National Diabetes Registry in Sweden
A literature review suggesting the implications for preventive healthcare approach towards diabetes in India

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Dr. Nimrat Kaur

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Dr. Monika Chaudhary

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Abstract

Diabetes has been a growing challenge for the entire world in this era of developing 21st century. The number of patients with type 2 diabetes is increasing rapidly in both developed and developing countries around the world. The emerging pandemic is driven by the combined effects of population ageing, rising levels of obesity and inactivity, and greater longevity among patients with diabetes that is attributable to improved management and early diagnosis using a single patient diseases registry. For India alone, the prevalence rate of diabetes worldwide is set to increase from 387 in 2014 to an alarming figure of 592 by 2035.

Diabetes is a major global cause of premature mortality that is widely underestimated, because only a minority of persons with diabetes dies from a cause uniquely related to the condition. Rising economic burden on the patient and the government also requires expert intervention. This review summarizes the burden of type 2 diabetes both globally and in India, gives the details of Diabetes care in Sweden specially focusing on the National Diabetes Registry suggesting a similar framework for India at a country level by stating the challenges to be faced by India giving a brief reference to the existing diabetes registry states of Goa and Puducherry.

Table of contents

List of tables

List of figures

List of abbreviations

DM	Diabetes Mellitus
BMI	Basal Metabolic Index
BP	Blood pressure
CAD	Coronary Artery Disease
CHC	Community health centre
CHD	Coronary heart disease
DALY	Disability adjusted life year
DCCT	Diabetes control and complications trial
eGFR	Estimated glomerular filtration rate
EHR	Electronic health record
EMR	Electronic medical record
GDP	Gross Domestic Product
HbA1C	Haemoglobin A1c
HDL	High density lipoprotein
HMIS	Health management information system
ICMR	Indian council of medical research
ICT	Information communication technology
IDF	International Diabetes Federation
IEC	Information education communication
IHME	Institute of Health Metrics and Evaluation
LDL	Low density lipoprotein
MoHFW	Ministry of Health and Family welfare
NCD	Non-communicable diseases
NPCDCS	National Program for Prevention and Control of Diabetes, Cardiovascular diseases and Stroke
OECD	Organization of economic cooperation and development
OGTT	Oral glucose tolerance test
OHA	Oral hypoglycaemic agents
OOP	Out of pocket (expenditure)
PHC	Primary health care
PHR	Personal health record
PVD	Peripheral vascular disease
QALY	Quality adjusted life year
RC	Centre of registers
RCH	Reproductive and child health
T2DM	Type 2 diabetes mellitus
UHC	Urban healthcare centre
UID	Unique identification number
UIDAI	Unique identify authority of India
UKPDS	U.K prospective diabetes study

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A literature review suggesting the implications for preventive healthcare approach towards diabetes in India

Aim of the study

Review of NDR in Sweden to propose Preventive healthcare towards Diabetes in India.

Objectives

1. Reviewing the NDR model of Sweden in order to combat Diabetes in Sweden

2. Deriving the lessons learned from NDR model of Sweden and replicating it for preventive approach towards Diabetes in India.

Background

“Diabetes mellitus (DM) is a disease of the metabolic system characterized by hyperglycemia. It is associated with abnormalities in carbohydrate, fat, and protein metabolism, and results in chronic complications, including retinopathy, nephropathy, and neuropathy (micro vascular) and ischemic heart disease, peripheral vascular disease, and cerebrovascular disease (macro vascular), resulting in organ and tissue damage in approximately one third to one half of people with diabetes’’ (1)(2). This set of disorders was first recognized by ancient Egyptians around 1500 B.C who defined it as a rare condition in which a person urinates excessively (mostly at night), feels thirst and loses weight. Aretaeus, a Greek physician, somewhere between 80-138 C.E., described the ‘sweet’ nature of urine excreted by diabetic individuals (3). Much of the present knowledge about diabetes, its complications and recent trends in its treatment are highlighted by a Dr. Joslin, a U.S physician, considered as a pioneer in diabetes (4).

Over the past two decades, the prevalence of diabetes has risen dramatically. Current numbers, as per the statistics available by International Diabetes Federation, say that about 415 million people are suffering from diabetes in the world and for upcoming year of 2040, this number would approximately rise up to be 642 million (5). Type2 Diabetes Mellitus (T2DM) is becoming a worldwide crisis that threatens the health and economy, in particular that of developing countries as it is one of the main chronic diseases currently affecting the humankind, regardless of socioeconomic status and geographic location with an increased risk of vascular disease in future. There is substantial evidence that it is changing into an epidemic in many low- and middle-income

countries. Come 2025 and there would be more than 75% diabetics residing in the developing countries like India and China, beating the numbers in USA (IDF Report 2014)

Diabetes and India

India, home to 1.324 billion people - 2nd most populated country in the World after China **1.379 billion** (2016 World Bank data), is country of great diversity in the context of landforms, culture and traditions. From dealing with rampant communicable diseases some decades back, India is now burdened with the rising trend of Non-Communicable Diseases. Following WHO data on Non-communicable disease profile for India (2014) justifies the above statement.

1. Percentage of Population Living in Urban Areas: 31.3%
2. Population Proportion Between Ages 30-70 Years: 40.1%
3. Life Expectancy at Birth Male/Female (Years 2015): 67/70
4. Probability of Dying Between 15-60 Years of Age M/F (Per 1000 Population 2015):216/142
5. Total Expenditure on Health Per Capital (2014): 267
6. Total Expenditure on Health As %Ag Of GDP (2014): 4.7

Table 1: Proportion mortality (%age of total deaths, all ages, both sexes)

Cause of Death	Proportion of mortality
Communicable diseases, maternal, perinatal and nutritional conditions	**28%**
Cardiovascular diseases	**26%**
Chronic respiratory diseases	**13%**
Other NCD's	**12%**
Injuries:	**12%**
Cancers	**7%**
Diabetes	**2%**

Total deaths estimate were approximately 98lakhs in 2014 and NCD's accounted for 60% of them. As per IDF data for 2015, India had 69.2 million people living with diabetes which is 8.7% prevalence rate and out of these, 36 million remained undiagnosed. Deaths due to diabetes were 346000(3.3 % of total deaths in 2015) with an annual increase of 2.7% from 1990, according to the Global Burden of Disease study. More alarming fact was that 55% of these deaths occurred in individuals aged <60years and 27% in age <50 years (5).

