has conducted verification for Elimination of Mother to Child Transmission of HIV (EMTCT) based on specific programme indicators.

The MIS System at the NGO/CBO level is linked to the SACS and the national MIS system. Linkage and consistency at all levels are critical to ensure the efficiency of data management and the usefulness of information for decision making and programme planning.

As part of the programme, the Basic Services Division (BSD), NACO conducts review meetings on BSD components at regular intervals both at the national and state level. This includes review meetings for SACS (ICTC/PPTCT) and STI components, National TB HIV Joint review meetings, National TB HIV Coordination committee (NTCC) and, National TB HIV Technical Working Group (NTWG) meetings. The primary purpose of these review meetings is to evaluate and validate the states/UTs under NACP.

Reliability

The Data Analysis and Dissemination Unit of the NACO have initiated the National Data Analysis Plan (NDAP) under NACP-IV to address programme needs concerning evidence and research and to make the best use of the data available in the program.

The establishment of the Strategic Information Management Unit (SIMU) is a step towards improving data quality from all data sources. It is envisaged to have an overarching knowledge management strategy that encompasses the entire gamut of strategic information activities, starting with data generation dissemination and practical use. A clear statement of roles and responsibilities would facilitate greater accountability and better quality of data and information use. Additionally, using information from various data sources systematically through triangulation would lead to better interpretations and programmatic decisions. NACP-III has established SIMU at the national and state levels to manage strategic planning, monitoring and evaluation, surveillance, and research. The SIMU helps track the epidemic and its effectiveness, and assess how well NACO, SACS, and all other partner organisations fulfill their commitment to meet the agreed objectives.

Additionally, periodic monitoring of activities is also conducted to track progress and to determine whether the ongoing and proposed actions are as per approved plans and in line with the requirements. A robust Management Information System (MIS) exists at the TI level with effective data capturing tools and reporting forms, designed to aid NACO affiliated NGOs implement an effective monitoring system.

The following parameters were taken into consideration at the TI level tool to collect reliable data:

Minimum time for reporting: The tools has been designed in a manner such that minimum time is spent on transferring the information onto the devices and later fed into the computer.

Flexibility: The tools were prepared with a view to merge/add new variables, if necessary.
Informative and straightforward: The tools are kept as simple as possible for ease of understanding by PE, ORW and other stakeholders in general.

Performance indicators: The tools have been designed to capture all the requisite information on indicators.

The most significant part of the field-level data is that the TI level tool provides information on the latest achievement, assessing progress, identifying strengths and weaknesses, checking effectiveness, and sharing experiences.

Timeliness

DAPCUs are expected to ensure that data quality is maintained while reporting from all the district's NACP facilities. The quality of data collected can pose a significant challenge for the M&E system, which needs to be addressed carefully. The data flow for collecting data involves multiple points where data quality can be verified and improved by DAPCU. The process begins with standardised formats and extends to conducting site visits at the reporting units to confirm the quality.

- ✓ DAPCUs need to ensure timely and accurate reporting from all the HIV/AIDS-related facilities in the district to SACS on a monthly basis
- ✓ DAPCUs ensure programme and financial reports are submitted by all the units
- ✓ DACPUs maintain a copy of all the monthly reports
- ✓ DAPCU provide feedback to all the facilities
- ✓ DAPCU help the reporting units in preparing the reports within the stipulated time period
- ✓ DAPCUs verify the data reported by all the facilities. In case of any errors, they are rectified immediately and conveyed to SACS
- ✓ Additionally, DAPCUs also submit their monthly report to SACS as per the timeline
- ✓ Monthly compilation by MIS officer and dissemination by PM (last working day of each month) and shared with SACS/TSU by 5th of each month
- ✓ ORW conduct weekly/monthly review meeting with peers to discuss the progress of the monthly work
- ✓ They also conduct outreach work and review and analyse peer data cards/registers at least twice a week
- ✓ **Monitoring by TSU /TI programme staff**- A three-day visit is paid to each NGO, on a monthly basis by the TSU team consisting of at least 1 Project Officer, and 1 Technical Officer (STI/M&E/ Advocacy/BCC/ Condom/Community mobilization/Finance) to provide field-based support to outreach workers and peers and a monthly analysis of SIMS data reported by all NGOs
- ✓ Bi-monthly field interviews are conducted with individuals who have accessed the program services previously (based on outreach or STI records)
- ✓ A quarterly review of each NGO is also carried out by the TSU Project Officer and TSU technical team to assess the project's performance based on the goals, and the

quality of implementation, in terms of significant outreach elements, including BCC, condom, STI, conducive environment, community mobilisation, M&E, finance, and other critical action points for the next quarter, reported in a formal project feedback note

- ✓ **Monitoring by SACS/JAT**- SACS NGO advisor pays monthly visits to each NGO to assess their financial systems and overall project implementation quality (including field visits to at least two sites and meeting with 50% outreach workers and 25% peers)

Completeness

The Mid-Term Appraisal (MTA) of NACP-IV found that significant coverage gaps in the testing of target population including key groups like TB patients, STD patients, pregnant women, spouses/partners of PLHIV, gaps in detection, linkage loss of HIV positive cases between ICTC & ART and increasing discordant between spouses pose as critical challenges for HIV counselling and testing services. It was recommended to include strategies to improve detection yield through strong linkages with other components and roll out newer and better strategies such as community-based testing, population, and geo-prioritisation strategies. Emphasis was also placed on effective integration with NHM to completely eradicate parent to child transmission of HIV. The geographic unit of data generation, analysis, and planning has shifted from the national to the state, district, and now sub-district level.

Relevance

Data Analysis & Dissemination Unit (DADU), a key component of Strategic Information, NACO focuses on strengthening data quality, use, management, systematic analysis, synthesis, development of standardised approaches, methods, quality monitoring, validation, and analysis of different data sets, etc. It is mandated to support and supervise the SACS to strengthen the capacity of staff appointed at various levels, particularly in analysing the data and effectively utilising it in decision making, performing on-site validations and verification for informed policymaking and program management at all levels,right from the field units to the central station.. DADU also emphasise on knowledge translation and their integral role in policymaking and programme management at all levels.

The integration of all IT applications operating under NACP, with SIMS to facilitate strong and better linkages, and individual patient tracking across various components of NACP has been identified as a critical challenge. The other issues included limited use of system-generated data for decision making, lack of ownership of programme divisions in the programme data, lack of dedicated staff to highlight the importance of data use, lack of assured funding to support research activities directed by NACO, and development partners

Officers from NACO and the State AIDS Control Societies and Partners regularly visit the states/UTs and service delivery centre as part of routine monitoring. During 2015-16, NACO officers visited Karnataka, Madhya Pradesh, West Bengal, Rajasthan, Maharashtra, Chhattisgarh, Telangana, Andhra Pradesh, Uttarakhand, and Delhi. The latest report is available for the purpose of analysis and to take evidence-based action and timely corrective measures for program me managers and policymakers. The report also provides details on activities at the grassroot level.

