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Surveillance of chronic diseases: Challenges and strategies for India

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Working Paper 322

**Surveillance of Chronic Diseases:
Challenges and Strategies for India**

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Abstract

This paper describes the status, challenges and scope for strengthening surveillance of chronic disease risk factors, morbidities and mortality in India. We draw upon the surveillance experience of four selected States of India namely Uttar Pradesh, Rajasthan, Kerala and Tamil Nadu to understand key requirements in relation to financing, infrastructure, human resources and governance. The public health system is grappling with resource constraints but there is room for more efforts to undertake systematic population-based chronic disease surveillance in India. Although there are no immediate policy goals to ensure population-based screening, opportunistic screening of selected chronic diseases is an important strategy under the National Programme for Prevention and Control of Diabetes, Cardiovascular diseases and Stroke (NPCDCS). However, surveillance activities under this programme are performing sub-optimally due to issues related to funding constraints, operational guidelines and inadequate clinical, technical and managerial staff. It is apparent that public health system should devote additional resources towards active population-based surveillance. Besides financing, there is a need to develop institutional mechanisms for engagement of adequate human resources for surveillance and disease management. Engagement of AYUSH and community health workers (ASHAs or others) is identified as reasonable options but would require sound incentive mechanism to ensure good coverage and programme outreach. Furthermore, local support, both social and political, is critical to create a conducive environment to contact beneficiaries and for information recording. In this endeavour, private sector is identified as a potential partner that needs enabling environment to come up with services under PPP.*

Keywords: Surveillance, chronic diseases, risk factors, morbidity, mortality.

JEL classification: C8, I18.

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1. Introduction

Globally, chronic diseases, particularly degenerative non-communicable diseases (NCDs) such as cardiovascular diseases, cancer and diabetes mellitus are causing more deaths than all other causes combined. The World Health Organization's (WHO) Global Status Report on NCDs 2014 suggests that out of the 56 million global deaths in 2012, 38 million, or 68%, were due to NCDs (WHO 2014). Principally, cardiovascular diseases, cancers, chronic respiratory diseases and diabetes accounted for 82% of NCD deaths (WHO 2014). Such increasing global burden of NCDs has major socioeconomic implications for low income countries that account for nearly three-quarters of the global burden of NCD-related mortality (WHO 2014). India, with a huge population, has very high-prevalence of chronic disease risk factors, chronic morbidities and mortality (RMM). As such, India accounts for over 15% (5.9 million NCD deaths) of the global NCD deaths (38 million) and around 58% of these deaths occurring before individuals attain age of 70 years (WHO 2014). Importantly, early onset of NCDs is a major concern and some earlier studies have noted that about 3-4% of adults (aged 20 and above) in rural areas and 8-10% in urban areas suffer from coronary heart disease (Reddy et al 2005). Such high prevalence of NCDs is estimated to cause a total damage of \$3.55 trillion in lost economic output during the 18 year period, 2012-30 (Bloom et al 2014). In fact, direct out-of-pocket (OOP) payments associated with chronic disease care have jeopardized the customary living standards of several households (Mahal et al 2005, Van Doorslaer et al 2007, Garg & Karan 2009, Selvaraj & Karan 2009, Ghosh 2011, Rao et al 2011, Modugu et al 2012, Joe 2015).

Given such intricate concerns, policy makers and public health authorities in India are displaying a greater commitment towards both prevention and treatment of chronic diseases to reduce the burden and possibly reverse the tide (Bloom et al 2014). However, to proceed with their intent, these interventions require considerable information on the varied dimensions of chronic diseases including insights on risk factors and morbidity across population subgroups. More specifically, this calls for greater focus on surveillance of chronic disease risk factors, morbidity and mortality in India (Deepa et al 2011). A good surveillance system is a prerequisite for effective control of chronic diseases and can significantly contribute towards planning and implementation of preventive measures. Against this background, this paper describes the status, challenges and scope for strengthening surveillance of chronic disease risk factors, morbidities and mortality in India. The paper essentially draws upon the surveillance experience of four selected states of India namely Uttar Pradesh, Rajasthan, Kerala and Tamil Nadu to list the key requirements in relation to financing, infrastructure, human resources and governance. The rest of the paper is organized as follows: Section 2 briefly highlights the merits of a good surveillance system. Section 3 and 4 presents an overview of existing surveillance mechanisms (health surveys, surveillance tools and similar other datasets) and lists the major challenges for India. Section 5 presents an alternative surveillance framework. Section 6 discusses the major requirements in relation to financing, infrastructure, human resources and governance for the proposed framework. Section 8 concludes by listing the major recommendations.

2. Significance of surveillance

“Public health surveillance¹ is the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice” (WHO 2015). Based on the 21st World Health Assembly, this definition emphasizes on a greater role of information and surveillance for action (WHO 1968). Clearly, unlike surveys, surveillance involves commitment to data collection on an ongoing, repeated basis to identify trends in the prevalence of risk factors². It is expected that a robust surveillance mechanism can not only serve as an early warning system for impending public health emergencies but also support impact evaluations and accordingly help prioritization in public health policy and strategies. In this regard, Box 1 summarizes the significance of surveillance for policymaking and prevention of chronic diseases.

Box 1: Significance of surveillance for policymaking and prevention of chronic diseases

- Regular surveillance can help understand natural history of diseases and identify priority areas for epidemiological and policy research.
- Surveillance can inform about potential social, economic, behavioural and political determinants associated with chronic diseases and provide guidance for policy, legislation and finance to reduce exposure to risk factors both at individual and population level
- Patterns of prevalence of chronic disease risk factors, morbidities and mortality across regions and population subgroups informs about overall disease burden and can help decide upon interventions and strategies for primary, secondary and tertiary prevention.
- Surveillance at local, regional and national level can be used by public health authorities for developing need-based health interventions and also support programme development, monitoring, mid-course corrections and impact evaluations.
- Distribution of risk factors, morbidity and mortality can inform about engaging potential public and private sector stakeholders and outline their roles and responsibilities in policy planning, coordination and implementation.
- Surveillance information can be used to decide upon financial, infrastructure, human resources and governance structure for programme implementation and also help prioritise between regions for programme investments across range of diseases and risk factors.
- Successful primary, secondary and tertiary prevention can increase population longevity, improve productivity of working age population and reduce financial and economic losses to both households and the national economy by curbing health care expenditure and consequent impoverishment.

¹ http://www.who.int/topics/public_health_surveillance/en/ (accessed on April 9, 2015)

² <http://www.who.int/chp/steps/Part1.pdf> (accessed on April 9, 2015)

3. RMM surveillance in India

3.1. History of RMM surveillance

The Health Survey and Development Committee chaired by Sir Joseph Bhore (1946) presented an elaborate set of recommendations for organization and collection of vital statistics including accurate statistics on causes of death in India. But such felt need for radical revision of the existing vital statistics system was not received with a sense of urgency and surveillance was confined to some selected public health concerns such as malaria. Although, the Mudaliar committee (1961) does focus on strengthening health care facilities for treatment of cancer and mental illness but during those years the need for surveillance of NCDs was not accorded any priority. Nevertheless, collection of vital statistics in India received a major boost with the enactment of the Registration of Births & Deaths Act, 1969 which under Section 10(2) and Section 10(3) provides for Medical Certification of Causes of Death (MCCD) and is expected to provide a reliable data base for generating mortality statistics (RGI 2009). Similarly, the introduction of Sample Registration System (SRS) in 1969-70 is an important policy initiative undertaken by the Office of the Registrar General of India. However, the SRS maintained an exclusive focus on demographic indicators and it was only recently that the deaths reported under the 2001-03 Sample Registration System (SRS) was used for studying the causes of death in India. For this purpose, the RGI implemented Special Survey of Deaths in India using an advanced form of Verbal Autopsy called the “RHIME” or Representative, Re-sampled, Routine Household Interview of Mortality with Medical Evaluation method.

The health surveillance system in India primarily focuses on prevention and control of potential spread of disease outbreaks. This is evident from the change in focus from cholera, malaria to more recent surveillance of infectious diseases such as HIV and AIDS. As noted by Coelho (2013), the existing surveillance systems for disease reporting in India referred to as the National Surveillance Programme for Communicable Diseases (NSPCD) is an important centralized system that focuses on strengthening of State, District and Taluka level identification of the epidemiology of communicable diseases to facilitate an effective and coordinated response. Under NSPCD, several key initiatives are undertaken including development and training of rapid response team, overall monitoring and evaluation of epidemic under surveillance, as well as strengthening of laboratory and communication networks.

Further, with the spread HIV infection in early 1990s, the Government of India had set up the HIV surveillance systems under the National AIDS Control Organization. The surveillance activities continued particularly for the high risk group population and were expanded under different phases of the National AIDS Control Programme. In 2004, instead of a vertical system of reporting, the Government of India (with the assistance of the World Bank) focused on a decentralized and State-based reporting initiative by launching the Integrated Disease Surveillance Project (IDSP). The IDSP aimed to detect and respond to disease outbreaks quickly. Under IDSP, weekly surveillance data on epidemic prone disease are collected from reporting units such as sub centres, primary health centres, and community health centres, hospitals including government and private sector hospitals and medical colleges. The data are

being collected on ‘S’ syndromic; ‘P’ probable; & ‘L’ laboratory formats using standard case definitions. The weekly data is analyzed and any report of rising incidence is taken up for further diagnosis and control of outbreak. In recent years, bulk of the cases of increasing incidence is mainly related to H1N1 influenza, diarrhoeal diseases, food poisoning and vector borne diseases.