Geographically, the prevalence of diabetes has been studied by many expert groups. The extreme locations contribute to variation in the prevalence rate not only across the length and the breadth of the sub-continent but, also across rural and urban areas of the country. "An ICMR study revealed that a very lower proportion of the population is affected in states of Northern India (Chandigarh 0.12 million, Jharkhand 0.96 million) as compared to Maharashtra (9.2 million) and Tamil Nadu (4.8 million) (6). The National Urban Survey conducted across the metropolitan cities of India reported similar trend: 11.7% in Kolkata (Eastern India), 6.1% in Kashmir Valley (Northern India) (7). 11.6% in New Delhi (Northern India), and 9.3% in West India (Mumbai) compared with (13.5% in Chennai, 16.6% in Hyderabad and 12.4% in Bangalore (8). A suggested explanation

for this difference is that the north Indians are migrant Asian populations and south Indians are the host populations." (9) However, this possible cause-and-effect has not been corroborated through further research. "Similar ethnographic differences have been observed in indigenous and non-indigenous populations in countries colonized by the Great Britain: indigenous people from New Zealand and Australia have been shown to suffer from diabetes and cardio-metabolic disorders more than the non-indigenous people (10)(11). Further studies are required in India to highlight cultural and ethnic trends and provide a more complete understanding of the differences in diabetes etiology between Indian and other ethnic groups within India''.

Epidemiology of diabetes:

According to the International Diabetes Federation (IDF), the prevalence rate of diabetes worldwide is set to increase from 387 in 2014 to an alarming figure of 592 by 2035 (5).

"In the WHO South-East Asia Region, almost 9% of the adult population has diabetes which is the second highest prevalence after the Eastern Mediterranean Region (Global report on diabetes. Geneva: World Health Organization; 2016). With an adult population accounting for 86% of 883 million, India is experiencing an economic growth rate second only to China (5) and this economic growth brings urbanization and increasing life expectancy which is linked to the projected increases in regional diabetes prevalence to 10% by 2035."

Genetic predisposition combined with lifestyle changes associated with urbanization and globalization, contribute to the rapid rise of diabetes in India. "Ethnicity plays a role as well, and in one example, there are lower thresholds for the effect of BMI on age-adjusted T2DM prevalence rates among Indians."(12) With the rise in disease burden, the economic burden due to diabetes in India is among the highest in the world. "However, the real burden of diabetes is due to its micro- and macrovascular complications, which leads to increased morbidity and mortality. It is also

known that almost 50% of people with diabetes remain undetected and hence some may even present with both micro- and macrovascular complications at the time of diagnosis'' (5). It can be rightly said that the Individuals known to have diabetes represent the tip of the iceberg, as an equal or even larger number of patients have undiagnosed diabetes. Unfortunately, >50% of people with diabetes in India remain undiagnosed (13) and if diabetes is not detected early and treated adequately, there is a high risk for developing both macrovascular (CAD, cerebrovascular, and/or PVD) and microvascular disease (retinopathy, nephropathy, and neuropathy). Population data on micro- and macrovascular complications of diabetes are available in urban India. However, such data are not available in rural India. This is largely because diabetes remains a neglected field in rural areas, as awareness levels and accessibility to diabetes health care remains woefully inadequate. Although the prevalence of diabetes is lower in rural India, the number of patients with diabetes in rural areas is much higher. This is because >70% of the population in India live in rural areas, and half of these individuals are below the poverty line and continue to fight for survival and health, although all of this is rapidly changing due to economic development.

"Despite Health being a State subject in India, the Government has supported the States in prevention and control of NCDs through several vertical programs since 1980s. However, during the 11th plan, there was considerable upsurge to prevent and control NCDs. New programs were started on a low scale and in limited number of districts. Nonetheless, there has not been any considerable change in the burden of NCDs. Based on experiences in the past, there is need to emphasize on health promotion and preventive measures to reduce exposure to risk factors. Facilities and capacity for screening, early diagnosis and effective management are required within the public health care system. Public awareness program, integrated management and strong

monitoring system would be required for successful implementation of the program and making services universally accessible in the country" (14).

Economic burden of diabetes in India

Diabetes is an expensive disease and the assessment of the economic impact of diabetes in India is important because according to an article published in 2007 (15), an estimated USD 2.2 billion is needed to sufficiently treat all cases of type 2 diabetes in India. Secondly, by 2025, most of the diabetics in the developing countries will be in the age group of 45-64 years thus threatening the economic productivity of the country and the income-earning ability of individuals (16). Thirdly, the management of diabetes of diabetes and prevention of its complications can be expensive posing a somber obstacle for the Indian healthcare system to strengthen the Government's plan to achieve universal health coverage by 2022.