The standard reports for vital components of NACO are prepared and uploaded on the SIMS application, which consists of monthly state-wise analysis of core & optional indicators to maximise the use of programme data regularly.

Box 7: NACO: Questions to be answered

NACO

1. What is the field monitoring process?

There are several monitoring checkpoints at the NACO, SACS, and DAPCU level. Also, TSU personnel and programme officers carry out the field inspections to monitor the progress. These visits are generally not recorded in any standard format. Hence, a concrete follow up is not possible for the ensuing visits. There are also no standardised and regular reviews scheduled for DAPCUs and SACS which can help them extract benefits from the regular feedback and modifications to their monitoring strategies during NACP III.

Monitoring and Evaluation System: There has been significant improvement in the SIMS reporting, with more than 90% of NACO-supported blood banks regularly reporting in the SIMS. However, at the same time, monitoring and supervision in the field has reduced.

2. **What are the steps undertaken to check the data validity after post collection?**

There are various information management systems in place to manage and monitor the patient records and data. The main information systems of NACO are SIMS (Strategic Information Management System), PALS (PLHIV ART Linkage System), IMS (Inventory Management System), and Excel Based Analytical Tool for Core Group at NGOTI level. Amongst all, SIMS is the backbone of programme monitoring and is currently hosted on MeghRaj-A Cloud Initiative by Government of India. The reporting rate is mostly 80% or more across the components. Sankalak, a bulletin for monitoring, evaluation, and surveillance division, aims to report National AIDS Response Progress with regard to key indicators, including those from the 2020 fast track targets. It summarises the data on the epidemic, at the national and state level, to show the progress made under prevention, detection, and treatment components. Sankalak also contributes to regular and systematic analysis and dissemination of critical indicators to policymakers, programme managers, technical staff, and other stakeholders in the NACP.

3. Once estimates are ready, are those compared with previous data or other sources of data?

Setting up a separate Data Analysis and Dissemination Unit at NACO consisting of one epidemiologist and one Programme Officer (Statistics) is a significant achievement towards reaching NACP IV's goals. The National Data Analysis Plan (NDAP), a flagship initiative launched during NACP IV, was a systematic effort to address all the priorities identified in NACP IV. The Data Analysis and Dissemination Unit of the NACO initiated the NDAP to address the evidence gaps in the programme and make the best use of the available data under NACP-IV. The NDAP is an attempt to analyse the massive amounts of data generated, develop analytical documents, scientific papers, journal articles, etc., for publication and wider dissemination, and provide scientific evidence for programme management by strengthening and upscaling appropriate strategies.

Nearly 28 institutions (ICMR, medical colleges, development partners, and multilateral agencies) apart from NACO and SACS collaborated with NACO in facilitating NDAP. As many as 68 analysts from various institutions, including SACS, ICMR, medical colleges, and consultants, were engaged for the purpose. Nearly 30 mentors including senior researchers with specialisation in HIV across the country were involved in mentoring the analysts. NDAP aims to develop skills among programme personnel and analysts for reviewing large programme data sets for quality issues, systematic analysis of data, the conceptualisation of research questions, and developing hypotheses, and scientific writing. For the purpose of product development, the Data Analysis and Dissemination Units have brought out the State Epidemic Fact Sheet, State Programme Fact Sheet, and District Epidemiological profiling report of states, in addition to NDAP reports and research articles.

Protocols followed in NACO

For a uniform and standardised approach, the NACO policy and guidelines have been revised on a regular basis. Visit **www.naco.gov.in/documents/policy-guidelines** for updated and detailed guidelines on various activities.

Data sharing policy

The data collected can be in different form, right for inventory information to patient disease details. With web-in ability, the data can be made available through the internet at all levels and to all partners who are involved. The data transfer process is gradually transitioning from sequential (RU→District→ State→ National) to direct web-based, so that information is available to all simultaneously. Adequate measures like multiple levels of permissions have been implemented to restrict access and strengthen data security. Due to the stigma associated with HIV/AIDS, it is all the more essential to maintain confidentiality

NACO's Data Sharing Guidelines were revised in July 2015 with the competent authority's approval. According to the revised guidelines, data up to the state level (including all facilities and district level that come under its purview) requires SACS approval only

Key challenges of SIMS

1. Integration of all IT applications operating under NACP with SIMS to facilitate strong linkages and individual patient tracking across various components of NACP is a critical challenge.
2. Remove Excel-based systems from various NACO divisions and make SIMS a single source of data/information to increase accessibility and quality.
3. TI – TG formats should be developed, and Masters of TI in SIMS should be updated and modified to gain users' confidence to start using the SIMS.
4. Separate ICTC Monthly New Format of SIMS into four different formats to reduce the bugs/errors reported during uploading and generate the output reports.
5. Development of ART Monthly MIS Format in SIMS & frequent changes in formats are also significant limitations of the system
6. Browser compatibility, Excel version update, & poor to absolutely no internet connectivity are some of the reported field-level issues. The users often expect tablet / Android-based data entry system.

7. The servers of SIMS are getting outdated; SIMS needs to be shifted to NACO Cloud, which is a significant challenge.

Protocol or guidance on roles and responsibilities

Role of Non-Governmental Organisations (NGOs)

NGOs implement TIs in their respective project areas, in compliance with the NACP guidelines to achieve objectives laid out by the project plan. All NGOs are required to report to the SACS/TSU and seek support wherever required. NGOs can also collaborate with DAPCU, local health authorities, and other NGOs while implementing TI. Each NGO prepares a project implementation plan under the supervision of the respective SACS/TSU. They work towards forming a CBO of HRGs and to transfer their project to at the end of five years.

Roles of TIs in the MIS

The MIS at the NGO/CBO level needs to be linked to the SACS and the national MIS. Linkages and consistency at all levels are critical to ensure the efficiency of data management and the usefulness of information for decision making and program planning, including assessment of progress.

At NGO/CBO level:

- ✓ MIS forms/reporting formats are filled in
- ✓ MIS forms are edited for completeness and quality
- ✓ Information from MIS forms is used by ORW and Project Manager for planning and monitoring

At SACS level:

- ✓ Data synchronisation
- ✓ Consolidation of MIS reports from each district (monthly, quarterly and annually)
- ✓ Data analysis for tracking programme performance
- ✓ Feedback provided to the District programme
- ✓ Data shared with NACO

At NACO level:

- ✓ Consolidation of MIS reports from each state (monthly, quarterly and annually)
- ✓ Data analysis for tracking program performance
- ✓ Feedback provided to each state

Roles of PE/ORW/PM/ANM

- ✓ ORW check the Outreach level formats and track PEs performance on a weekly basis
- ✓ ORW check HRG registration format for newly identified HRGs
- ✓ ORW check the daily diary cum tracking format for PE, on a daily basis
- ✓ ORW field diary is filled during each field visit
- ✓ The Project Manager (PM) is responsible for the maintenance of stock/training registers/movement registers and is required to update it every week
- ✓ At the clinical level, the registers are filled and checked by the doctor and a weekly inspection is done by ANM
- ✓ SACS/TSU staff is responsible for monitoring and providing technical support during the field visits.