Table 1: Household surveys collecting information on non-communicable disease risk factors in India since 2000

Survey and year	Population age group	States/ UTs	Rural/Urban	Sample	Periodic
<i>National, representative of states or regions</i>					
Longitudinal Aging Study in India	45+	31	Both	-	Yes
Global Adult Tobacco Survey 2009-10	>14	31	Both	69296	No
National Family Health Survey 2005-06	15-49 Females 15-54 Males	35	Both	198754	Yes
<i>National, nationally representative only</i>					
Indian Human Development Survey 2004-05	Households	33	Both	41000	No
National Household Survey of Drug and Alcohol Abuse 2000-01	Males 12-60	24	Both	40697	No
<i>Multiple State, representative</i>					
WHO World Health Survey and Study on Global Aging and Health					
2007-08	>17	6	Both	12198	Yes
2003	>17	6	Both	9994	Yes
IDSP NCD Risk Factor Survey 2007-08	15-64	7	Both	38054	No
Population Council's Youth in India Survey 2006-08	Females 15-24 Males 15-29	6	Both	50848	No
National Nutrition Monitoring Bureau Surveys					
2005-06	1 and above	10	Rural	51700	Yes
2000-01	1 and above	9	Rural	51300	Yes
Tobacco use in Karnataka and Uttar Pradesh 2001	>9	2	Both	64084	No
<i>Multiple State, non-representative</i>					
Indian study on epidemiology of Asthma, Respiratory symptoms and chronic Bronchitis					
2006-09	15-85	14	Both	169575	Yes
2002-04	15+	4	Both	73605	Yes
ICMR Risk Factor Surveillance					
2005-06	15-64	6	Both	7874	Yes
2003-04	15-64	5	Both	39429	Yes

Cardiovascular disease surveillance in industrial settings 2002-03	20-69	10	Both	19973	No
Prevalence of diabetes in India study, 1999-02	25+	108 centres	Both	41270	No
National Urban Diabetes Survey 2000	20+	6	Urban	11216	No
Coronary Heart Disease Risk Factors in Northern India 1995-2000	15+	3	Both	7169	No
<i>Single-State, representative</i>					
Kerala Risk Factor Study 2003-04	30-74	1	Both	6579	No
<i>Single-State, non-representative</i>					
Tamil Nadu Diabetes and risk factor survey 2006	20+	1	Both	7066	No
Diabetic retinopathy study, Theni District 2005-06	30+	1	Both	25969	No
Chennai Urban Rural Epidemiology study 2001-04	20+	1	Both	26001	No
Trivandrum oral cancer screening study 1996-2004	35+	1	Rural	164072	Yes
Mumbai cohort study follow up 1997-2003	35+	1	Urban	90282	Yes
Substance abuse in Arunachal Pradesh 1998-2000	10+	1	Rural	5135	No

Source: Based on Raban et al (2012).

Broadly, it may be concluded in the last century chronic disease surveillance did not receive adequate focus in India. Nevertheless, as an exception, it is important to note that unlike other important chronic illness such as cardiovascular diseases and diabetes, there were explicit policy efforts for collection of vital statistics related to cancer in India. This was possible because of the National Cancer Control Programme (NCCP 1975) which listed establishment of data base of cancer cases as an important requirement. Specifically, the National Cancer Registry Programme (NCRP) was initiated in 1982 by the Indian Council for Medical Research (ICMR) to provide an understanding of the magnitude and patterns of cancer in India. As reported in the NCCP programme overview documents, there are two types of registries; Population Based Cancer Registry and Hospital Based Cancer Registries, which was started in January 1982. The Population-based registries take the sample population in a geographically defined area while the Hospital-based registries take the data from patients coming to a particular health institution. At present, India has 21 Population-based registries and 6 Hospital-based registries in different parts of the country. However, since 2001, data from all cancer registries and all medical colleges are collated for the “Development of an Atlas of Cancer in India” (www.canceratlas.india.org) to get an idea of patterns of cancers in several other parts of the country, including those not covered under the NCRP. Nevertheless, with growing burden of NCDs, in the last decade two important NCD risk factor surveillance efforts were initiated in India. These studies are namely; the WHO-ICMR NCD risk factor surveillance and the NCD risk factor survey under the Integrated Disease Surveillance Project

(IDSP). Some other studies and surveys also aim to provide information regarding prevalence of selected chronic diseases in India (Table 1). The India Research Site Landscape Analysis project³ of the Public Health Foundation of India (PHFI) has listed key public health demographic surveillance sites in India. These sites are supported by various funding agencies and facilitate research and intervention studies.

- CEL Shivgarh, Uttar Pradesh
- INCLEN Palwal, Haryana
- PGIMER, Chandigarh
- JIPMER, Puducherry
- MDRF, Chennai
- NIE, Chennai
- NIRT, Chennai
- SHARE, Ranga Reddy, Andhra Pradesh
- St. John's Mugalur, Karnataka
- St. John's, Palamaner, Andhra Pradesh
- SCTIMST, Trivandrum
- Ekjut, Jharkhand and Odisha
- NICED, Kolkata
- SBCC, Purulia, West Bengal
- SHDS, Birbhum, West Bengal
- Deepak Foundation, Vadodara, Gujarat
- KEM, Vadu, Maharashtra
- SEARCH, Gadchiroli, Maharashtra

3.2. *Surveillance under NPCDCS*

In 2008, Government of India launched the pilot phase of NPCDCS (National Programme for Prevention and Control of Diabetes, Cardiovascular diseases and Stroke) with two objectives: 1) risk reduction for prevention of NCD's (diabetes, CVD and stroke), and 2) early diagnosis and appropriate management of diabetes, cardiovascular diseases and stroke. In 2010, the Government of India launched the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) by merging the National Cancer Control Programme (NCCP) and the National Programme for Prevention and Control of Diabetes, Cardiovascular diseases and Stroke (NPDCS). The programme is under implementation in 100 districts and will be expanded to cover all districts nationwide during the 12th Five Year Plan in a phased manner. NCDs surveillance is outlined as an important

³ <http://research-sites.phfi.org/index.php/about-the-project>

strategy under the NPCDCS. The focus particularly is on early diagnosis and the programme has emphasized on strengthening opportunistic screening at selected facilities. The opportunistic screening involves clinical examination comprising of relevant questions and easily conducted physical measurements (such as history of tobacco consumption and measurement of blood pressure etc.) for persons above the age of 30 years at the point of primary health facility contact to identify those individuals who are high risk of developing diabetes and CVD, warranting further investigation/action. It is expected that screening will have inherent elements of mass awareness creation, self-screening and trained health care providers. The screening activities are linked to NCD clinics established under the programme at Community Health Centre (CHC) and District Hospital (Table 1).

The key functions of the NCD clinics are as follows:

- The NCD clinic shall conduct comprehensive examination of patients referred by lower health facility /health workers as well as of those reporting directly to the clinic
- The clinics will advise laboratory investigations of the patients to rule out complications or advanced stages of common NCDs
- The district NCD clinic will provide common essential drugs for NCD management including for stroke patients
- The NCD clinics shall also provide counseling services and undertake awareness generation activities regarding NCDs and associated risk factors
- The NCD clinics will maintain regular database and send reports in the prescribed formats at regular intervals

Table 2: Establishment of NCD clinics under NPCDCS, 2013-14

State	State NCD Cell	District NCD Cells	District NCD Clinics	CHC NCD Clinics
Kerala	1	5	5	0
Rajasthan	1	7	7	0
Tamil Nadu	1	5	5	0
Uttar Pradesh	1	5	4	0

Source: Annual Report 2013-14, Dept. of Health and Family Welfare, MoHFW.

Kerala – Active surveillance with greater community engagement: Prior to the launch of the NCDs programme under the NHM, there was only a separate program for cancer screening, TB and HIV AIDS whereas there were no specific strategies for surveillance of other chronic NCDs such as diabetes, hypertension or stroke. Following the launch of the NPCDCS programme there is regular screening and free delivery of drugs for diabetes and hypertension through the health centres under the NCD clinics. There are nodal officers appointed for each districts and the state has also engaged key HR including doctors, staff nurse, physiotherapist, dietician, and data entry operator for smooth functioning of the programme. The programme follows the NPCDCS guidelines and is implemented by state programme officers through the health system with support from ASHAs. Training and capacity building of medical staff and

ASHAs is conducted but the emphasis is more clinical aspects and not much on programme management. However, there is no involvement of district programme managers or medical officers in activity planning.

Tamil Nadu – TNHSP supported facility-based surveillance in all the districts: NCDs screening activities for diabetes, cardiovascular diseases, cervical and breast cancer (along with prevention and treatment) is being implemented in all the 32 districts of Tamil Nadu under the World Bank supported Tamil Nadu Health Systems Project (TNHSP). Under the programme public health facility-based screening is provided to all individuals attending any of the government health facilities which includes 1753 PHCs, 267 GHs and 23 Government Medical College hospitals and attached institutions, ESI dispensaries and Hospitals and 100 selected Municipal health facilities in the State. Prior to up scaling in all the 32 districts of Tamil Nadu, Government of Tamil Nadu carried out Pilot initiatives for Hypertension and cervical cancer in two selected districts each during 2007-10. The NHM programme data provided along with the Tamil Nadu State PIP 2015-16 suggests that about 2344 trained NCD Staff Nurses have been exclusively appointed on contract to provide screening and follow up services under the program. All the regular staff including Medical Officers, Pharmacists, Lab Technicians etc. have been trained under the program for the complete delivery of services. NCD–Online Screens have been developed and the data is captured online. Besides, the Reports are received and performance analyzed for necessary action.

Rajasthan – Surveillance through NCD clinics in selected districts: Under the 11th five year plan seven districts of Rajasthan were selected for rolling out NCD programme for screening, prevention and treatment. State and District NCD Cells were constituted and contractual staff is appointed as per the operational guidelines but in most cases with the key exception of district programme officers and medical doctors. However, with the implementation of the 12th plan (2013-17) all interventions of the NPCDCS will be scaled up and implemented across all the districts in a phased manner. The screening would be carried out at various levels of health care delivery and opportunity such as mobile medical units visit, health checkups during camps, mother and child health and nutrition days. Programme will also focus on attendants of patients visiting health care centres as well as participants at panchayat meetings for opportunistic screening. Further, the screening activities will be expanded to urban slums of selected large cities as well as through routine check-up of students under the school health programme. Screening of individuals with observed NCDs risk-factors as well as opportunistic screening for common cancers (breast, cervical and oral) will be strengthened.