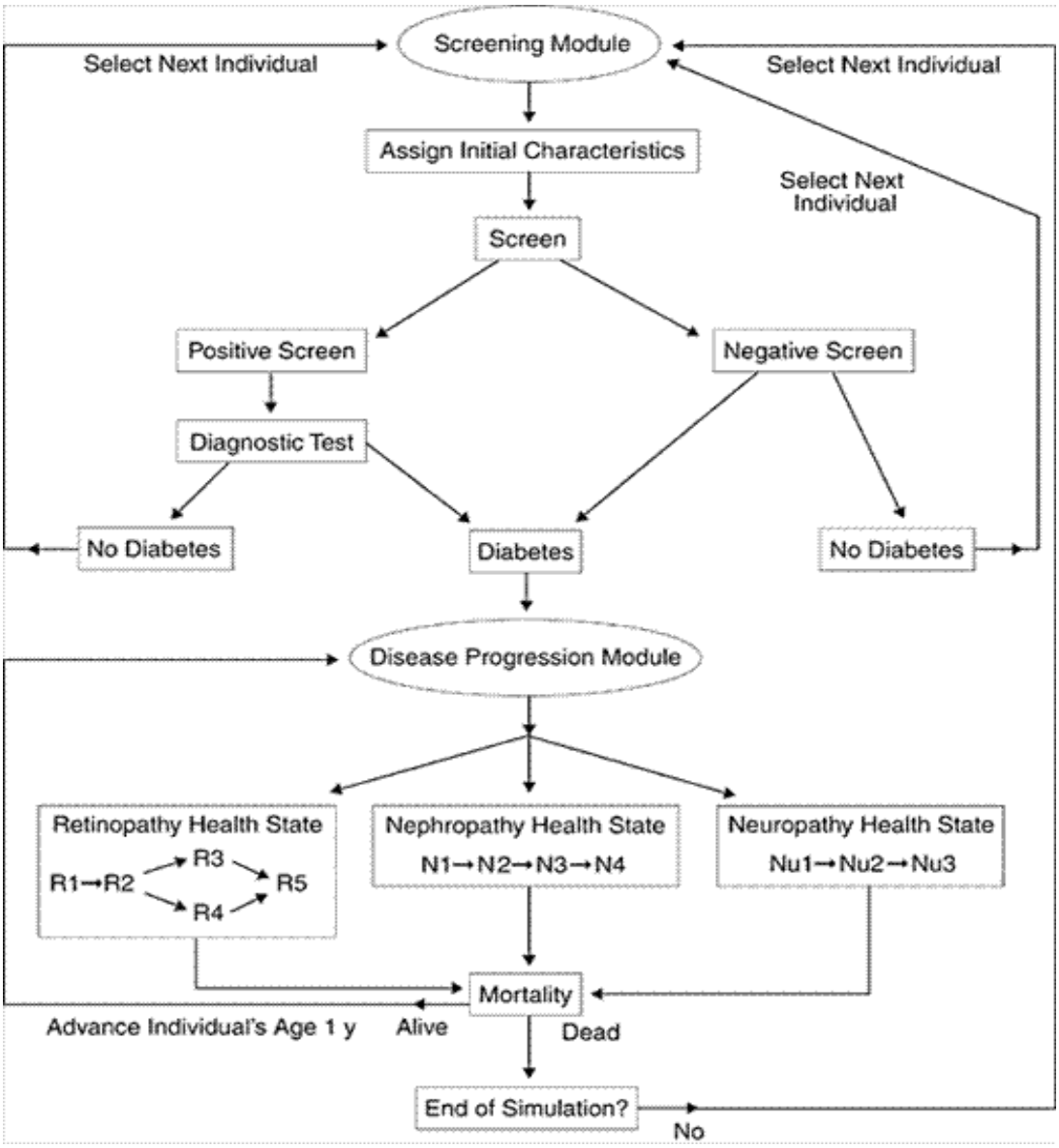
A cost-effectiveness study on screening for type 2 diabetes was conducted on a theoretical cohort of 10,000 persons with newly diagnosed diabetes from the general US population (17). "The objective of this study was to estimate the cost effectiveness of early detection and treatment of type 2 diabetes.'' The methodology involved developing a Monte Carlo computer simulation model (figure 1) to estimate the lifetime cost and benefits of 1-time opportunistic screening (performed during routine contact with the medical care system) for type 2 diabetes and compare them with current clinical practice. The results of the study concluded that screening is more cost effective and early diagnosis and treatment through opportunistic screening of type 2 diabetes may reduce the lifetime incidence of major microvascular complications and result in gains in both life-years and Quality Adjusted Life Years (QALY's).

Table 2: IHME report 2013

NCD	DALYs	% of total DALYs	Deaths	% of total deaths
CVD (including coronary heart disease and stroke/ischemic heart disease)	48,793,600	9.4	2,095,930	21.1
Chronic respiratory disease (including asthma; chronic obstructive pulmonary disease [COPD]; and occupational lung diseases, such as chronic bronchitis or emphysema)	35,880,300	7.0	1,176,740	11.8
Cancer (including lung; lip/oral cavity and other pharynx-related cancers; and cervical, breast, and ovarian cancers)	19,094,000	3.7	663,032	6.7
Diabetes	**7,968,930**	**1.5**	**223,999**	**2.2**

The above table is from Institute for Health Metrics and Evaluation, 2013. "The report also mentions that between 1990 and 2010, the annual number of DALY's attributable to diabetes in India nearly doubled from about 4.1 million to nearly 8 million. Meanwhile, the annual number of deaths due to diabetes in the country increased more than twofold, from about 100,000 in 1990 to 223,999 in 2010 (IHME 2013). While the contribution of diabetes to overall DALY's in the above table is substantially lower than CVD and COPD, most of the morbidity and mortality for people living with diabetes is ultimately due to CVD's." This again proves that screening of Diabetes is the need of the hour to be realized by the MoHFW India and a robust National Level Diabetes Registry to be developed focusing on screening of pre-diabetics and diabetics.

Figure 1: Monte Carlo simulation model



Based on this Monte Carlo simulation model, a similar model can be replicated for NDR in India as it will prevent duplication of data and incorporate the complications history of the patient as well. Assigning initial characteristics would include assigning unique patient identification number.

Sweden: Demographics and Health

Sweden, officially the Kingdom of Sweden, is a Scandinavian country of Northern Europe. Though being the 3rd largest country in the European union by area, it houses only 10.0 million. It has the world's 11-highest GDP per capita income (IMF 2016- 51,165 US$) and ranks highly in several metrics of national performance, including quality of life, health, education, protection of civil liberties, economic competitiveness and human development.