Role of M&E Assistant

The key role of the M&E Assistant's is to strengthen the DAPCU team by monitoring all the HIV/ AIDS-related data/activities in the district and providing timely feedback to the team for better implementation of HIV/ AIDS eradication plans.

Role of the Technical Support Unit (TSU)

The TSU oversees the implementation of the plan in different states along with SACS. The TSU stringently follows the NACP guidelines developed by NACO, along with other partner organisations to facilitate better performance. It also aids in designing, planning, implementation, and monitoring of targeted interventions in the states and provides management and technical support to the SACS.

The TSU regularly visits partner organisation to ensure that adequate coaching and mentoring to NGOs and TI staff is available. It also carries out periodic reviews of all partner organisations and provides necessary inputs. The TSU staff mainly includes project officers who regularly assess the quality of STI services, outreach, and M&E.

District ICTC Supervisor (DIS)

DIS is assisted by the DACO and DPM in monitoring the ICTC program (including PPTCT) and HIV-TB coordination according to the NACO operational guidelines.

Roles and Responsibilities of the District Administration

- ✓ Review district dashboard indicators every month
- ✓ Convene quarterly DAPCU meetings to facilitate the mainstreaming of HIV in Line departments.
- ✓ Facilitate PLHIV and HRG access to socially beneficial schemes through DAPCUs.
- ✓ Support troubleshooting for programme implementation of NACP at the facility/district level.
- ✓ Leverage resources for district-specific prevention, care, support, and treatments of HIV/AIDS.

Roles and Responsibilities of SACS on DAPCU

- ✓ Recruit staff for DAPCU as per the Operational Guidelines.
- ✓ Provide infrastructure and office equipment to DAPCU teams as per Operational Guidelines.
- ✓ Appoint a Nodal Officer for DAPCUs.
- ✓ Appoint a District AIDS Control Officer (DACO) in consultation with DC.
- ✓ Ensure a decentralised annual action planning processes.
- ✓ Conduct periodic review meetings of DAPCUs.
- ✓ Review the monthly reports of DAPCUs and provide feedback.
- ✓ Ensure that visits to all the districts are in coordination with DAPCU teams.
- ✓ Ensure induction training is provided to all DAPCU team members.
- ✓ Ensure refresher training is provided on a need basis.
- ✓ Ensure timely release of grants for DAPCU expenses.
- ✓ Ensure timely provision of information regarding financial releases to facilities.

Roles of NACO on SIMU/SIMS

The Strategic Information Management Units (SIMU) were established at the national and state levels to work in close coordination. Their responsibilities at the national and state level are given below:

At National Level

- ✓ Develop and manage overall National M&E plan and Strategic Information Management System
- ✓ Establish a Technical Resource Group for providing guidance, consisting of experts from education sector, research institutes, and related ministries and international agencies.
- ✓ Direct state SIMU and affiliated institutions to collect, collate, and analyse M&E data for HIV prevention and control activities across the country.
- ✓ Report data on the HIV epidemic to the ministry for completion of annual and periodic reports for policy and strategic planning
- ✓ Be the focal point for short- and long-term planning for national HIV prevention and M&E activities; guide other units to implement HIV M&E activities.
- ✓ Monitor, evaluate, and supervise activities related to HIV M&E across country
- ✓ Organise training in collaboration with academic institutions for the SIMU Staff
- ✓ Evaluate and add indicators as deemed suitable for a realistic situation

At State Level

- ✓ Develop and implement state M&E plans and activities and share the report with national M&E
- ✓ Collect, verify and process data on HIV related activities from all the units within the state
- ✓ Implement HIV M&E activities locally. Ensure the data quality, accuracy, completeness, and timeliness and report the same to the National SIMU
- ✓ Prepare a report, to be submitted to the state government, with accurate data, and analysis and evidence to guide the program decisions.
- ✓ Provide technically and professional guidance, in addition to supervising and supporting data collection for M&E indicators from the districts
- ✓ Organise M&E training on a need basis

State-level review meetings

State AIDS Control Societies (SACS) are expected to conduct review meetings of DAPCUs, every quarter. Detailed planning and preparation for these meetings can ensure focussed and productive discussions and capacity building of DAPCU staff. A systematic process for conducting streamlined DAPCU reviews combined with the capacity building can lead to optimal resource utilisation.

Roles and Responsibilities of NACO

- ✓ Approve and allocate funds for DAPCUs/SACS as per the Annual Action Plan (AAP)
- ✓ Issue Operational Guidelines and training curriculum for induction training of DAPCUs/SACS
- ✓ Information regarding re-categorisation of districts should be provided by NACO to SACS for the establishment of DAPCUs, if necessary
- ✓ NACO, in association with other resource agencies, is required develop a mentoring system to support DAPCUs, and later share it with SACS
- ✓ NACO must conduct periodic performance review of DAPCUs through SACS

3.8 National Tuberculosis Elimination Program (NTEP)

NTEP is a public health initiative of the Government of India that organises and streamlines its anti-tuberculosis efforts. It functions as a flagship component of the National Health Mission (NHM) and provides technical and managerial leadership to anti-tuberculosis activities in the country. The programme provides, various free of cost, quality tuberculosis diagnosis and treatment services across the country through the government healthcare system. With the Government of India's steadfast commitment towards achieving End TB targets by 2025, increasingly taking momentum, the NTEP formerly known as RNTCP, made a series a series of rapid and progressive advancements. In this paper, we have assessed the quality of programme implementation using following data quality parameters.

Accuracy: A robust mechanism has been adopted for monitoring TB services on real time basis. There is a list of indicators which are assessed on regular basis to ensure accuracy of the data reported, for example, number of TB patients diagnosed, number of TB patients whose contacts are being investigated etc. Programme Managers use Nikshay application, for this purpose, the National TB information system which addresses all the requirements and monitors programme activity and performance throughout the country. Nikshay has completely digitised the TB register which was maintained at the Tuberculosis Unit level (TU). This has enabled programme managers to access a patient's information and verify them on demand, from anywhere in the world., An additional interoperability layer also permits advanced interaction with other MIS in use. For example, the Nikshay APIs allows a hospital Information/ Medical Records to send TB notification information to Nikshay automatically. ICT based self-adherence reporting is also monitored through this system. In the paper-based transmission of information, one of the biggest challenges was systematic delays, sometimes extending up to a year, in data being reported to the centre and state,

Validity: The Central TB Division assesses the states' achievements and performance with regard to nine key indicators using the State TB Score. Specific service indicators are also adopted for quality control, for example, average time taken to visit HWC for the diagnosis of TB, percentage of patients visited by ANM /MPW, etc. An Internal Evaluation is carried by central level officers regularly to ensure good program practices are being adopted and quality services are being provided to the community. In addition to the Central Internal Evaluations, a two-day intense review is also done to provide guidance to the states.