Uttar Pradesh – No momentum on surveillance through NCD clinics in selected districts: It is suggested that in Uttar Pradesh the NPCDCS programme is operational in 28 districts with proposal to include one more district in the next financial year. However, very few interventions have been planned for NCD management in Uttar Pradesh and there is no clarity regarding roles and responsibilities in this vital area of NCDs screening and surveillance. State Officer for the NPCDCS programme for Uttar Pradesh could only report information on aspects of programme costs and a few process indicators such as the number of glucose strips used in a year and haphazardly compiled statistics regarding screening. The discussions suggest that

programme officers are unable to describe targets and expected outcomes for the actions taken so far. This is primarily because of unavailability of data related to NCDs. Notwithstanding data availability, the policy approach and NCD prioritization is yet to pick momentum in the state.

3.3. *Other initiatives for NCDs surveillance in the four selected states*

Nalamana Tamizhagam in Tamil Nadu: *Nalamana Tamizhagam* is an initiative of the Government of Tamil Nadu which aims to screen the population and identifying the risk factors in the rural populations in Tamil Nadu. This is attained through health promotion, behaviour change in the community. The programme is implemented by the State NCD Cell under the overall supervision of the Directorate of Public Health & Preventive Medicine. The programme has envisaged an NCD risk scoring method called the “*ennscore*” to devise effective screening strategies to unmask hidden burden of the disease. Under the programme, free state-wide adult NCD risk profiling (above 30 years) and screening for diabetes and hypertension in rural Population was performed for about 1.2 crore families in rural Tamil Nadu. The screening programme has a strategy of engaging 1 village volunteer per 50 houses for risk profiling of the community using “*ennscore*” algorithm. After screening, individuals at risk were advised to attend village level screening camps conducted by Village Health Nurse & Health Inspector with further registration of identified cases into a PHC based registry and subjected to further management as per the protocols.

Amrutham Aarogyam in Kerala: On 6th April 2013, Government of Kerala announced launch of a year-long action plan to create awareness about the importance. The state has issued guidelines for organizing screening camps in the state as per NPCDCS. Diagnostic kits (glucometer and strips) for diabetes testing have been distributed to the SCs, PHCs and CHCs. For effective disease diagnosis, it was proposed that medical teaching centers should have preventing lifestyle diseases diabetes and CVDs as part of the “*AmruthamAarogyam*” programme. Under the programme when 1 crore people were screened, 25% had hypertension (on treatment) and 23.5% had diabetes (on treatment). The new case detection was 5.9% and 4.9% for hypertension and diabetes, respectively. About 1 crore 20 lakh adults has been screened under the programme.

LEAP programme in Kerala: A survey conducted recently by School Health Programme (an initiative of NRHM) among students in Kerala found that about 2.7 per cent of the 10 lakh children in Government schools are overweight and 0.8 per cent obese. The survey alerted the life style diseases among youth Kerala. Thus, a comprehensive programme to prevent life style diseases among school children in the State, the Lifestyle Disease Education and Awareness Programme (LEAP) was initiated. The Programme is a joint initiative of the National Rural Health Mission and the State Departments of Health and Education. The new initiative complements the peer programme titled *AmruthamAarogyam* for adults in the State. As part of the programme, students will be screened by health workers and their details will be recorded. For every 2,500 students, a school health nurse is being appointed for this purpose. A list of students prone to lifestyle diseases will be made and special care will be availed to them. The class teacher will keep the records of students and access the lifestyle diseases preventive

measures. Each school will have a LEAP ambassador from the health club to help accelerate the activities.

Sampoorna clinic in Uttar Pradesh: Population Services International (PSI) is providing technical support to the Uttar Pradesh for screening, prevention and treatment of NCDs. Under this collaborative initiative PSI has plans to pilot the strategy of *sampoorna* clinic in five selected districts. Currently, the NCD clinics established under the NPCDCS programme are functioning from the District Hospital (Male) whereas it is likely that the District Hospital (Female) is not focused. Under the concept of *sampoorna* clinic, PSI will establish screening facilities District Hospital (Female) along with two selected CHCs in the same district. PSI has plans for engaging exclusive human resources for the screening activities at the DH level. This involves one medical doctor, one staff nurse, one nursing assistant and one support staff. In addition to screening for cervical cancer, the focus will be also on other NCDs including diabetes and CVDs. The *sampoorna* clinic will be operated on a daily basis at the district hospital level. At the CHC level the *sampoorna* clinic will be planned on a weekly basis and the HR for the clinic will be drawn from the existing CHC staff. PSI would also provide training to medical staff from CHCs for conducting the screening. Also, an assistant manager from the PSI will be providing management support to the District Programme Managers. Importantly, the screening data will be collected using a *tab* and it can facilitate quick recording, updating and sharing of the programme data for surveillance.

Swasthya slate in Uttar Pradesh: The NCD programmes in Uttar Pradesh may also benefit from the programmes and interventions planned by the Technical Support Unit (TSU) of the India Health Action Trust (IHAT). The TSU essentially has the support structures in select divisions, districts, and blocks to advice and support government structures (state/district/divisional level machinery, PHCs, sub-centers, and ICDS centers, etc.), frontline workers (FLW) and other service delivery points. IHAT has been developing an intervention strategy for NCDs screening and surveillance. This intervention involves use of ICT based automated diagnostic system – a *tab* referred to as the *swasthya slate*. The objective of the intervention is to strengthen primary health care so that the patient load at higher facilities including DH and CHCs is reduced. For this purpose, there are plans to engage the AYUSH health care providers in the rural areas to serve as a bridge between the rural population and the higher health facilities. The programme also envisages a role for male community health workers including quacks to act as motivator and thereby aims to gain greater control on their practice. However, the cost implications of the programme are being worked out as well as its HR structure and implementation strategy.

Sai Rural Diabetes Specialties Centre (SRDSC) in Chennai: The Madras Diabetes Research Foundation in Chennai has initiated a rural diabetes prevention programme in Chunampet, Tamil Nadu, which aims to prevent diabetes in about 5,00,00 individuals residing in about 42 villages, using village health workers and a mobile telemedicine unit for screening (Mohan et al 2011). The telemedicine facility is a unique project to track the disease burden in rural areas and to explore innovative healthcare models, both accessible and affordable to the rural populous. The SRDSC is a unit of Dr. Mohan's Diabetes Specialty Clinic set up at Chunampet

in Kancheepuram District, Tamil Nadu about 100 kms away from Chennai in the year 2007. The project fits with the Non-Communicable Diseases Surveillance Project of the Indian Council of Medical Research (ICMR), the World Health Organization (WHO) and the Government of India. The same centre is utilized for the “*Rural India Diabetes Prevention Project*”, started by Madras Diabetic Research Foundation in collaboration with the World Diabetes Foundation (WDF), with the support of Indian Space Research Organization ISRO (Vijayaraghavan and Mohan 2011).

Kidney Help Trust (KHT) in Chennai: The Kidney Help Trust of Chennai has run a programme to prevent chronic renal failure by regular screening of an entire population of 21,000 in selected villages of Sriperumbudur Taluk and has supported treatment of diabetes and hypertension with the cheapest available drugs. The program has recently been expanded to cover the adjacent area with a population of 21,500. Both the original population and the new population have been surveyed and information on key surveillance indicators is recorded. The programme is mainly operated through community health workers (females) who have completed their schooling. The KHT team trains the health workers to perform the simple diagnostic tests and tasks and closely monitor their work for the first few weeks till the health workers understand and perform the tasks with confidence and reliability. The demographics of the entire area are also mapped out. Due to resource constraints the screening of every person in the area once in 18 months where the health workers ask a simple set of questions: have you ever had swelling of the feet, difficulty in breathing, pain on passing urine, blood in the urine, the need to pass urine frequently (more than twice in an hour) or to get up from sleep at night to pass urine, or pain in the back over the kidneys. A sample of urine is examined at the site for sugar and for protein. The blood pressure is recorded for all individuals over the age of 5. Thereafter, all who test positive by answering any of the questions in the affirmative, who have a high blood pressure (over 140/90), or who have sugar or protein in the urine, are examined by a doctor of the Kidney Help Trust who makes regular visits to each village.

Neonatal diabetes and maturity onset diabetes of young (MODY) registry in Chennai: The Dr. Mohan’s Diabetes Specialities Centre (DMDSC) in Chennai is a World Health Organization (WHO) Collaborating Centre for NCDs Prevention and Control. The Centre has also a focus on neonatal diabetes (refers to a form of diabetes with onset below 6 months of age) and monogenic diabetes or Maturity Onset Diabetes of the Young (MODY). In this regard, the Centre has started a national registry for Neonatal diabetes and MODY to understand more about these conditions. For this purpose, the Centre has invited doctors treating patients with Neonatal Diabetes and MODY to register their cases in this registry. They also invited patients, their parents or close relatives who might have one of these conditions to register at this site. However, all information provided is treated as confidential.