Quality of life indicators (WHO)

1. "Life expectancy at birth m/f (years-2015): 81/85
2. Probability of dying between 15-60 years m/f (per 1000 population-2015): 64/42
3. Total expenditure on health per capita (2014): 5,219 USD
4. Total expenditure on health as %age of GDP (2014): 11.9"

WHO NCD profile: Sweden 2014

1. "Percentage of population in urban areas: 85.2%
2. Population proportion between 30-70 years: 50.9%"

Table 3: Proportional mortality (%age total death, all ages, both sexes): WHO report

Causes of death	Proportional mortality
Cardiovascular diseases	41%
Cancers	25%
Other NCD's	18%
Communicable, maternal, perinatal and nutritional conditions	5%
Injuries	5%
Chronic respiratory diseases	4%
Diabetes	2%

"For Sweden, NCD's contribution to a total of 91000 in 2014 was 90% with Cardiovascular diseases and Diabetes being the leading causes for DALY's. The Swedish health care model is of "Beveridge model" kind, with a strong orientation towards local levels, i.e. municipalities and regions. The responsibility of healthcare is distributed amongst the central government, county councils and municipalities. Though being tax funded at all the levels, the municipalities in addition levy proportional income taxes to cover the services that they provide and a fee to be paid at the time of use. Primary and secondary care is funded and delivered at county level. This high level of decentralization of health system leads to variation in care provision. To overcome this, the government created national guidelines for common diagnoses including diabetes by developing 'chains of care' that identify and bridge the gap between different care-givers. Diabetes is treated by teams consisting of experts at primary or secondary care level. Patients with Type 1 DM are treated at the hospitals while the Type 2 diabetics are managed at primary care. The first adaptation to be made by Indian health care system."

“Another game changer for healthcare in Sweden is the use and applicability of Electronic medical records (EMR) (18) which are Personal Healthcare Records (PHR) being used by the majority of care givers, and then linked to the National Diabetes Register (NDR) as well as to other national disease registers. EMR/PHR are furthermore used for referrals within or between county councils. There are set guidelines and protocols for patients with/without complications. Like, for patients with complications, the care involves specialist units at the hospital in collaboration with primary care and medical assistance in the home for patients with complications and for diabetics without complications, the level of care and allocated resources can be defined by national guidelines. These chains of care are challenging to define so the government has defined quality indicators in order to keep the incidence of complications as low as possible. For healthcare spending in Sweden, private health insurance plays a negligible role resulting in less out of pocket expenditure by the nationals. As reported by OECD report on Health statistics 2015, the Government spending as a share of total spending on health in Sweden stood at 84% in 2013 and OOP spending, 15% in 2013. It is justified to say that the Swedish health-care system combines is *decentralization*, *a high degree of specialization*, and *professional organization* in a system where common health-care goals can be maintained.” (18)

Diabetes care in Sweden

This health care system is generally organized by 25 regional county councils, and hospitals with outpatient center for medicine and PHC’s. Diabetes care at such hospital centers is managed by specialists in internal medicine (Endocrinology) and by specialized nurses. Patients follow up is regular(18). The health care at PHCs is normally delivered by two or more specialists in general medicine with individual responsibility for each patient and by specialized nurses. The patients in

PHCs visit their general practitioners at least once a year, but when complications occur, and they also visit their nurses several times per year.

National Diabetes Register (NDR)

Representatives of European governments, patients, and experts came together in Saint Vincent (Italy) on 10-12th October 1989 to form an alliance to jointly reduce the burden of diabetes in future (19) and so St. Vincent Declaration came into being and listed a number of key measures to be taken by nations and organizations (20). It expressed that there was a need to ‘’Establish monitoring and control systems using state of the art information technology, for quality assurance of diabetes health care provision and for laboratory and technical procedures in diabetes diagnosis, treatment and self-management.’’ The National Diabetes Register (NDR) took shape in concert with the Swedish law which, states that ‘’the quality of health care should be developed and assured systematically and continually’’ (20). It was initiated in the beginning of 1990’s but the first patients were reported in 1996. National guidelines for diabetes care were also introduced at the same time along with indicators of quality. These guidelines contain the National Board of Health and Welfare's recommendations concerning the care of adults with diabetes. They are a revised version of the *National Guidelines for Diabetes Care* from 2010 and hereby replace these. The recommendations concern targeted screening, prevention and lifestyle, glycemic control, cardiovascular disease, nursing, diabetic complications and diabetes in pregnancy.

The NDR was started as a tool for local quality control and benchmarking against the national treatment aims, based on trials like Diabetes Control and Complications Trial (DCCT) and the U.K. Prospective Diabetes Study (UKPDS) (21)(22)(23). One aim of the NDR was that all the diabetic patients in Sweden should ideally be reported yearly, based on registered annual data from

actual patient visits in PHC or hospital outpatient clinics for departments of medicine. Demographic data, diabetes education, treatment modalities, as well as various risk factors and complications were to be reported. The healthcare centers inform patients that they are reported to relevant quality registers as there are several in different diagnoses. Patient demanding his/her exclusion is a provision though, it is rare.

"NDR was and still probably is the major national diabetes register in the world, and the unique size of it, with repeated annual surveys and with geographical distribution all over Sweden. It is therefore a valuable comparison of these repeated population based data of NDR annually in order to investigate whether clinical practice in the management and care of diabetes has changed in recent years, as measured by changed in mean/median levels of the variables, e.gm HbA_{1C} And BP levels. Today NDR is a part of the RC at the region of Western Sweden, located in Gothenburg and is being funded partly by this local health care provider and partly by The Swedish Association of Local Authorities and Regions. RC not only staffs people working singularly for NDR but also engineers and statisticians involved in the development and maintenance of similar national quality registers for psychiatric and pulmonary diseases as well as the Swedish Hip Arthroplasty Registry. NDR comprises a steering committee of deputies of the bodies that once participated in its launch, a scientific advisory board and a working group."