The Nikshay Application maintains a comprehensive record of all TB patients for providers in all sectors and consistently aligns itself with the latest changes in guidelines and operational processes. Such a system is essential to ensure accuracy in the recorded data.

Reliability: The Community Health Officers are required to maintain all records on the Nikshay Application. Additionally, physical records are also to be maintained for a list of services, including TB notification register and referral slips for further check-up. The records are reviewed on a weekly basis within the health facility itself. Discussion with all staffs is conducted on a monthly basis including review of patient's management. These periodic meetings also include regular monitoring of the states. In addition to the annual review meetings of all the states which is done at the national level involving the state TB officers, Directors (STDC, IRL/ NRL), microbiologists, and WHO consultants, regional level review meetings are also initiated for focussed and concerted services.

Completeness: Systematic active TB case finding has been implemented across the country with aims to intensify case finding efforts. Line listing and sensitisation of private players and NGO for case findings is also done. Besides, a reminder mechanism has been adopted through Medlife call centre which reminds the due date 15 days, 7 days and 4 days, in advance for monthly refill. The National Strategic Plan (NSP 2017-25) for ending TB has framed appropriate strategies for universal coverage. The programme prescribes decentralised Drug Resistant TB treatment to the district level to make services more accessible to patients. The most important part in the monitoring of the services delivered is the collection and collation of patient-wise data which is done through Nikshay. To improve access to the data, the android version of the mobile app has been made available on GooglePlay. This new version, dubbed Nikshay Version 2.0 had a rapid countrywide roll out in September 2018 and serves as a surveillance tool under National TB Elimination Programme: The entire TB care cascade referral for testing & notification.

Timeliness: Private-sector institutions are engaged to cater to block specific requirements to minimise the delay in diagnosis and treatment initiation. The lab supervisor ensures that the DMC shares the list of tested TB patients with the HCWs on a weekly basis. Additionally, ASHA ensures treatment adherence and timely follow up of patients. It is mandatory for the designated official to visit the patients periodically and maintain interaction. Furthermore, the staff nurse is required to prepare a detailed monthly report as per the decision of PHC MO

Annual report (2020) shows how the implementation of advanced interventions across the country varies from district to district, with some of them already in an advanced stage of progress towards these targets.

Relevance: The system operating NTEP provides comprehensive data on TB case detection, active case findings, and management in a Primary Care health facility ,for the health officers and policymakers. Policymakers generally use NTEP annual reports for determining the targets and programmes for eliminating TB.

Box 8: NTEP: Questions to be answered

1. **What is the field monitoring process?**

   Answer- The Programme Officers use the Nikshay application for real-time monitoring. Additionally, the supervisor monitors work done by ASHA and other officials in the heath facility.

2. **What are the steps taken to check the data validity post collection?**

   Answer-An internal evaluation is done by a central level officer regularly. The Nikshay application is also used as a validation system to ensure data accuracy The application is constantly updated to adapt to the changing guidelines and operational processes. Physical records are also maintained for a list of services, e.g. TB notification register and referral slips for further check-up.

3. **Once estimates are ready, are those compared with previous data or other sources of data?**

   Answer- The annual report presents trends of utilised services and the targets achieved over the years. Comparative studies are published in 'Nikshaya Patrika', a quarterly publication of central TB division.

Quality indicator	Yes/No	Steps taken
Accuracy	Yes	Data is recorded and monitored on real time basis through a web-based app called Nikshay.
Validity	Yes	The performance and achievements are assessed with regard to nine indicators, using the state TB score. The Nikshay app unifies the operation and ensures data is collected as per the latest guidelines.
Reliability	Yes	Regular review meetings are conducted by the community healthcare officers to supervise the staff
Completeness	Yes	A reminder mechanism is adopted to ensure full coverage. Also, systematic active TB case finding has been implemented across the country.
Timeliness	Yes	The annual reports are regularly pulished, in addition to NikshayPatrika, which is published every three months.
Reliability	Yes	The system provides comprehensive data on TB case detection, active case finding and management in a primary care healthcare facility. This data plays an integral part in decision making.

Section 4: Best practices

4.1. Best Practices in Civil Registration System in Germany

1. Civil registration became mandatory in all German states on 1 January 1876.The law states that every German has to be officially registered at the locality of residence. The concerned registry office needs to be notified of the child 'birth within one week of the birth. The birth certification process is carried out only after compulsory notification by a hospital or any other birth facility. In case of birth at home, the parents or midwives are obliged to notify the registration office. Further, in case of relocation, every citizen has to register his/her new address at the local registration authority.

   The law also states that it is also mandatory to register all the deaths that have taken place in the country. It mandates that cremation or burial must take place within 96 hours and a death certificate must be obtained before the burial or cremation. If a death takes place in the hospital, then the onus is on the hospital to provide a death certificate. In the event of a death occurring at home, a doctor must be immediately notified, who will confirm the date and time of the death and fill out the death certificate. The event must also be reported to the local registrar. Often, the family of the deceased report it themselves, but it may also be done by the funeral home. Relevant documents such as passport, residency permit and deceased's birth certificate are required for death registration. In case, next-of-kin does not live in Germany, and no friends or family members in Germany agree to notify the next-of-kin, the authorities contact the relevant Consulate. It is the responsibility of the Consulate to then notify the next-of-kin themselves. In Germany, however there is no specific registration process or certificate for infant deaths. Certain questions are included in the general death certificate for the same purpose. Civil death records often exist for individuals who have no birth or marriage records.

   Earlier, each registration authority maintained their own register where changes were recorded. In order to make any corrections in the register, bicommunication was required between the different local registration offices. Also, the Civil Registration was regulated at three government levels: the federal level, federal states and local registration offices, which often led to many differences in the proceedings and processes.

To facilitate secure and faster data transfer, the German government introduced Online Service Computer Interface (OSCI), that made use of standard software and internet enabled network to facilitate secure and accurate data exchange in the civil registration system. The system also provided the citizens with the facility to change their address online. The use of OSCI was made mandatory for all registration offices from 2007 onwards, which resulted in the timely receipt and better quality of data (up to 20 % better quality data). It also speeded up the registration process. Features like pre-filled in registry information forms that are required by the civil registries in case of relocation, reduced the paperwork significantly. Furthermore, the use of e-governance and strict implementation of laws resulted in 100 per cent birth and death registration in Germany.