4. Challenges for chronic disease RMM surveillance

- i. **Need greater awareness on NCDs surveillance:** The draft National Health Policy 2015 acknowledges the rising burden of NCDs and calls for developing of a comprehensive model by drawing lessons from States where NCD prevention and treatment interventions have been rolled out. However, the draft can also focus on highlighting the merits of investing surveillance system for chronic disease risk factors, morbidities and mortality. Unlike the case of communicable, infectious or vector-borne diseases, it appears that development of a robust surveillance system for NCDs and NCDs risk factors screening is also increasingly becoming important. Although, the current discourse emphasizes on programme based NCDs screening but conceptually it is a different approach than establishment of a full-fledged surveillance system.
- ii. **Augmenting public health capacity:** The public health system in India faces severe constraints in terms of both financial and human resources. Development of a robust surveillance system requires strengthening of local capacity and devolution of additional resources towards health care infrastructure and human resources. This involves establishing a number of surveillance units at local level and staffing them with appropriately trained and qualified personnel. This also demands further investments in public health education and creation of public health cadre as a specialized division to implement and supervise the surveillance activities.
- iii. **Challenge of designing a NCDs surveillance system:** Chronic diseases are caused by the complex interaction between the risk factors and the social, economic, political, cultural, environmental factors. This makes the surveillance of chronic diseases challenging as this poses a question as to what and how the data has to be collected to reflect on the rising burden of chronic diseases. This also questions as to how the surveillance system for chronic diseases has to be designed so that it captures the risk factors and the determinants which will direct for better health planning and making policy decisions. However, NCD surveillance under NPCDCS suffers from huge gaps and the system has not responded to this effectively. Also, based on the experience of the RCH based HMIS it is unlikely that HIS strengthening would lead to improvements in NCDs and NCDs risk factor surveillance in the country. Moreover, its potential coverage and use for policy evaluation and planning remains a distinct concern as there are no protocols or guidelines for effective use of data for decision-making. Also, lack of review of data disallows quality checks and restricts the scope for data collection and analysis by involving State-level institutions, private sector stakeholders and NGOs.
- iv. **Limitations of opportunistic screening:** The NPCDCS has a clear emphasis on facility based opportunistic screening of persons above the age of 30 years at the point of primary contact (village, CHC, District hospital, tertiary care hospital). However, opportunistic screening has its own limitations and it will be unable to capture huge sections of population who are at risk of NCDs. Also, this will not lead to early diagnosis of cases. Opportunistic screening is turning out to be a one-time affair and there are no efforts to ensure appropriate regular screening as well as treatment and follow up with identified

NCDs cases. Such discontinuity does not help development of surveillance systems and affects our policy approach towards NCDs. In this regard, a genuine concern raised by a medical practitioner is as follows: *“I have reservations against the kind of screening which is happening these days across the country. Screening is not a one-time affair. It has to be continuous. In case of NCDs, you just can’t screen the person once and label that he/she has that particular disease. This is the problem of mislabeling. Blood pressure/Sugar fluctuates so much. For this, there should be a dedicated team who will do the screening and will make sure that the patients come back for follow up”* (Director & Head of Internal Medicine, Private Hospital, Jaipur).

- v. **Challenges in following protocols for physical measurement:** Physical measurement is an elementary task but its accuracy (error minimization) significantly depends on use of appropriate equipment, measurement protocols and providing regular training and standardization of NCD clinic staff. In this regard, the scope for error is notably large in case of hypertension assessment as blood pressure measurements are subject to high degree of variations and inaccuracies. The measurement not only depends on the room environment but also is affected by accuracy of equipments as well as training and experience of the nursing staff.
- vi. **Human resources for community outreach:** ASHAs are overburdened with RCH and other NHM activities and hence their proposed involvement in NCD prevention efforts and health education activities has to be carefully planned. In this regard, a professor in a leading medical university in Lucknow has suggested that *“the structure for NCD Management should be designed in such a way that the existing staff (including ASHAs) does not feel overburdened.”* However, the major issue is that the nature and tasks of a community outreach and health worker for NCD prevention and treatment programmes vis-a-vis RCH programme is totally different. This will require different set of skills and the activities are likely to be more intensive. This point is summarily discussed by one of the respondents who argued that *“ASHA cadre was conceptualized to be the link between community and health services. Now we want everything to be done by ASHA. I am not convinced that ASHA should be converted into a service provider. We need to decide whether we want an activist or a service provider? These are important and larger issues. The decision should not be based on perception rather it should be based on evidences”*. In this regard, a major challenge is find appropriate HR who can perform this important task for fostering health system and community link. The issue is further complicated by the fact that such HR will be needed at village level will have to cover substantial proportion of population at risk of NCDs. The financial aspects of any such HR policy have to be well-thought to ensure quality and sustainability of such proposal.
- vii. **Training for screening activities:** It is often taken for granted that medical staff possesses necessary skills and expertise for conducting screening activities for NCDs. However, the fact is that ability and potential of health workers does vary and it is important that medical doctors and nursing staff are regularly trained and advised on screening activities. Particularly, ANMs do need greater support because often they may

be unable to understand the equipment related errors while measuring blood pressure and as such hypertension is a clear parameter for NCDs. There are also plans to engage ASHAs with screening activities but again this will require good basic training and regular supply standardized equipment with timely inspection and checks to ensure good quality of screening activities. In this regard, it is important to realize that “*quality of training gets deteriorated once it goes to the district level officer. Quality of training remains good till it is in the hands of medical faculty. [Furthermore], there are issues with sufficient number of trainers to train all the peripheral health workers. Monitoring is another issue for training done at the district level*” (Director, SIHFW, Jaipur)

- viii. **Poor data management and reporting by NCD clinics:** The surveillance system for NCDs in Rajasthan and Uttar Pradesh are largely dysfunctional. While the facilities maintain a register with details regarding symptoms and treatment but often the programme data is based on OPD prescription information provided by the pharmacist. The most common way of reporting and forwarding data is to examine the annual trends and come up with an average number of cases by diseases for reporting. On most occasions the physician does not mention the diagnosis on the patient card and other times it may not be legible to read. Hence practically there is no record or patient history of patients visiting the OPD, the only data that is available is from IPD. This also raises the concern about the reliability of data.
- ix. **Search for cost-effective surveillance model:** The states are generally following the technical inputs provided by the national leadership on NPCDCS for surveillance activities through NCD clinics. However, it is clear that there is a dearth of alternative surveillance models for testing and implementation. The state-level officials have not shown any engagements with review or research on primary prevention models that can be adopted in the local context. Also, combination of screening strategies for different NCDs is not considered from a financing perspective in order to optimize resource allocations and maximize the programme impact. In this regard, a few stakeholders have also suggested for adding an NCD arm to the already existing communicable disease surveillance program. Besides, the existing human resources can be utilized to collect basic details on NCD from those being monitored for the communicable diseases.
- x. **Strengthening role of AYUSH system:** Given that, doctors and physicians are already in shortage and screening patients in the existing system will be an added burden for them. Majority of the experts had the views that AYUSH can play an effective role in screening. To quote, “*AYUSH can help in screening. If you are not getting MBBS doctors, at least at the CHC level they should be involved for screening*” (State Nodal Officer for NPCDCS, Uttar Pradesh). The AYUSH doctors are willing to serve in rural and remote areas but it is important that logistics (drugs and equipments) and technical support is provided to facilitate routine screening and treatment of NCDs. Also, there should be guidelines and protocols for ensuring continuum of care for the patients.
- xi. **Data sharing by the private sector:** The major challenge for a regular surveillance system which feeds data on the NCD burden and the risk factors, as commented by the

stakeholders interviewed, is the underutilization of the public health system for NCDs treatment. A major section of the patients with hypertension or diabetes seek care from private providers and public health facilities are utilized by a smaller section of the population. This will leave us with incomplete statistics on the NCDs. In fact, as pointed out by a public health expert “...*without involving private sector, we won’t be able to do a proper surveillance*”. Clearly, private sector can be useful partner in prevention activities by partnering in NCDs surveillance. However, private sector would need support and enabling environment to come up with services through public-private partnership (PPP) mode. Also, the public sector should develop institutional capacity to facilitate and support PPP initiatives.

- xii. **Sustaining NCDs surveillance efforts:** Notwithstanding the limitations of the existing NCDs screening and surveillance system, the NPCDCS programme has provided financial support for human resources, infrastructure, and reporting and management system. However, it is now up to the state governments to ensure quality improvement as well as sustainability of efforts in the area of NCDs surveillance. The recommendations of the 14th Finance Commission regarding sharing of resources between Centre and the States has also put the onus back on the state governments for investing in health.

5. Proposed surveillance framework and strategies for India

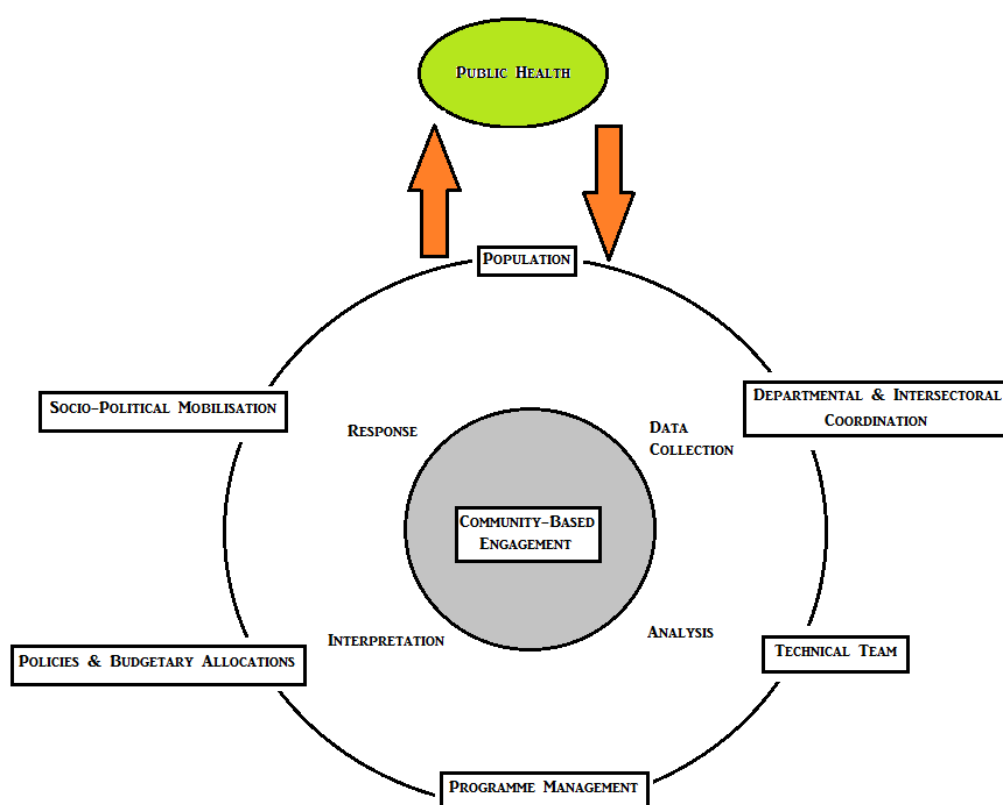
This section presents an alternative model for population-based surveillance of NCDs and NCDs risk factors for India. The model is based on insights from various surveillance models examined during the field visits and draws upon the feedback of various stakeholders regarding nature and strategies of an effective surveillance system.