Reporting of results in NDR

Initially most patients registered had type 1 diabetes and were reported from outpatient departments of the hospitals. It was reported that the clinicians at the PHC where both type 1 and type 2 diabetes patients were visiting, had no access to the register. With the passage of time, a web-based interface was created which allows any caregiver, in primary care or in the hospitals

with patients with type 1 or type 2 diabetes, to participate. This saw a steady increase in the number of registered patients (figure)

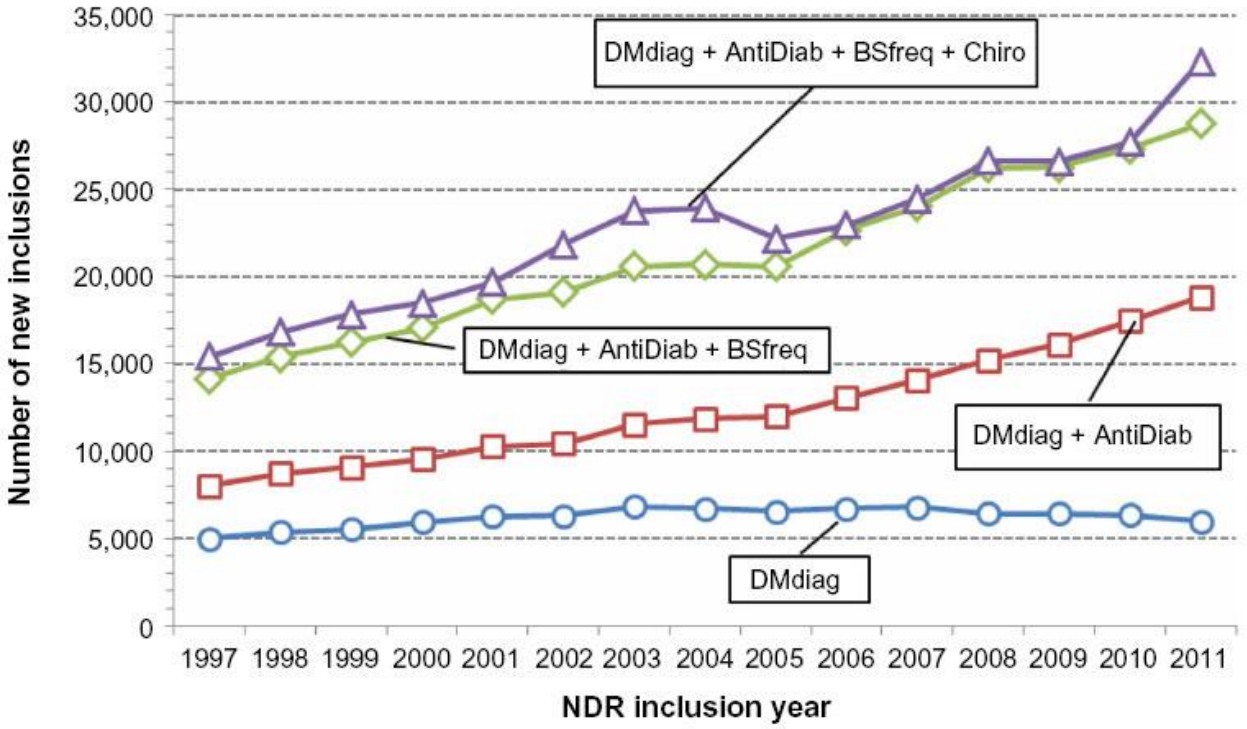


Figure 2: NDR report 1997-2011

outlines are used by many clinics in Sweden within the parameters of the medical record system to verify that all the information of the patient is relevant to diabetes and of good quality. Once done, the data is exported to NDR. To add more value to this system, details regarding medications and risk-factor control as well as regarding referrals and planned appointments are also included.

The deadline of annual report of NDR is mid-January. "The report contains characteristics of the population of patients with type 1 and type 2 diabetes in Sweden, including national means of risk factors, treatments, complications and procedures such as eye and foot examinations. Clinic and hospital based results are also presented. Standard statistics are generated online on a real time and readily available website. It also possible to generate tailored statistics for example, results in

specific age groups, gender, or other patient groups, and to generate lists of individuals fitting such criteria. Regional reports are also produced and delivered to the respective representatives of the health-care provider which are further used to analyze the region-specific results and find scope of improvement. In co-ordination with the national guidelines, results from NDR as well as other official sources (e.g., in-patient register, death register) are used to monitor health care in terms of clinical results and use of techniques and in different diagnoses. Many studies suggest that this register-based improvement approach can help closing the gap between clinical practice and evidence-based guidelines in the participating centers."

Research studies done based on NDR data

The NDR published its first report in 2003 detailing the demographic characteristics of the patients from 1996-1999, the type of diabetes (Type 1 or 2), and the predisposition to development of risk factors. Studies were performed to link the development of risk factors and diabetes mellitus leading to development of complications like cardiovascular diseases and ultimately culminating in death. The Swedish Cause of Death Register, Hospital Discharge Register and the NDR were linked to further include information on prescriptions filled at pharmacies, after 2005. This linkage was made technically possible by providing all databanks and registers with the same 10-digit unique identification number written in the form of year/month/day of birth followed by three random digits and a control digit, generated by the computer.

Recently, it has been observed and reported that the data from NDR is not just beneficial for managing Diabetes but following studies have also been conducted from the NDR data:

1. **"Congestive heart failure is commonly incident in type 1 and type 2 diabetes and**

related to glycemic control."(24)(25)(26).

Lind M et al followed the patients included in the Swedish National Diabetes Register during 1998-2003 until hospitalization for heart failure or death on 31st December 2009 to examine the relationship between glycemic control and hospitalization for heart failure in patients with type 2 diabetes. The result showed that in 83,021 patients with type 2 diabetes, 10,969 (13.2%) were hospitalized with a primary or secondary diagnosis of heart failure during a mean follow-up of 7.2 years concluding that a poor glycemic control (HbA1c > 7%) is associated with an increased risk of hospitalization of heart failure in patients with type 2 diabetes. Blood pressure levels around 130–135/75–79 mmHg is associated with lower risks of cardiovascular disease in patients with type 2 diabetes (24)(25)(26).