2. German Development Cooperation considers birth and death registration and the strengthening of Civil Registration and Vital Statistics (CRVS) systems as key prerequisites for the protection of human rights as well as evidence-based policymaking and effective planning of public healthcare service delivery.
3. In Sweden, the task of registration has been simplified through computerisation. It is fast because a task never needs to be registered more than once. The information which is required for registration is easily available via the terminal. Moreover, the removal certificate's introduction has helped the control process ensure a person is not registered as a resident in more than one place.
4. In Brazil, linking birth registration with cash transfer programme and child grant programme contributed to 20% and 37% of the national birth registration, respectively. (World Bank, 2018)
5. In Bangladesh, July 3rd is observed as the National Registration Day. Through promotional efforts and information campaigns, the nation has drastically improved its statistics. Birth registration has been made compulsory for obtaining machine-readable passports, national identity cards, marriage registration, government and non-government recruitment, land registration, vehicle registration, and other such documents.
6. In Canada, once the micro data for a reference year is extracted, a reconciliation of data holdings occurs. Different data sources are gathered during the process, including the electronic National Routing System (NRS) message, and digitised image of the event registration number reported by the jurisdiction. These are compared to verify whether

all the records have been received. For example, there are more records on the cause of death coded data than electronic death messages for a particular jurisdiction; the jurisdiction is contacted and asked to send the missing data. Elimination of duplicates records is done within two years at the central office and is based on a set of key fields within a jurisdiction.

7. Micro data is further run through a series of validation edits. Automated corrections or data conversion have been programmed for systematic errors, based on other data elements' information. For example, where the province of residence is missing, and the postal code is available, the province is derived by looking at the postal code's first letter. Also, certain edits correct logical errors, such as verifying marital status as single for deaths of children under the age of 15.

   The cause of death requires a separate process. A review of records is undertaken to ensure consistent application of the classification and to address the persisting problems with the automated mortality classification system. Validity checks such as age and cause, sex, and cause are addressed during the editing process.
8. In Uganda, cell phones are used to insert data into the national registry instantly (Unicef, 2013).
9. In the Netherlands, citizens must provide data once, either at birth registration or at death registration in case of death. Ten separate, fundamental, and interconnected registers operate on agreed systems and standards to ensure interoperability between them. The Netherlands does not run a census; census data is extracted directly from civil registration records.
10. In Peru, registration services have improved for indigenous communities. Using mobile registration units, information is exchanged between the public and private sectors. Currently, integrated strategies are being followed using IT, wherein birth and death registration and certification are provided online.
11. In Armenia, electronic system and data interoperability between the ICT systems of the police and the Ministry of Justice shows that the building blocks of the country's identity system can be distributed among different authorities without giving up on the efficiency. Soon after the birth registration, information on the new-born’s identity and data on the child's parents are transferred from the civil register to the population register. It is also done for other vital events. As new vital events add new layers of identity information, it is sent to the population register post registration. It ensures that identity data in the population register is updated regularly. When death is

registered, this information is sent to the population register, where the personal record is permanently retired.

12. The website (e-verify.am) offers a simple interface that one can use to enter the 12-character code from the medical or civil registration certificate. This lets one verify whether the document is valid. The website displays only the type of document and the document number and no other personal data. Government authorities who need registration certificates can use this platform to verify a document that a person presents, including at consulates abroad.
13. Assigning a reasonable cause of death in compliance with ICD guidelines is relatively complex and requires well-trained high-level coders. In the USA, the automation of cause of death coding uses the ACME program to select and code the underlying cause of death. The MICAR input the computer the diagnostic information reported in the natural language without any clerical intervention.

    Also, the US vital registration and statistics system exemplifies cooperation between the federal and state governments. The co-operative atmosphere produces records that satisfy individuals and their families' legal requirements while protecting the records' security and preventing fraudulent uses. These co-operative efforts include developing and promoting electronic systems standards, certificates of live birth, death, training and quality control programmes, and model legislation.
14. In Kerala, validations are provided in the application to handle discrepancies like registration date before the date of birth and date of death, unacceptable values of age at marriage, age at conception, period of pregnancy, weight of the baby at the time of birth, order of birth, and age at the time of death. The incorrect are corrected through a process, and details of rectifications are noted in an appropriate order both in the electronic form and the manuscript.
15. In France, local civil registration databases are linked to a dedicated network of data exchange called COMEDEC (Electronic Data Exchange of Civil Status Data), which is implemented jointly by the National Agency for Secure Documents and the Ministry of Justice. This system enables the electronic exchange of civil status data between civil status data recipients and the local civil registration authorities. This electronic exchange is widely accepted in the system since January 2014.
16. In Estonia, the database is linked to facilitate exchange of information between state entities and private entities. Individuals have control over their data, and consent is

required to see other's data. Such a system ensures maximum control and secured access to data. Abuse of data by public officials is punishable by imprisonment.

17. In Peru, national health insurance schemes and private insurance companies provide coverage for burial expenses as a benefit. To receive reimbursement, funeral homes must file paperwork that includes a medical certificate of cause of death and a death certificate issued by the registration agency. To facilitate the procedures to obtain the medically certified cause of death and death certificate, funeral home workers must ask family members for the limited power of attorney (POA). The POA allows the funeral home to represent the next of kin before various public bodies that manage death registration and certification of cause of death and seek reimbursement for the burial. The main incentive for funeral homes is the certainty regarding the amount to be reimbursed. This is a common practice and is regulated by law and the family of the deceased is also often relieved of the paperwork involved in registration.
18. In Colombia, birth registration is linked with cash transfer programmes and school enrolment to incentivise birth registration.
19. Ukraine provides an incentive for timely birth registration in the form of a lump-sum childbirth grant. (UNICEF, 2013).
20. In Uganda, in 2012, the government waived the registration fee payable by a refugee to register a birth or death. Previously, refugees were required to pay $40 to obtain a birth or death certificate.
21. In Mongolia, the online registration process drastically reduced the mistakes caused by manual errors. Also, a significant amount of time is saved in an online process as data only has to be entered once, and many errors are avoided due to automatic checks. (United Nations, 2018).
22. In the UK, to facilitate the registration of intersex people, anonymous sex may be registered. In Netherlands, if no medical statement is submitted or the if sex cannot be determined, the new birth certificate indicates that it is impossible to decide on the sex. Once the individual has decided on their sexual identity, they can change the civil code registration. There is no set time limit for this process.
23. In Chile, when the Unique Identity Code (UIC) of the registrant is entered, the system automatically fills in the fields retrieved from family members' records. These fields are hardcoded, so only authorised registrars can modify them. The security features allow verification of the validity of the information and electronic transmission of data.

24. In Australia, community engagement and awareness-raising initiatives have been introduced to increase registration. For example, a community liaison officer must ensure birth and death registrations are promoted in remote and regional communities. There is a partnership between government agencies and hospitals to ensure births are registered. Registries partner with other government agencies, that visit communities to promote birth certificates and enable young people to obtain a driving license. Effective communications programme can prove to be beneficial in debunking some of the myths about registration; for example, many believe that registration is a costly affair. It is important to draw their attention to the benefits of both registration and certification.