Surveillance objective: To develop a population-wide system of data collection, analysis, interpretation and dissemination to empower decision makers to lead and manage the increasing burden of chronic NCDs in India.

Conceptual framework: The surveillance and response framework presented in Figure 1 is adapted from the basic notion of the two hemispheres of surveillance: data generation and data use (Nsubuga et al 2006). At the core of the framework is a community-based approach for surveillance. The framework calls for departmental and inter-sectoral coordination for production of surveillance data on critical aspects of public health. The framework identifies a significant role for the technical team in terms of data analysis and interpretation. The interpretation is further dependent on the capacities of the programme management who have a strong role in deciding upon policies and budgetary allocations for the concerned public health problem. The data is then expected to be disseminated with an expected response of greater socio-political commitment towards public health.

Indicators for surveillance: The WHO STEPS methodology is regarded as a standard approach for NCD and NCD risk factor surveillance. This methodology is particularly useful for countries who are aiming to initiate and establish a chronic disease and risk factors surveillance system. The STEPS methodology suggests data collection in three STEPS: Step 1 –behavioural information; Step 2 –physical information and; Step 3 – biochemical information. Under each step, data collection on core items is mandatory whereas countries, depending on their resource and capacity, can choose to gather information for items mentioned under the expanded and optional list (Table 2).The WHO STEPS methodology classifies the risk factors into two categories namely behavioural and biological risk factors. Tobacco use, harmful alcohol consumption, unhealthy diet (including low fruit and vegetable consumption), and physical inactivity as major behavioural risk factors whereas overweight and obesity, raised blood pressure, raised blood glucose, and abnormal blood lipid profile (including raised total cholesterol) are noted as major biological risk factors. These risk factors are selected for surveillance because through modification in these risk factors can have the greatest impact on chronic disease mortality and morbidity. Also, from surveillance perspective, information collection on these risk factors is relatively straightforward and their measurement is possible using appropriate ethical standards.

Figure 1: surveillance and response conceptual framework



Source: Adapted from surveillance and response conceptual framework in Nsubuga et al⁴ (2006)

Table 3: STEPS core, expanded and optional items for chronic disease surveillance

Step	Core Items	Expanded Items	Optional Items
<i>Step 1 - Behavioural</i>	Basic demographic information, including age, sex, literacy, and highest level of education ⁷	Expanded demographic information including years at school, ethnicity, marital status, employment status, household income	Mental health, intentional and unintentional injury and violence, oral health and sexual behaviours
	Tobacco use	Smokeless tobacco use	
	Alcohol consumption	Past 7 days drinking	
	Fruit and vegetable consumption	Oil and fat consumption	

⁴ Nsubuga et al (2006) Public health surveillance: A tool for targeting and monitoring interventions in D T Jamison et al (eds) Disease control priorities in developing countries, second edition, The World Bank and Oxford University Press, United States.

	Physical activity	History of blood pressure, treatment for raised blood pressure	Objective measure of physical activity behaviour
		History of diabetes, treatment for diabetes	
<i>Step 2- Physical measurements</i>	Weight and height, waist circumference, blood pressure	Hip circumference	Skin fold thickness, assessment of physical fitness
<i>Step 3 - Biochemical measurements</i>	Fasting blood sugar, total cholesterol	HDL-cholesterol and fasting triglycerides	Oral glucose tolerance test, urine examination

Source: WHO (<http://www.who.int/chp/steps/Part1.pdf> accessed on April 9, 2015)

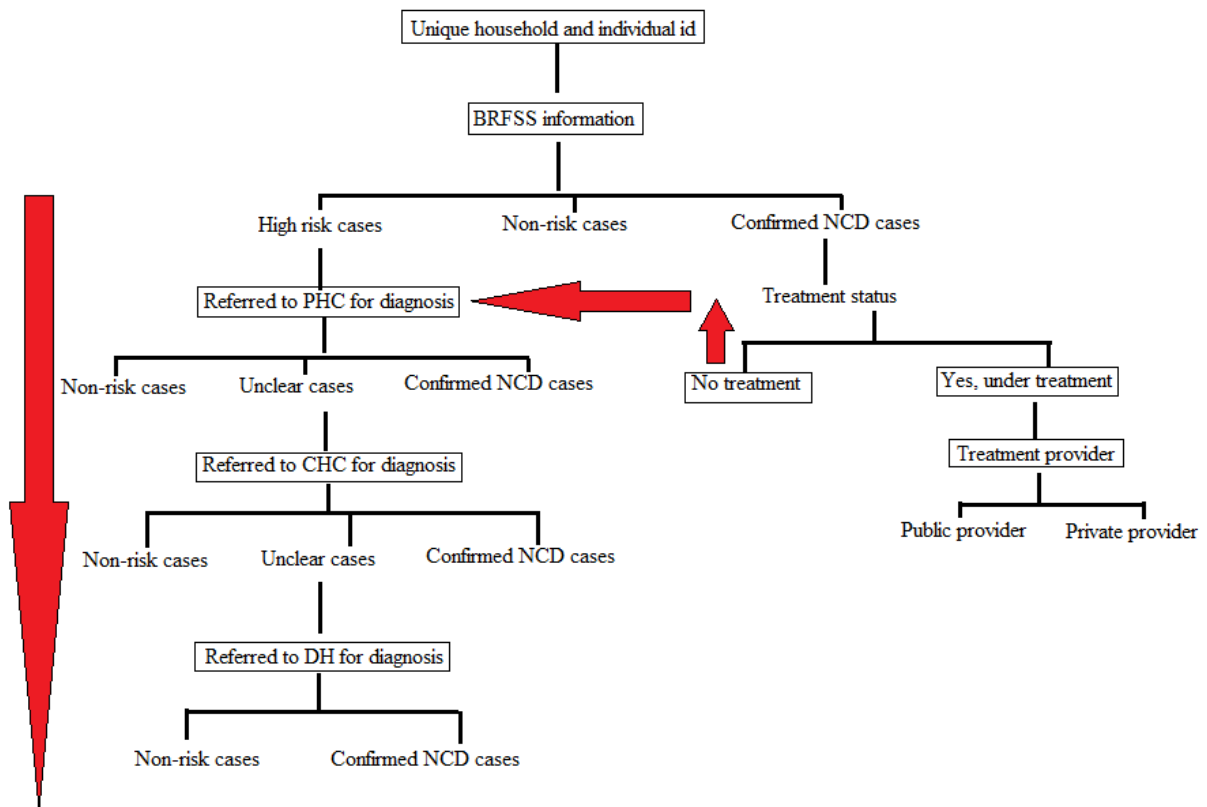
Surveillance strategy: Following the WHO STEPs approach the surveillance strategy can have two stages:

- Stage I: Population based behavioural risk factor assessment
 - Stage I should be a component of surveillance will be an annual home-based population wide surveillance for NCDs related behavioural risk factor assessment of all individuals aged 30 and above. The process is required to serve as a mapping exercise and is expected to come up with the number of cases with or at risk of NCDs.
 - State-specific approach may be devised by considering aspects such as cost and human resources requirement. However, it is suggested that this activity may be conducted in collaboration with volunteers (with secondary education) and enrolled from higher secondary schools, colleges and the community who should be provided with three-day training on behavioural risk factor assessment related to NCDs.
 - The activity planning can be carried out at the block level and volunteers can be assigned different villages for risk factor assessment. At the block level household identity number and patient identity number should be generated.
 - Overall a two-week work plan has to be generated included training of the volunteers and incentives and honorarium for the task should be considered for the activity. Community health workers of the concerned villages will be assigned with the task of supporting the risk-factor screening.
 - The volunteers will have to calculate the NCDs risk factor score, get information regarding treatment and care seeking status as well as inform the concerned person about clinical tests and diagnosis at the PHC level. The volunteers would be required to complete the behavioural risk factor assessment forms and compile the village level statistics and submit it to the Block Programme Manager.
 - This two-week community volunteers based process should be conducted annually.

- Stage II: Clinical tests and diagnostics of high risk cases
 - In Stage II, the role of community health workers is critical as they will be provided with the list of high risk cases identified for clinical tests and diagnosis at the PHC level for following up.
 - The unique identification number for the patient should be generated with adequate information retained by the system for ensuring a quick search for patient history in future visits.
 - At the PHC level clinical tests and diagnostics for diabetes and hypertension can be performed under the supervision of medical or AYUSH doctor.
 - The data on total screening, total high risk cases, total confirmed NCD cases, total cases aware of condition, total cases under treatment, total cases initiated treatment and total cases referred to higher facilities should be collected through an online data management system.
 - For selected higher level clinical tests the PHCs can refer the patient to CHCs and DHs. Community health workers should be asked to motivate regular visits and treatment follow-up.

At each facility the nature of information recorded by the system should be mutually exclusive. BPMs to generate block level unique household identity number based on information provided by concerned village panchayat or electoral rolls. Volunteers should be trained to add the individual serial number to the household identity number to generate patient identity. Volunteers should complete the behavioural risk factor assessment for each individual using a simple questionnaire and calculate the NCDs risk factor score, and report information regarding confirmed cases and treatment status. Data entry to be performed by data entry operator provided by the system or volunteer contribution can be considered depending upon financial, technical and human resources constraint. List of high risk cases to be generated from the system to be transferred to PHCs and SCs for recording. Individuals currently unaware about their NCDs status should be motivated by community health workers and volunteers for visiting PHCs for clinical tests and diagnostics. Alternatively, village level camps may be organised to facilitate the basic diagnostics. The PHCs have to meet the annual target by conducting clinical investigations for all the reported number of high risk cases. The data reported by the PHCs should be the total number of cases, tests conducted and the outcomes. Besides, a unique identification code has to be generated at PHC level and a NCD card has to be issued for referral purposes. The CHCs and DHs will be required to maintain data only for specialized clinical investigations and would be required to report the number of cases referred, patients received, tests conducted and outcomes.