2. **"The non-HDL: HDL-cholesterol ratio is a better marker of risk for CHD than LDL-cholesterol in type 2 diabetes."**(27)

   The aim of the study was to assess the association between different blood lipid measures and risk of fatal/nonfatal coronary heart disease, which has been less analyzed previously in type 2 diabetes patients. It was an observational study of 46,786 patients with type 2 diabetes, aged 30-70 years, registered with Swedish NDR and were followed for a mean of 5.8 years. Baseline and updated mean low-density lipoprotein (LDL), high-density lipoprotein (HDL), non-HDL-cholesterol and non-HDL-to-HDL-cholesterol ratio were measured. The study suggested that lower levels of non-HDL: HDL are a better risk marker for CHD than LDL-cholesterol below 3mmol/l. (27)

3. **"Metformin treatment lowers risk of cardiovascular dis- ease in type 2 diabetes also in patients with renal impairment (estimated glomerular filtration rate, eGFR, 45–**

60ml/min/1.73m^2) and is not associated with increased risk in patients with eGFR 30–45 ml/min/1.73 m^2." (28)

The study included 51,675 patients with type 2 diabetes, registered in the Swedish NDR and on continuous glucose-lowering treatment with oral hypoglycemic agents or insulin. The objective was to evaluate the effectiveness and safety of metformin use in clinical practice in large sample of pharmacologically treated patients with type 2 diabetes and different levels of renal function. The conclusion was that metformin showed lower risk than insulin for CVD and all-cause mortality and slightly lower risk for all-cause mortality compared with other OHA in those 51,675 patients followed for 4 years (28).

4. **"Low physical activity leads to a 25% greater risk of coronary and cardiovascular events than high activity, and 70% greater risk of a fatal CV event in type 2 diabetes."**(29)

   A total of 15,462 patients, aged 60 years, registered in the Swedish NDR were followed for 5 years from baseline in 2004-2009 to estimate risks of coronary heart disease (CHD), cardiovascular disease (CVD) and total mortality with low or higher levels of physical activity. After comparing patients with low and high-level baseline physical activity and taking into consideration the hazard ratios for fatal/non-fatal CHD/CVD and total mortality, the study showed a considerable increased risk for CVD and mortality with low physical activity (29).

It is evident from the details of the above-mentioned studies that a single database containing descriptive patient records for one specific diseases is useful in correlating the same with a number of other life-threatening diseases thereby making healthcare provision more specific and evolved.

Based on the success of these studies, Sweden has several other important ongoing projects in the same line of diabetes prevention and control (27):

1. "The effects of oral hypoglycemic agents and insulins in type 2 diabetes.
2. The role of ethnicity and migration.
3. Renal disease in type 2 diabetes.
4. Cancer in diabetes mellitus.
5. Patient-reported outcomes in diabetes care.
6. The incidence of type 1 and type 2 diabetes."

Future of Diabetes in Sweden

"NDR remains as the obvious part of diabetes care in Sweden serving multiple benefits to the patients though its original purpose to monitor the results of health centers and to compare these with national and regional means, still hold the utmost importance while continuous follow-up of guidelines, treatments and complications are also held important. Recent report from the National Board of Health and Welfare confirmed that the results from diabetes care are slowly improving (30), but some emphasis must be placed on continuous improvement in

- The proportion of patients with unsatisfactory glycemic control.
- The number of leg amputations.
- The proportion of patients checked for microalbuminuria.
- The proportion of patients with regular physical activities.

- The number of smokers.
- Providing patient education in groups.
- Providing culturally adjusted patient education."

Porter and Teisberg in their publication, "*Redefining Health Care. Creating Value-Based Competition on Results: Harvard Business School Publishing"* declared that "measurement and public reporting of patient results in the single most important step in reforming health care systems" and NDR is proving this statement to be right.

Challenges faced by India in diabetes management

Unlike Sweden, variety of stakeholders from both governmental and private sector provide healthcare. It is a network of sub-centers, PHC and CHC in rural areas and district hospitals, tertiary care hospitals and medical colleges in the cities. "Though the system works on the principle of state responsibility for free health care for the people without regard to their ability to pay, the focus still continues to be on delivery of maternal and child health services." (31)Diabetes care is not an explicit part of the roles and responsibility assigned to health personnel in the rural health care set-up nor are the pre- and in-service training of personnel. As far as primary level healthcare is concerned, only a few PHC's and CHC's across the country have testing of blood glucose levels as a part of the standard tests and the supply for this test are not a part of the central supply list (32)(33). "This under-utilization of the public service is due to reasons of location, unreliable functioning of health facilities and increased indirect expenditures involved (31). The load of such patients is taken by the tertiary care hospitals where patient usually arrives with a set of complications.

The private health sector in healthcare is an unregulated market with huge variations in the quality and type of care on offer (33)(34). Urban settings observe the aggregation of qualified practitioners while rural settings see and influx of bare minimum and less than fully qualified health care providers. The variety of health care providers, their number and qualification, lack of national guidelines and protocols for health care services, makes it difficult to monitor and assure quality services across the nation. The strengthening of Health systems with development of generally accepted management procedures for all levels of health care along-with appropriate monitoring of quality and accessibility are the foundation for improved health care across the board. NCD's also adds onto the financial burden of the country. Along with effective service delivery, to ensure risk pooling and reduced financial burden on poor household, a state-of-the-art financing mechanisms will have to be developed."