4.2 Best Practices in Sample Registration System

1. In China, the data that is entered into the internet-based system is subjected to several levels of quality control. An internal system evaluates the timeliness of death registration, record completeness, and accuracy of data entry. Errors that are detected are corrected through re-inquiry (Yang et al., 2005). Additionally, each death registration is reviewed by local prefecture and provincial level CDC staff for completeness, correct ICD 10 coding, and correctness underlying COD (Liu et al., 2016). The data is also evaluated using statistical measures. (Yang et al., 2005).
2. In Indonesia, the National Institute of Health Research and Development (NIHRD) holds coordination meetings at the national and district level to monitor the SRS. The institute also reviews compiled data at the national level to assess the data's quality and assign the appropriat**e ICD-10 codes (Usman et al., 2019).** The Indonesian SRS is aligned with the national CRVS system, a capacity-building measure working towards complete registration (Rao et al., 2010).
3. The best SRS practice is observed in India, where it is based on a dual recording system. Records collected by both part-time enumerators and supervisors are matched for an accuracy check. The supervisor or a third party carries out the re-verification of non-matched and partially matched events. In case the third party finds out an event has been missed by both supervisor and enumerator, a necessary update in the respective forms is done. Besides, an inspection of 10 per cent of records by a supervisor or department officials is carried out in the sample unit. In the case of verbal autopsies (VA), records are reviewed by two separate trained physicians. They assign the COD based on ICD-10, from information in the VA and other medical record documentation. If the two physicians do not agree on COD, then reports are returned for discussion and reconciliation on the cause of death. However, if no decision is made, a third physician is introduced to adjudicate. The dual recording system and rigorous quality control procedures have made SRS a reliable data source among policymakers and researchers. For details on data quality protocols, please see the previous section on SRS.

4.3 Best practices in Disease Surveillance: Canadian Chronic Disease Surveillance

The Canadian Chronic Disease Surveillance System was created in 2009 to facilitate standardised, national estimates of chronic disease prevalence, incidence, and health outcomes. It was earlier a part of the National Diabetes Surveillance System (NDSS), which was established in 1999, as a collaborative network of provincial and territorial (P/T) diabetes surveillance systems and was supported by Health Canada and the Public Health Agency of Canada (PHAC). The CCDSS rests on the premise that a surveillance system requires standardised data over time and across jurisdictions to facilitate decision-making at national and P/T levels.

The CCDSS primarily relies on linked health insurance registration files, physician billing claims, and hospital discharge abstracts. Standardised case definitions and standard analytic protocols are applied to each P/T; aggregate data is shared with PHAC and is summarised for reports and open access data initiatives.

Accuracy: A national pilot study is conducted following feasibility studies to check the chronic disease case definition methodology in all jurisdictions. SAS analytic code developed by PHAC is distributed to all P/Ts for implementation. If the national pilot study is successful, then the chronic condition is moved to ongoing surveillance. The Science Committee comprising of P/T representatives and scientific experts from academia, review feasibility studies, and approve methods for developing chronic disease case definitions and other measures required for ongoing surveillance (e.g., co-morbid conditions, healthcare service use, and costs). It also provides oversight for issues of data quality and priorities and opportunities for validation activities. The P/Ts identify and assign technical resources to implement standardised protocols for data processing, implement and maintain the CCDSS, produce data for national reporting, reconcile data provided to PHAC to ensure its consistency and accuracy, and create regional reports as per P/T priorities for chronic disease surveillance.

The CCDSS methodology facilitates comparisons across significant determinants of health, including age, sex, and region. These comparisons are useful for describing the absolute and relative impact of multi-morbidity on different population groups and can help streamline health promotion and disease prevention activities.

Availability, timeliness, and completeness: Data quality surveys are routinely conducted as part of the surveillance process to identify database characteristics that may result in biased disease estimates over time or across P/Ts, or otherwise adversely affect the implementation of the analytic code. These surveys address various topics, such as the availability, timeliness, and completeness of administrative data elements.

Reporting: Both the Science and Technical Committees approve the aggregate data produced in each P/T. This summary data is submitted to PHAC for further analysis and reporting. Data is typically reported as annual age and sex-standardised incidence and prevalence rates; age- and sex-specific rates are also provided. Dissemination of CCDSS data occurs in many forms, including peer-reviewed publications, electronic reports, and web-based open data resources.

Frequency of reporting: Disease-specific reports are produced on a regular basis. Special reports are produced on an ad hoc basis. Fact sheets, which provide highlights about current results, are shared broadly.

Data quality: Data quality is assessed using various methods, including validation studies and narrative reports about changes in data coding practices from P/T administrative staff. This information provides contextual information for the interpretation of P/T prevalence or incidence estimates. A Data Quality Working Group (DQWG) was established in 2016 to synthesise this data quality information and conduct ad hoc studies

Web-based tools facilitate the analysis of publicly available data. PHAC has created Data Cubes, interactive open data resources that enable users to create tables and figures via their web browsers. A recent comparison between the CCDSS and other population-based data sources revealed that the CCDSS produces higher prevalence estimates of hypertension when compared to self-reported data from the Canadian Community Health Survey and clinical data from the Canadian Health Measures Survey.

Advantages:

1. Routine data quality surveys facilitate the interpretation of estimates PHAC facilitates data analyses and report preparation.
2. Federal and P/T experts share their knowledge and expertise on an ongoing basis. Surveillance capacity building occurs in all P/Ts.
3. The CCDSS respects the custodial data responsibilities of the P/Ts. The Methods to initiate surveillance of new chronic diseases is based on a collaborative model.
4. Longitudinal estimates of prevalence, all-cause mortality, and incidence enable comparisons over time. Technical expertise to develop the methodology is not required in each P/T.

Challenges:

1. At present, the methodology does not allow for comparisons across other essential determinants of health, such as socioeconomic status
2. The CCDSS's reliance on minimum set of data elements is prevalent in all P/Ts and balances disclosure guidelines with comprehensive data reporting.
3. Low measurement validity of disease diagnosis codes for some chronic conditions and the potential for changes in measurement validity of diagnosis codes overtime must be continually addressed to ensure the scientific rigor of the CCDSS methodology.
4. Heterogeneity in administrative databases across jurisdictions and changes in data quality over time threaten the production of standardised disease estimates.
5. A limited set of databases is common to all P/Ts, which hinders potential CCDSS expansion. It is imperative to balance comprehensive reporting with P/T disclosure requirements to protect privacy.

Table 5.1: Limitations of various data sources and recommendations to improve the data systems

Data Source	Limitations	Recommendations
CRS	• Irregular inspections by senior authorities • Interdepartmental meetings are not organised regularly. • Shortage of staff in the system, and thus most functionaries perform registration work as additional work. • Frequent transfer of staff from one department to another. • No regular training or workshops are organised. • Records of deaths by age and sex are not adequately provided. • Records on infant deaths and sex ratio are incomplete. • Data on adult and maternal mortality are not provided at the state and district level. • Data on sex ratio is missing for some states. • Many states did not submit data on registration completed within the prescribed time limit of 21 days	• Strong need for intensive supervision and regular monitoring. Triangulation method can be used to ensure validity. • Regular training of all staff, particularly at the local levels is strongly suggested. • Linking registration with other schemes can create demand for more registration. For example, a birth certificate is mandatory for the Ladli scheme. • IEC activities are suggested for creating awareness about the procedures and benefits of birth and death registration. • Online registration at all the units can speed up the processes.