Figure 2: Information flow in the system



Model surveillance forms: Form 1

Form 1: Surveillance form for behavioural risk factor assessment

Block name:								Village code:					
Block code:								Household id:					
Investigator code and Date of investigation:								Any diabetic in your family: (Yes/No)					
Sl. No.	Name/ Aadhaar ID	Age/ Sex	Height (in cm) / Weight (in kg)	Fruit / Vegetable Diet	Physical activity	Tobacco	Alcohol	NCD Diagnosis		NCD Treatment		NCD score	High-risk case
								Diabetes	Hypertension	Diabetes	Hypertension		
1													
2													
3													
4													
5													
6													
7													
8													
9													
10													

*Use additional sheets if required.

Table 4: NCD risk scoring algorithm for behavioural risk factor assessment:

Indicator	Score description
Any diabetic in your family	Yes – 20 points
Age	Above 60 years – 30 points 41-60 years – 20 points 30 – 40 years – 10 points
Weight	Female: Above 60 kg – 20 points 51 - 60 kg – 10 points 50 kg and below – 20 points Male: Above 65 kg – 20 points 51 - 65 kg – 10 points 50 kg and below – 20 points
Tobacco use	Yes – 20 points
Alcohol use	Yes – 20 points
Physical activity	Sedentary – 20 points Moderate – 10 points
Confirmed NCD case	60 points

NCD risk score cut-off: 60 points

Individuals with NCD risk score of 60 points and above will be classified as high risk case and will be referred to PHCs for clinical investigations. Also, those who are not receiving treatment for the diagnosed NCD cases will be referred to PHCs.

Surveillance system data points:

- | | |
|------------------------------|---------------------------------------|
| 1. State, District and Block | 9. Occupation |
| 2. PHC | 10. Social group |
| 3. SC | 11. Diabetes and treatment status |
| 4. Village | 12. Hypertension and treatment status |
| 5. Household id | 13. Cancer type and treatment status |
| 6. Patient id | 14. Stroke and treatment status |
| 7. Age and Sex | 15. Last visited and Last referral |
| 8. Education | |

Form 2 Items: Surveillance form for clinical assessment

Date of registration:

Name of the institution:

Patient identification code:

Socioeconomic background:

Name of the patient:

Age (in years):

Sex:

1. Male
2. Female
3. Transgender

Education:

1. Illiterate
2. Primary
3. Secondary
4. Higher

Occupation:

1. Farmer (own land)
2. Farmer (unskilled labourer)
3. Non-farm labour
4. Self-employed (vendors)
5. Self-employed (others)
6. Public sector employee
7. Private sector employee
8. Housewife
9. Unemployed
10. Others

Social group:

1. Scheduled tribes
2. Scheduled caste
3. Other backward class
4. Others

Religion:

1. Hindu
2. Muslim
3. Others

Address:

Behavioural factors:

Currently smoking tobacco

1. Yes
2. No

Currently chewing tobacco

1. Yes
2. No

Currently over-consuming alcohol

1. Yes
2. No

Physical activity:

1. Sedentary
2. Moderate
3. Heavy

Physical examination:

Height (cms):
Weight (kgs):
Waist (cms):
Systolic BP (mmHg): (at least 2 readings)
Diastolic BP (mmHg): (at least 2 readings)
Pulse (per minute):

Body mass index (kg/m²)

1. Underweight (below 18.5)
2. Normal range (18.5 – 24.9)
3. Overweight (25 – 29.9)
4. Obese (≥ 30)

Patient history:

Hypertension: Yes/No
Diabetes mellitus: Yes/No
Heart disease/Stroke: Yes/No
Chronic kidney disease: Yes/No
Joint pain/diseases: Yes/No
Cancer: Yes/No
Asthma/COPD/bronchitis: Yes/No

Family history:

Hypertension: Yes/No
Diabetes mellitus: Yes/No
Heart disease: Yes/No
Chronic kidney disease: Yes/No
Joint pain/diseases: Yes/No

Counseling on life style modification

Cessation of smoking/alcohol abstinence: Yes/No
Use of low salt: Yes/No
Restrict intake of red meat: Yes/No
Restrict fried food and use less oil: Yes/No
Restrict simple sugars: Yes/No
Increase green vegetables and fruits intakes: Yes/No
Avoid overeating: Yes/No
Increase physical activity: Yes/No
Avoid obesity: Yes/No
Reduce stress: Yes/No
Conduct regular diagnostic tests: Yes/No

Clinical investigations and diagnostics:

1. RBS mg/dl:
2. FBS mg/dl:
3. PPBS mg/dl:
4. Sr. Cholesterol mg/dl:
5. Sr. Creatinine mg/dl:
6. Blood Pressure: (2 readings)
7. Urine protein:
8. ECG/ECHO findings:

Referral details:

Angina / IHD / Heart failure
Dyslipidaemia
CVA / Stroke / TIA
ECG / ECHO abnormalities
Diabetic Neuropathy
Diabetic foot ulcer / foot care
Lack of BP / Blood glucose control
Others

Information for surveillance system:

Confirmed NCD case: (Year of diagnosis)

1. Diabetes mellitus (Yes/No):
2. Hypertension (Yes/No):
3. Cancer type (Yes/No):
4. Stroke (Yes/No)

Table 5: Domains for surveillance

Approach	Age group	Target	Method, frequency	Nodal agency
Population based surveillance	30+	Individuals	BRFSS, Biennial	State Health Dept.
Employment based	All	Employees	STEPS, Biennial	Employer
Employment based	All	Employees	BRFSS, Annual	Employer
School Health	6-14	Students	BRFSS, Annual	State Education Dept.
Higher education	15-21	Students	BRFSS, Annual	State Education Dept.
Population based	All	Individuals	Sample survey, Quinquennial	Central government
Opportunistic screening	30+	Patients, Relatives	BRFSS, health facility based	State Health Dept.
Programme based screening	30+	Target group	BRFSS, health facility and outreach based	State Health Dept.
Local level surveillance	30+	Individuals	BRFSS, Annual	State University
Old age homes	60+	Elderly	STEPS, Annual	Central government
Self-help groups	30+	Women	BRFSS, Annual	State government
Urban slums	30+	Individuals	BRFSS, Biennial	State Health Dept.

6. Requirements of financing, infrastructure, human resources and governance

6.1. Financing

- In 2015-16 there was a significant reduction in total approved outlay for various flagship programmes under the Ministry of Health and Family Welfare from INR 35,163 crore to about INR 29,653 crore. This has also impacted the overall approved outlay for NHM during the year 2015-16. NCDs are yet to receive any major attention under the NHM though in recent years the share of NCDs related programmes has increased from over one percent to over two percent (2.6%) of the total NHM budget. Expenditure related to the urban component of the mission (NUHM) and communicable disease programme have a share of seven percent each. Strict budgetary constraints also implies that States have received less funding for NPCDCS than what is demanded through the programme implementation plans. National Tobacco Control Programme (NTCP) is also another programme whose activities could be affected due to funding constraints. The total importance of these programmes in the overall scheme of NHM is also minimal as these programmes receive a much smaller share of the total budget. In 2014-15, the share of these two programmes in total NHM budget varied from 0.9% (Uttar Pradesh) to 2.2% (Kerala).
- Meanwhile there is a growing stress on households due to increasing out of pocket expenditures on chronic disease care. The National Sample Survey (2014) data informs of very high average medical expenditure for inpatient care related to cancer, CVD and stroke. In fact, around 30 % of total medical expenditure in India is incurred on seven chronic diseases (Cancer, Diabetes, CVDs, Stroke, Asthma, TB, and HIV) while rest 70 percent is on other diseases. In rural (urban) areas average expenditure on CVD and cancer constitutes 21% (25%) per cent of total medical expenditure.
- Central government and State governments should allocate more resources towards health sector in general and NCDs in particular. State government should adopt a pro-active approach to generate resources for the health sector. It should demonstrate a political will to allocate necessary resources to develop a functional health system and supporting infrastructure. The state should approach private sector and non-governmental organizations for resource mobilization and strategic partnerships in service delivery. States should consider allocating greater share of public health spending towards primary health care with a focus on health information on all major public health concerns and strengthening of primary prevention and population-based surveillance using cost-effective community-based models.
- It is important to strengthen the NPCDCS programme by providing additional funds for consistent implementation and further planning of outreach activities. Wherever practicable, future NPCDCS activities should seek to put in place contractual arrangements which facilitate timely, efficient and effective programme roll-out, without compromising transparency and accountability, and that ensure local government and implementing agencies responsibilities do not conflict. The choice of local NGOs or implementing agency

for any future NPCDCS activities should also take into account the ability of the agency to follow up on project implementation at the grassroots level.

- The States should also learn about efficient ways and means of sub-contracting processes such as community outreach and IEC activities including monitoring of partner efforts to build the capacity of local NGOs. This will also support the local NGOs to be able to implement future IEC activities independently. Pre-contract workshops and discussions with potential NGOs should be conducted to facilitate more inclusive and consultative contract negotiations.
- Establishment of district-level NCDs fund mechanism can be an effective strategy for capacity building and decentralization efforts. However, to make it efficient and effective, (i) more control of NPCDCS funds should be given to respective district health societies; (ii) make the procedures for NPCDCS fund simpler; (iii) put in place systems that will avoid delays in fund disbursement; and (iv) minimize the paperwork and reporting requirements. Alternative sources of contribution for the NPCDCS programme should be identified. As such, in many districts considerable NPCDCS funds are left unutilized and therefore efforts for its effective utilization are desirable.