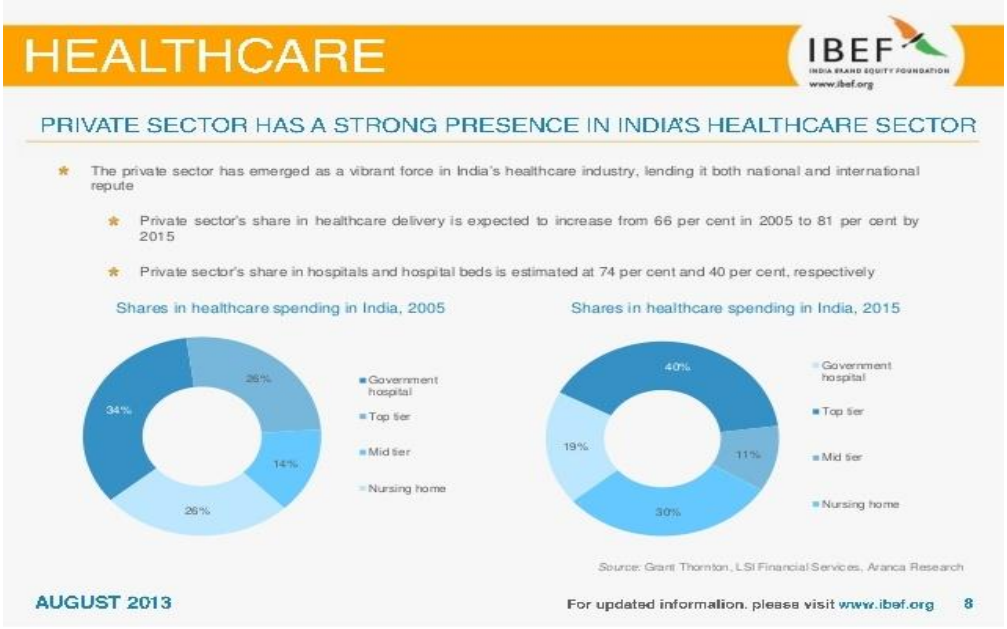
The National Program for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (NPCDCS)

Observing the increasing burden of NCD's in India, Ministry of Health and Family Welfare G.O.I., launched the National Program for Prevention and Control of Diabetes, Cardiovascular diseases and Stroke (NPCDCS) on 4th January 2008 on a pilot basis in ten districts in ten states. This pilot program was focused on health promotion and health education advocacy at various settings (35). "The objectives were providing effective promotion, prevention and control strategies to provide for an integrated action plan for chronic diseases. Following interventions were planned in the program

- health promotion and health education for the community;
- early detection of persons with high levels of risk factors (at the risk of developing disease) through screening; and
- strengthening health systems at all levels to tackle NCDs and improvement of quality of care including treatment of sleep disorders and augmenting facilities of dialysis."

The lacunae of this program are that there is no registered mechanism that would be utilized by the primary or the tertiary care hospitals. Death registers present at the hospitals mention the cause of death as CVS or Stroke for which diabetes is most of the times the causal factor. With a national level program in place, India also needs to establish a national level diabetes register, like the one in Sweden. As seen from the analysis of diabetes care in Sweden, it is evident that screening forms the core essential part of any management and prevention, may that be diabetes or any other such health problem/disease. The inter-mixing of health care providers from both government and private sectors pose as a difficulty in forming a NDR. For the same reason, India has been struggling with the initiation of a National Health Insurance Scheme considering the extensive OOP expenditure on health care building huge amount of financial burden on the nation. Sweden has a simplistic approach to health care with the government taking the wheel and following the global path of bringing down the prevalence of diabetes with the help of a steering committee. With OPP being as less as 15% (2013 OECD report) the share of private sector stays low. On the contrary, private sector walks away with the highest proportion of healthcare spending in takes the cake India (figure 3).

Figure 3: IBEF Report, August 2013



Implications of having a Health Management Information System (HMIS) for health policy formulation.

Health policy formulation involves stringent decision-making across all health system building blocks and the foundation of this decision-making is sound and reliable information. The decision taken by policy makers based on the collected information is crucial for health system development and implementation of various policies, governance, research in health, human resource development, health education and training, service delivery and financing.

Any HMIS to provide the underpinnings to policy makers for decision-making follows four key functions:

1. Data generation

2. Data compilation
3. Data analysis and synthesis
4. Data communication and use

Data is collected by HMIS from the health sector (state and district level to central level), the quality, relevance and timeliness of the data is ensured and analysis is done to convert data into information for health-related decision-making. The components of this data collected by HMIS are health surveys, birth and death registration, census, health facility reporting, health system resource tracking.

Components of HMIS

HMIS comprises of following subsystems and indicators:

1. "Demography and vital events.
2. Environmental health statistics
3. Health status: mortality, morbidity, disability and quality of life
4. Health resources: availability and accessibility of services, human and financial resources
5. Utilization and non-utilization of health services: attendance, admissions, waiting lists
6. Indices of health outcomes of medical care
7. Financial statistics (cost, expenditure) related to the particular objective."

A fully developed and functional HMIS system provides improved and readily available appropriate information for decision-making, improves the accessibility for all people (patient and health care provider), improves the productivity of all health workers, improvises cost-efficiency

and effectiveness, there is improvement in the utilization of heath care resources and at last, improved quality of care.

Rationale for having a NDR in India

A national diabetes register in India would help track the patients with type 2 diabetes and have records of their detailed medical history all in one place. It would be used as an important epidemiological tool: to monitor the prevalence and incidence of diabetes, provide a sampling frame for epidemiologic and clinical studies, provide information to health service providers and planners on risk factors and complications and hence, assist in the overall monitoring of diabetes control program (36)(37). A comprehensive database including both dates and values for crucial interventions will be used to identify patients who are either overdue for a monitoring intervention (such as blood pressure, glycosylated hemoglobin, or lipids) or have a laboratory result showing the need for further therapeutic intervention. Data in the registry can be categorized as:

The Goa became the first Indian state to have a Diabetes Registry, which was launched in association with Denmark's Novo Nordisk Education Foundation (NNEF) on 24th June 2011 and also Mobile Diabetes Van(45). The aim of the registry was to capture details of every individual diabetes patient in the State and further aided government health services to monitor each patient-based on a unique patient identification number. The screening of diabetes patients was an extensive exercise. 105 Mobile Diabetes Camps were conducted at 28 different CHC/PHC/UHC in which 13, 450 people were screened of which, 2341 were found to be diabetics, of which 79% had HbA1c>6.5%. House to house surveys were conducted to create awareness regarding the registry and also make people with diabetes to register with the Government which further provided free medication including Insulin analogues to have better control of diabetes thus leading to reduction of complications and have a better quality of life.
After the success of The Goa Diabetes Registry, Puducherry is the second state with a state-level diabetes registry, currently in its phase I of Data entry and compilation of diabetes register. The second phase involves setting up a management information system based on monthly reporting. of a number of patients with diabetes, glycemic control, referrals, and compliance to treatment.