	• Desired information on certificate issuance is not provided in the report. • Few states did not submit statistical reports on time, which delayed the publication of the corresponding national report.	
SRS	• A review of COD is done by two separate trained physicians in urban hospitals. Its application is not consistent, which can affect the quality of the data. • There is no clear documentation on how often or how the coded COD data can be transmitted to the RGI for analysis and publication purposes. • The agencies' technical personnel are inclined to pay more attention to departments' regular work and do not consider SRS work as priority. • Information on the number of events matched between the half-yearly surveys and continuous enumeration has currently not been published.	• Coordination between two or more departments and centralised monitoring is required to cover vital events in the sample units. • Publication of information on the number of events matched by both agencies would be useful for evaluating completeness of the system.
NSSO	• The data contain identification, enumeration and tabulation errors. Despite the fact that this survey is much more representative of the entire population, its	• Data should be collected and tabulated properly. • Uniform definition should be used at all levels for obtaining valid results.

	findings have limited scope, when representing true estimation of prevalence rate, association with the age, and difference in two settings, because of the limitations of the survey itself (Lakhan R and Ekúndayò OT, 2015). • There are systematic differences in the quality of field work between centre and state level organisations. The reasons for such differences have not been investigated and corrected yet. • Thorat, A. (2004) documented that there are issues in the reference period and consistency of concept used. • NSSO does not generate district level estimates based on its survey due to inadequate sample size, although there is a high demand of district level data for decentralised planning. • In view of the data quality issues, the Ministry had decided not to release the Consumer Expenditure Survey results of 2017-2018, as there were concerns regarding potential under-reporting and reliability of the consumption data due to the increasing divergence between the household-level data and the	• NSSO should provide data at district level for decentralised planning. • The ground-level staff of NSSO needs to be strengthened but the process is often hindered due to the time-consuming appointment procedures. • A more reliable methodology should be adopted to find the distribution of consumption among different income levels and how it can be estimated to produce a close figure to the GDP.

	corresponding consumption data provided by the national accounts. • Mitra S (2018) documented that the methodology adopted for the PLFS indicates departures from the earlier EUS rounds and therefore would not be fully comparable with the earlier rounds of NSSO-EUS.	
HMIS	• Records suffer from incompleteness and low quality. • There is also a tendency to over-report the outcomes. Irregularities in report generation, data duplication, and data inconsistencies have been commonly observed. • Death reporting issues are some of the common issues at the field-level. • A study documented that underreporting and discrepant reporting occurs occasionally, which is not verified by HMIS (Dehury RK et al., 2018). • Data is incomplete and inaccurate. • No regular training is provided to the staffs	• Officers should improve the accuracy of the records entered into the system. • Complete recording and timely reporting of data is needed.
MCTS	• Staff is often overburdened with work, which may affect accuracy.	• Data should be entered into the system on real time basis.

	• The utility of the data for programme review is limited because the huge volume of data fed into the MCTS database is not being used to generate reports at various levels. • Lack of feedback from higher centres and lack of auto generation of reports were found to be the major challenges for use of information.	• There should be regular review meetings and feedback for improvement in data quality. • Accountability of the staff should be improved through strict supervision.
IDSP	• Regulation of IDSP laboratory needs strengthening • A lack of understanding of standard case definitions can limit the functioning of effective case detection and registration. • Healthcare workers are overburdened, which often results in underreporting and irregular reporting. • The already existing weak and diversified healthcare systems within districts and states are a hindrance for effective surveillance system. • There is weak integration of the private health sector. • The importance of a data-driven and evidence-based policymaking is unclear in this programme. • The lack of data on mortality is a major limitation of this surveillance system.	• Surveillance should be promoted through major hospitals (both in public and private sector) and active surveillance should be promoted through healthcare system staff and community. • There should be capacity building for data collation, analysis, and interpretation to recognise warning signals of an impending outbreak, and institute public health action. • IT infrastructure should be promoted for data transmission, analysis, routine communication (e-mail.) and video conferencing, troubleshooting, consultations and epidemiological investigations.

		• There should be rigorous and proper training for the healthcare workers involved in the reporting of diseases. • Laboratory and diagnostic services should be strengthened.
NACO	• There have been incidents of acute crisis in laboratory testing due to false results generated by HIV test kits and thereby leading to transfer of kits and problems in storage of specimens. • The methods of sampling have been reported to be non-uniform in some cases. There is a possibility of selection bias especially at ANC sites with large attendance and which are operated by many specialists. • Geographic coverage of the population is limited STD sites under HSS are mostly located in referral and tertiary hospitals and hence may not represent the entire gamut of STIs. • STD data is no longer being used for HIV estimations and epidemic analysis. Hence, there is no	• Proxy indicators should be regularly analysed to derive meaningful conclusions on HIV incidence in different risk groups. • System evaluation and preparatory work for HIV Case Reporting should be undertaken at the earliest. Since the SIMS Application is in the process of roll out, It is the right opportunity to make any necessary changes that are required. • Mechanisms should be devised in consultation with the Basic Services & CST divisions at NACO to ensure the use of this data as HIV Case Reporting.

	clear benefit in conducting HIV Sentinel Surveillance at STD sites. • Data collection is not designed for surveillance, primarily. Wide variations exist in methods of data recording, entry, and reporting. Hence, even if the program coverage is expanding, the extent to which the data is usable is not known. • At the national level, where the entire bulk of surveillance data, programme data and research outcomes in the country converges, there is no cadre for knowledge management (data analysis and ensuring data use). • Availability of technical manpower, especially the state epidemiologists, has been a key constraint for surveillance and epidemiological work in many states.	• Epidemiological and analytical work must be undertaken at the national level. • Technical work must be promoted and mentored at the state and district levels. • Effective data use should be ensured at all levels
NTEP	• Online reporting is not possible in remote areas where internet services are limited. • Peripheral healthcare staff who deal with all programmes at field level tend to give less attention to TB ACSM due to priority issues.	• Invest in TB surveillance unit to enable data for action. • Provide reinforcements to existing workforces with proper funding. • Scale up the quality of private provider engagement.

Bibliographies

Gupta M, Chalapati Rao, Lakshmi P, Prinja S, Kumar R. Estimating mortality using data from civil registration: a cross-sectional study in India. Bull World Health Organ. 2016;94(1):10-21.

James KS, Kavitha N, George A, Kulkarni PM, Prasad S, Kumar S. Preliminary assessment of the quality of civil registration system in Kerala, Odisha and Rajasthan. New Delhi: UNFPA; 2013. Available on http://india.unfpa.org/sites/default/files/pub pdf/ReportonCRS-Final.pdf, accessed on July 27, 2017

Mahapatra P. An overview of Sample Registration System in India. 2010

Yang et al. Mortality registration and surveillance in China: history, current situation and challenges. Population Health Metrics 2005; 16(1):3.