6.2. *Human Resources*

- State governments should fill up all sanctioned posts on a priority basis including the programme funded HR positions. In this regard, a medium-term plan for about five years is necessary to have clear understanding regarding the positions which will be continued to be funded by the central government. HRH management is a neglected aspect in the design of the national programmes. In this regard, it is critical to put in place management systems for regular and timely recruitment, performance appraisal, rational salary scales, monetary and non-monetary incentives as well as greater assurance for a career in a public health by strategic planning and long-term vision for integration of the contractual staff in the state health system.
- Recruitment of one more community health worker for primary prevention and screening activities is critical. This position can be of a male community health worker who in addition to the existing ASHA worker can be entrusted with task of community mobilization, follow-ups and screening for risk factors. Recruitment of community health worker for urban areas is also desirable as a significant share of the incidence of NCDs is likely to be in urban areas.
- Creation of public health cadre with sub-divisions a) public health doctors b) health sector managers and c) data and research wing is critical. Such cadre can have required skills for planning, implementation, capacity building, data management and evaluation of the health policies and programmes. There needs to be a greater emphasis on capacity building and skill development of AYUSH doctors for their utilization in NCDs programme with involvements in the areas of screening, primary prevention, and early treatment.
- A more formal system for recruitment of community health worker based on education and training certification should be devised. Regular monitoring and support to community

level health workers is critical to ensure service delivery and to replace non-functional health workers at the local level. A database for community level health workers should be created to facilitate timely and systematic recruitment, training and capacity building.

6.3. Infrastructure

- Use of ICT platform for NCD surveillance (screening and data management) is important. States should increase computerization of facilities with adequate IT infrastructure and manpower for enabling data capture and transmission to higher levels. Standard features of data portal such as dash board and query builder should be integrated.
- Improved accessibility through the provision of infrastructure both large and small scale through NPCDCS can prove significant in improving primary prevention and surveillance activities in rural areas. It is recommended that improvement of CHCs and PHCs should be emphasized and given importance in future NPCDCS activities.
- Screening and prevention of NCDs needs integration with tertiary-level institutions for continuity of care. There is a gap of such institutions and specialists in high-focus districts of Rajasthan and Uttar Pradesh. Arrangement for referral transport and communication between the two facilities should also be improved.
- There is a need to improve data management and reporting for outpatient and inpatient attendance with at least disaggregated recording by gender and age and for the nature of ailment. This huge data base and can provide a reasonable starting point for a passive surveillance of NCDs.
- NCDs surveillance should be strengthened by improving epidemiological understanding of the diseases and by collection of robust screening data through national programmes such as NPCDCS or through morbidity and mortality reports from the hospital management information systems of both public and private sector hospitals. This information can feed into programme management and policy discussions.

6.4. Governance

- States and districts should work to ensure greater inter-sectoral convergence. At a local level such convergence should be in the areas of health, school education, sports, and law and order at the grass root level. At the district and state level, convergence between health department and industrial organizations is recommended for IEC, screening and primary prevention activities.
- Regular review meetings of the programme management unit on NCD programmes is necessary for sensitizing senior officials regarding the needs and concerns and also to discuss strategies for resource allocations and activity planning. Senior officials should also not be burdened with management and coordination of multiple programmes.
- Linkages with schools are an important aspect of IEC activities for primary prevention of NCDs. Awareness through screening, identification and management of chronic illnesses among students, teachers and parents should be encouraged. Community health workers

and local health providers at the PHC level should be entrusted with follow-up activities and accountability, respectively.

- Gender sensitivity in screening, prevention and treatment activities is important and should be made part of quality management protocols. This also includes sensitizing and training the service providers on gender concerns and gendered patterns of certain chronic NCDs such as cervical and breast cancer.
- State governments should link all the existing economic and social welfare programmes for the elderly with the health sector to facilitate exchange of data and information and also to promote prevention and early treatment of NCDs. Community-based activities should promote elderly clubs for information dissemination on aspects of NCDs and to discuss about the various benefits and components under the NCDs programmes.
- Avoid overdependence on the implementation of activities through technical partners who are not financed and not controlled by the NPCDCS programme.

6.5. Overall conclusions

Chronic disease risk factors, morbidity and mortality surveillance is at a nascent stage in India. Mainly, the attempt is supported by donor funding and desires greater financial and technical support from the State and Central Governments. Although, there have been a number of household surveys and surveillance studies to understand the trends and patterns in prevalence of NCDs and NCDs risk factors but none of these can be truly regarded as a surveillance system as most of them lack continuity and have limited role in strategic planning and action. Besides, there are a number of challenges related to quality of the data, nature of information and its representativeness. Given such intricate concerns, it is important that greater ownership and use of data by Central and State governments is encouraged as it can be useful and self-sustaining mode to develop a robust surveillance system. In fact, the State health systems should integrate core components of prevention, surveillance, screening and management at primary and secondary level.

Also, capacity of health providers including public health nurses and staff at primary health centre and health sub-centres should be strengthened by imparting training in prevention and management of NCDs. As such, most of the chronic disease surveillance studies in India have been site-specific or State-specific and with good dissemination strategy at State level this could be demanded for strategic planning at State level. Efforts should be made to encourage use and discussion around such information for planning or promoting of initiatives by the legislative assembly or by concerned elected representatives. This can help generate a greater degree of public awareness thereby translating into better coping and prevention in the community. Based on the review, the final section of this paper lists some of the key recommendation with respect to financing, infrastructure, human resources and governance for the surveillance strategies in India.

7. Major recommendations

1. **Increasing investment for NCDs surveillance:** It is necessary to increasing public spending for health sector in general and a fair amount of resources needs to be devoted for strengthening the existing screening and surveillance system. This is also a productive investment, if the screening activities are able to identify NCD cases and reverse or delay onset of multiple morbidities. In this regard, state governments should adopt a pro-active approach to generate resources for the health sector. It should demonstrate a political will to allocate necessary resources to develop a functional population-based surveillance system and supporting infrastructure. The State should reach out to the private sector and NGOs for resource mobilization and strategic partnerships in surveillance.
2. **Strengthening ICT and HMIS platform:** Use of information and communication technology (ICT) platform for NCD surveillance (screening and data management) is important. States should increase computerization of facilities with adequate IT infrastructure and manpower for enabling data capture and transmission to higher levels. A cross cutting recommendation was that HMIS across all the hospitals and laboratories engaged in diagnostics should be integrated to gather information about the patient ailments and to monitor incidence across hospitals through a nationwide HMIS system.
3. **Linkage with School Health Programmes:** School Health Programmes can help in screening activities at a community level. Schools have good geographic spread and coverage of population. Even with the existing infrastructure it is feasible to engage schools in supporting surveillance activities. A direct benefit of such initiative would be observed in the form of greater awareness on NCDs and its impact on primary preventions. Similarly school-based NCDs screening and awareness models have been operated by NGOs in other states of India. These volunteers can also work on a mapping and screening exercise to understand village health status while implementing various community interventions.
4. **Involvement of AYUSH in NCDs screening and surveillance:** There needs to be a greater emphasis on capacity building and skill development of AYUSH doctors for their utilization in NCDs programme with involvements in the areas of screening, primary prevention, and early treatment. With increasing demand of AYUSH for the management of chronic ailments it is advisable to develop a cadre of AYUSH specialists who can be posted at PHCs, CHCs as well as district hospitals. AYUSH practitioners should further be considered for training and certification in skills related to NCDs screening and prevention activities.
5. **Commitment of programme officials, managers and technical staff:** Programme managers and officials need further support, motivation and self-recognition to display greater intent to work for surveillance. The current challenge thus is to find motivated programme managers, officials and technical staff who have passion or public health surveillance and display greater commitment towards collection, classification, storage, retrieval, analysis and presentation of surveillance data.
6. **Recruitment of additional community health worker:** Recruitment of one more community health worker for primary prevention and screening activities is critical. This

position can be of a male community health worker who in addition to the existing ASHA worker can be entrusted with task of community mobilization, follow-ups and screening for risk factors. Recruitment of community health worker for urban areas is also desirable as a significant share of the incidence of NCDs is likely to be in urban areas.

7. **Designing behavioural risk factor surveillance system:** Behavioural risk factor surveillance system (BRFSS) is defined as an active system of repeated surveys to measure health behaviours that are known to cause certain diseases. This information can be used for designing intervention programme for preventing onset or reducing the incidence of such diseases. India should develop a community based Behavioral Risk Factor Surveillance System (BRFSS) to collect data on health-related risk behaviours and chronic health conditions on a regular (annual) basis. Community health workers (ASHAs or male health worker) can be the key HR in this exercise supported by a robust ICT system for data management. The availability of such data can prove effective for targeting and building health promotion activities.
8. **Inter-sectoral convergence and engaging private/NGO sector:** NCD surveillance should not remain within the boundaries of health department and other governmental departments as well as private and the NGO sector should be involved in surveillance activities. The panchayat meetings can also be a useful platform for promotion of surveillance activities and for information sharing to gain cooperation for population-wide surveillance in rural areas. Gender sensitivity in screening, prevention and treatment activities should be made part of quality management protocols.
9. **Towards comprehensive primary health system:** The directorate of health services is entrusted with all aspects of primary health care and has a major focus on provision of community based maternity and child health services including family welfare but areas such as prevention and control of NCDs and positive behaviour change through universal primary health care is a neglected aspect of the primary health system in most of the states. This is an area which may require greater hand-holding by technical partners. In this regard, there should be a clear demarcation of responsibilities as envisaged under primary, secondary and tertiary level care. The administrative structure and programme strategies of the public health system are also oriented towards reproductive and child health. This implies that conception of strategies will also require re-examining the needs and priorities associated with NCDs.
10. **Creation of public health cadre:** Creation of a separate public health cadre is an important governance challenge at the state level. This will ease out the administrative, teaching and clinical roles of the health officials and will allow scope for improving programme management through development of professional expertise. This will further attract medical professionals towards public health. Currently, there is a lack of capacity to carry out policy formulation and planning at the state levels. Also, the medical officers are reluctant in community interaction and are disinterested with increasing burden of administrative tasks. Such issues lead to a clear divergence between the National NCD Policy and delivery mechanism at the grass root level.

Annexure

Table 1A: Profile of the selected states

Indicator	Kerala	Rajasthan	Tamil Nadu	Uttar Pradesh	Sources
Infrastructure					
Sub-Centres (SC)	4575	14407	8706	20521	<i>Rural Health Statistics, 2013-14</i>
PHCs	829	2082	1369	3497	
CHCs	224	567	385	773	
Mobile Medical Units	17	52	385	133	
% PHC with electricity	100%	89%	100%	94%	
% PHC with water supply	100%	85%	100%	92%	
% CHCs with functional X-Ray machine	13%	66%	58%	46%	
Demographic indicators					
Districts	14	33	32	75	<i>Rural Health Statistics, 2013-14</i>
Villages	1018	44672	15979	106704	<i>Statistics, 2013-14</i>
Total population	33406061	68548437	72147030	199812341	
% Rural population	52.3%	75.1%	51.6%	77.7%	<i>Census of India, 2011</i>
Population density	860	200	555	829	
Crude birth rate	14.7	25.6	15.6	27.2	
Crude death rate	6.9	6.5	7.3	7.7	
Infant mortality rate	12	47	21	50	
Human resources					
Vacant position: Doctors (PHC)	-	451	473	2300	<i>Rural Health Statistics, 2013-14</i>
Vacant position: Specialists (CHC)	-	860	-	1615	
Vacant position: Radiographers (CHC)	-	515	153	304	
Vacant position: Pharmacists (PHC/CHC)	-	668	214	69	
Vacant position: Lab Tech. (PHC/CHC)	-	1204	792	368	
Financing					
Per capita health expenditure by central and state governments 2009-10	580	457	580	373	<i>Chowdhury & Amar Nath (2012)</i>
Average total medical expenditure for treatment per hospitalisation case	16775	13976	18006	22540	<i>NSSO 2014</i>

Table 2A: Key chronic NCD indicators for Kerala and Tamil Nadu, DLHS 2012-13

Indicator	Place	Kerala	Tamil Nadu
Reported prevalence of chronic illness (%)	Total	7.0	3.9
	Rural	6.9	3.8
	Urban	7.0	4.0
Reported prevalence of respiratory disease (%)	Total	14.0	12.8
	Rural	15.3	12.4
	Urban	12.6	13.2
Reported prevalence of cardiovascular disease (%)	Total	14.5	5.1
	Rural	15.8	5.6
	Urban	13.0	4.6
Reported prevalence of tuberculosis (%)	Total	0.6	0.9
	Rural	0.6	1.1
	Urban	0.5	0.6
High blood sugar level (>140mg/dl) for age 18 and above (%)	Total	24.7	13.0
	Rural	24.5	11.3
	Urban	24.9	14.8
Hypertension (Systolic >140 mm of Hg & Diastolic >90 mm of Hg) for age 18 and above (%)	Total	34.5	22.3
	Rural	36.6	20.7
	Urban	32.0	24.0

Source: Factsheet, District Level Household and Facility Survey 2012-13 (DLHS - 4), IIPS, Mumbai.

Table 3A: Key chronic NCD indicators for Rajasthan and Uttar Pradesh, AHS 2012-13

Indicator	Place	Rajasthan	Uttar Pradesh
Diagnosed for any kind of chronic illness (%)	Total	4.3	10.6
	Rural	3.8	10.8
	Urban	5.8	10.1
Diagnosed for asthma or chronic respiratory disease (%)	Total	0.7	0.9
	Rural	0.7	0.9
	Urban	0.6	0.8
Diagnosed for tuberculosis (%)	Total	0.2	0.3
	Rural	0.2	0.4
	Urban	0.2	0.3
Diagnosed for diabetes (%)	Total	0.4	0.5
	Rural	0.2	0.3
	Urban	1.1	1.0
Diagnosed for hypertension (%)	Total	0.8	0.8
	Rural	0.6	0.6
	Urban	1.6	1.2

Source: Factsheet, Annual Health Survey 2012-13 (AHS), Office of the Registrar General of India, New Delhi.

Table 4A: Performa for reporting NCD clinic at district hospital under NPCDCS

Form -3 B							
National Programme on Prevention & Control of Cancer, Diabetes, CVD & Stroke							
Reporting Performa for NCD Clinic at District Hospital							
District Hospital:	District:	State:	Year:	Month:			
Indicator		During the Reporting Month			Cumulative during the year		
		Male	Female	Total	Male	Female	Total
No. of persons attended NCD Clinic							
No. of persons attended NCD Clinic							
Patients diagnosed with	Diabetes						
	Hypertension						
	Cardiovascular Disease						
	Cancer						
No. of persons referred to Medical College/ Tertiary Hospital	Diabetes						
	Hypertension						
	Cardiovascular Disease						
	Cancer						

Source: pbhealth.gov.in/NPCDCS-NCD%20Clinic%20at%20CHC.xlsx (accessed on Sep. 4, 2015)

Table 5A: Performa for reporting NCD clinic at CHC under NPCDCS

Form -2 B								
National Programme on Prevention & Control of Cancer, Diabetes, CVD & Stroke								
Reporting Performa for NCD Clinic at Community Health Centre								
Name of the CHC:		Block:	District:	State:	Month & Year:			
Indicator			During the Reporting Month			Cumulative during the year		
			Male	Female	Total	Male	Female	Total
No. of persons attended NCD Clinic								
Patients diagnosed with	Diabetes							
	Hypertension							
Persons with suspected Cardiovascular Disease								
Persons with suspected Cancer								
No. of persons referred to District Hospital								
No. of Home Visits made								

Source: pbhealth.gov.in/NPCDCS-DH.xlsx (accessed on Sep. 4, 2015)

Table 6A: NPCDCS guidelines regarding reporting of programme information

Level	Reporting Form	Person in charge	Reporting to:	Frequency of submission
Sub-centre	Form 1	ANM/MHW	MO I/c NCD Clinic CHC	Monthly
CHC	Form 2 A	MO I/C NCD Clinic	District NCD cell	Monthly
	Form 2 B	MO I/C NCD Clinic	District NCD cell	Monthly
District	Form 3 A	DPO (NCD)	State NCD cell	Monthly
	Form 3 B	MO I/C NCD Clinic	District/ State NCD cell	Monthly
	Form 3 C	DPO (NCD)	State NCD cell	Monthly
State	Form 4 A	SPO (NCD)	National NCD cell	Quarterly
	Form 4 B	SPO (NCD)	National NCD cell	Quarterly

Source: NPCDCS Operational Guidelines, MoHFW.

Note: MO I/C – Medical Officer In Charge; DPO – District Programme Officer; SPO – State Programme Officer; ANM – Auxiliary Nurse and Midwives; MHW – Male Health Worker

Table 7A: Number of districts and institutions under NPCDCS Kerala, 2014-15

District \Centres	CHCs	PHCs	SCs
Pathanamthitta	13	43	261
Alapuzha	16	56	366
Idukki	14	40	309
Thrissur	26	79	471
Kozhikode	16	62	419
Kannur (newly proposed)	10	83	411
Malappuram (newly proposed)	21	84	591
Total	116	447	2828

Source: Kerala State Programme Implementation Plan 2014-15.

Table 8A: Number of districts and institutions under NPCDCS Rajasthan, 2014-15

Districts	DHs	CHCs	PHCs	SCs
Bhilwara	1	18	69	540
Jaisalmer	1	07	17	169
Jodhpur	1	19	70	673
Bikaner	1	10	46	433
Nagour	1	22	93	841
Shri Ganganagar	1	12	46	428
Barmer	1	16	69	760
Alwar	1	28	79	728
Tonk	1	7	48	308
Baran	1	9	40	269
Banswara	1	17	42	470
Bharatpur	1	14	59	405
All	12	179	677	6024

Source: Rajasthan State Programme Implementation Plan 2014-15.

Table 9A: Number of districts and institutions under NPCDCS Uttar Pradesh, 2014-15

Districts	DHs	CHCs	PHCs	SCs
Agra	1	16	45	383
Aligarh	1	13	35	333
Allahabad	1	20	60	551
Ambedkar Nagar	1	10	43	390
Bahraich	1	16	49	310
Barabanki	1	17	53	353
Bareilly	1	15	50	398
Etawah	1	8	27	162
Faizabad	1	11	28	257
Farrukhabad	1	10	26	192
Firozabad	1	7	57	220
Gonda	1	16	50	322
Gorakhpur	1	15	11	529
Hardoi	1	19	57	432
Jalaun	1	6	36	277
Jhansi	1	6	38	326
Kannauj	1	11	27	188
Kanpur Nagar	1	10	35	391
LakhimpurKheri	1	11	54	386
Lalitpur	1	5	24	191
Lucknow	1	9	28	323
Meerut	1	12	31	315
Mirzapur	1	16	35	251
Moradabad	1	3	5	271
Raebareli	1	13	42	268
Sitapur	1	14	66	468
Sultanpur	1	10	43	390
Varanasi	1	7	28	306
All (28 districts)	28	326	1083	9183

Source: Uttar Pradesh State Programme Implementation Plan 2014-15.

Table 10A: Proposed and approved budget for NPCDCS and NTCP under NHM State Programme Implementation Plan, 2014-15

States	Proposed budget (in Rs. Cr)			Approved budget (in Rs. Cr)			% Approved	% NHM Budget
	NPCDCS	NTCP	Both	NPCDCS	NTCP	Both		
Kerala	54.8	0.87	55.7	11.2	1.42	12.6	22.6%	2.2%
Rajasthan	67.0	6.65	73.6	21.2	2.36	23.5	31.9%	1.2%
Tamil Nadu	59.0	3.1	62.1	11.8	1.22	13.0	20.9%	1.1%
Uttar Pradesh	133.0	12.1	145.1	30.9	4.73	35.7	24.6%	0.9%

Source: NHM State Programme Implementation Plans 2014-15 (Main and Supplementary).

Note: Total NHM state programme implementation plan budget approval (in Rs. Crores) for 2014-15 are as follows; Kerala 569.35, Rajasthan 1930.87, Tamil Nadu 1236.59, and Uttar Pradesh 3832.16.

Figure 1A: NCD clinic treatment card and register at sub-centre level in Kerala

ADVICE	
Date	Advice

NCD CONTROL PROGRAMME

TREATMENT CARD

Name of District _____

Name of Panchayath _____

Name of CHC/PHC _____

Name of Sub Centre _____

Name of patient _____

Address _____

ID No.

1a: Page 1, NCD clinic patient card

[illegible]

1b: Page 2, NCD clinic patient card

[illegible]

1c: Sub centre NCD clinic register

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