Liu et al. An integrated national mortality surveillance system for death registration and mortality surveillance, China. Bulletin of the World Health Organization. 2016; 94:46 57

Jha et al. Prospective study of one million deaths in India: Rationale, design, and validation results. PLoS Medicine. 2006; 3(2): Supplementary materials S1.

(PDF) The Canadian Chronic Disease Surveillance System: A model for collaborative surveillance. Available on: https://www.researchgate.net/publication/328202737_The_Canadian_Chronic_Disease_Surveillance_System_A_model_for_collaborative_surveillance [~~accessed Oct 12 2020~~].

Lix LM, Ayles J, Bartholomew S, Cooke CA, Ellison J, Emond V, Hamm NC, Hannah H, Jean S, LeBlanc S, O'Donnell S, Paterson JM, Pelletier C, Phillips KAM, Puchtinger R, Reimer K, Robitaille C, Smith M, Svenson LW, Tu K, VanTil LD, Waits S, Pelletier L. The Canadian Chronic Disease Surveillance System: A model for collaborative surveillance. Int J Popul Data Sci. 2018 Oct 5;3(3):433. doi: 10.23889/ijpds.v3i3.433. PMID: 32935015; PMCID: PMC7299467.

Feely, A., Lix, L. M., & Reimer, K. (2017). Estimating multimorbidity prevalence with the Canadian Chronic Disease Surveillance System. *Health promotion and chronic disease prevention in Canada : research, policy and practice*, *37*(7), 215–222. https://doi.org/10.24095/hpcdp.37.7.02

Padmanabha, P. (1984). VII. USE OF SAMPLE REGISTRATION SYSTEMS FOR STUDYING LEVELS, TRENDS AND DIFFERENTIALS IN MORTALITY: THE EXPERIENCE OF INDIA.

Sharma, A., Rana, S. K., Prinja, S., & Kumar, R. (2016). Quality of health management information system for maternal & child health care in Haryana state, India. *PLoS One*, *11*(2), e0148449.

Khandade, T. N., Kumar, R. K., & Chattopadhyay, S. P. (2013). Status of reporting at health sub-center level in Bihar. *Indian Journal of Public Health*, *57*(4), 283.

Samal, J., &Dehury, R. K. (2016). Perspectives and challenges of HMIS officials in the implementation of health management information system (HMIS) with reference to maternal health services in Assam. *Journal of clinical and diagnostic research: JCDR*, *10*(6), LC07.

Mahapatro, M., & Kumar, A. (2009). Maternal mortality among the marginalized: A case study of a scheduled tribe of Orissa. *Indian Anthropologist*, 85-97.

Mavalankar, D., Vora, K., &Prakasamma, M. (2008). Achieving Millennium Development Goal 5: is India serious?. *Bulletin of the World Health Organization*, *86*(4), 243-243A.

Ramani, K. V. (2004). A management information system to plan and monitor the delivery of healthcare services in government hospitals in India. *Journal of health organization and management*, *18*(2-3), 207.

Panjamapirom, A., & Musa, P. F. (2010). Health Management Information System Governance, Policy, and International Perspectives: HMIS Globalization through E-Health.

Government of India, Ministry of Health and Family Welfare. (2010). HMIS Managers' Manual: User Manual for Web Portal & DHIS2, NHSRC, New Delhi.

Dehury, R. K. (2014). The progress and impact of Health Management Information System (HMIS) in monitoring and evaluation of health programs in India. *Indian Journal of Basic and Applied Medical Research*, *3*(4), 116.

Dehury, R. K., & Chatterjee, S. C. (2018). Assessment of health management information system for monitoring of maternal health in Jaleswar Block of Balasore District, Odisha, India. *Indian Journal of Public Health*, *62*(4), 259.

Pandey, A., Roy, N., Bhawsar, R., & Mishra, R. M. (2010). Health information system in India: issues of data availability and quality. *Demography India*, *39*(1), 111-28.

Kumar, R., Mehendale, S. M., Panda, S., Venkatesh, S., Lakshmi, P. V. M., Kaur, M., ... & Sharma, A. K. (2011). Impact of targeted interventions on heterosexual transmission of HIV in India. *BMC public health*, *11*(1), 549.

Prinja, S., Manchanda, N., Aggarwal, A. K., Kaur, M., Jeet, G., & Kumar, R. (2013). Cost & efficiency evaluation of a publicly financed & publicly delivered referral transport service model in three districts of Haryana State, India. *The Indian Journal of Medical Research*, *138*(6), 1003.

World Health Organization. (2010). *Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies*. World Health Organization.

Kumar, R. (1993). Streamlined records benefit maternal and child health care. In *World health forum 1993; 14 (3): 305-307*.

Verma, R., &Prinja, S. (2007). Over reporting of RCH services coverage and operational problems in health management information system at the sub-center level. *Indian Journal of Community Medicine*, *32*(3), 185.

Husain Z, Saikia N, Bora RS. Opportunities and challenges of health management information system in India: a case study of Uttarakhand. MPRA Paper No. 40014. 2012; Available from: http://mpra.ub.uni-muenchen.de/40014/.

Dehury RK, Chatterjee SC. Assessment of health management information system for monitoring of maternal health in Jaleswar Block of Balasore District, Orissa, India. Indian J Public Health 2018;62:259-64.

Krishnan A, Nongkynrih B, Yadav K, Singh S, Gupta V. Evaluation of computerized health management information system for primary health care in rural India. BMC Health Serv Res. 2010;10:310.

A field-based guide to NGOs for quality data collection and monitoring at Ti level, National AIDS Control Organisation, New Delhi.
http://naco.gov.in/sites/default/files/Quality%20guide%20for%20TIs.pdf

Karan, A., Negandhi, H., Nair, R., Sharma, A., Tiwari, R., &Zodpey, S. (2019). Size, composition and distribution of human resource for health in India: new estimates using National Sample Survey and Registry data. *BMJ open*, *9*(4), e025979.

Rajanna D, Kapila S. 2016. HMIS, a technical note.

Bodavala, R. (1998). Evaluation of Health Management Information System in India: Need for Computerized Databases in HMIS. *RanganayakuluBodalava, Takami Fellow in International Health, Harvard School of Public Health*, *665*.

Gera, R., Muthusamy, N., Bahulekar, A., Sharma, A., Singh, P., Sekhar, A., & Singh, V. (2015). An in-depth assessment of India's mother and child tracking system (MCTS) in Rajasthan and Uttar Pradesh. *BMC health services research*, *15*(1), 1-14.

Nagarajan, P., Tripathy, J. P., & Goel, S. (2016). Is mother and child tracking system (MCTS) on the right track? An experience from a northern state of India. *Indian journal of public health*, *60*(1), 34.

India TB Report (2020). Central TB Divison. MoHFW, New Delhihttps://tbcindia.gov.in/showfile.php?lid=3538