1. Demographics: age, sex, type of diabetes, date of diagnosis, payer group
2. Glycemic control: HbA1c results, results of homes blood glucose testing and medications
3. Coronary risk factors: B.P, lipids (total cholesterol, HDL, LDL, triglycerides), smoking status and medications (if any)
4. Microvascular end organ disease data: micro albumin assessment for neuropathy and retinopathy, renal function tests and medications (if any)

Depending on the information collected from above, a relational database will be created which will allow users to design different data tables for each aspect of care, all of which will be linked by unique identifiers like patient record number. Though development of such a database seems complex and expensive but, the advantages of having comprehensive automated patient record in one place, the aggregation of individual practices to evaluate the performance of the entire delivery system for quality improvement and providing a facility of multiple disease management programs cannot be side-lined.

Framework of a replicable model in India

The primary objective of developing a National Diabetes Registry would be to understand the disease pattern with geographical variations within the country and will also give estimate of the burden of its complication. The secondary objectives would be:

1. To expedite research in the area of basic, clinical- including designs of care and survival, epidemiological, genetic and molecular levels of type 2 diabetes;
2. To help promote understanding about the magnitude of problem among professional's and public health associates, garnering Public Private Partnership.

3. To help understand the impact of state level initiatives to curtail diabetes
4. To assist in the formulation of diabetes management guidelines
5. To provide skilled manpower specific to diabetes epidemiology

PHASE I
DEVELOP DIABETES SPECIFIC HMIS

Develop an HMIS system which will be capturing the data on type 2 diabetes directly from PHC level which will be linked to the national level database system directly to reduce the incidence of data lost to transition from one level to the other.

PHASE 2
SENSITIZATION OF THE COMMUNITY

The health care providers at PHC, CHC, District hospital and State/tertiary level hospital regarding disease burden and in developing IEC material by conducting seminars, webinars and workshops by collaborating with diabetes registry experts from Goa and Puducherry.

PHASE 2A
EDUCATING THE TARGET POPULATION

Sensitize and educate the patients and their families regarding diabetes and the importance of being registered.

PHASE 3
PATIENT REGISTRATION WITH UID

Collecting and compiling demographic, family history, history of any diabetes related complications or any other chronic condition, fasting blood glucose level and HbA1c data at PHC level.
Further this data will be transferred to the country level data mart to be analyzed.

PHASE 4
DATA TRANSFER TO ICMR

The collected data will be retrieved from the data base by the data analytics team. Further this data will be analyzed using different statistical software's by the analyst at ICMR for producing evidence based reports for specialists to understand the trend of Diabetes and of its complications.
The insights drawn from the reports will be used by physicians for tracking diabetic patients every 3 months for follow up and free medications.
This system will be linked to the MIS which would provide regular updates to the physicians and patients for further management

PHASE 5
POLICY FORMULATION BY NPCDCS

The final reports published by ICMR would guide policy makers at NPCDCS to review and formulate better diabetes screening, prevention and management policies.

Costing framework for screening pre-diabetics and diabetics: Projections for The State of Punjab

Aim of screening: The main aim of screening for diabetes is multipurpose:

1. To detect asymptomatic people with undiagnosed diabetes.
2. To identify people at a higher risk of developing diabetes in the future
3. To reduce the risk of complications in people with diabetes mellitus.

Criteria for Diabetes screening: "Screening for prediabetes can be done using HbA1C, Fasting Plasma Glucose, or 2-hr Plasma Glucose after 75-g OGTT provided (38).

- Various risks and complications with diabetes are identified
- Screening children and adolescents who are overweight or obese and have two or more risk factors for diabetes: Family history of type 2 diabetes in a first- or second-degree relative, Signs of insulin resistance or conditions associated with insulin resistance such as Acanthosis nigricans, hypertension, dyslipidemia, polycystic ovarian syndrome, or small-for-gestational-age birth weight and Maternal history of diabetes or GDM during the child's gestation.
- Type 2 diabetes specific screening should be performed in adults of any age who are overweight or obese, and who have one or more above mentions diabetes risk factors. Testing should begin at age 45 and If test is normal, repeat it at least every 3 years."

Challenges

A major challenge would be the capacity of the system to carry out screening, follow-up and diagnostic testing and its capacity to manage effectively the newly detected cases of diabetes. The identification of people with Impaired Glucose Tolerance and Impaired Fasting Glucose (early metabolic abnormalities that precede diabetes) is a by-product of screening for type 2 diabetes and any screening policy needs to specify a clear care pathway for such people. Another challenge of the system would be to evaluate individual risks by using routinely available data (39).

Economic considerations

Descriptive data shows that health care expenditure on screening is relatively low as compared to the subsequent treatment of diabetes which are much higher. The expense on screening depends on the costs of the materials, staff at the given setting, acceptability of the methods in the population and the levels of sensitivity and specificity etc. that are required. The variation occurs if the screening is done at a special camp or at a primary care infrastructure, the former being clearly expensive (39). It is difficult to build a rational economic argument since in India, direct (cost to individuals and their families including medical care, drugs, insulin and other supplies) and indirect costs (cost of lost production) are incurred by different public and private sectors and the funding of screening and subsequent treatment may come from different budgets lines. It has also been seen that cost of screening can be reduced by using routinely available information or by linking other screening programs.

1. **Cost of screening –**

According to the 2011 census, Punjab houses 27.7 million people with Chandigarh, the capital city, set to become diabetes capital of the country as reported by a pan-India level study conducted by ICMR in 2016. Two studies in Chandigarh showed high prevalence of diabetes, INDIAB study showing a prevalence of 13.6% (40) and The Chandigarh Urban Diabetes Survey (CUDS) reporting a high prevalence of diabetics and pre-diabetics i.e. 11.1 and 13.2% respectively (41). There are 211 PHC's and 115 CHC.

At PHC Level: according to Indian Public Health Standards (IPHS), 1 PHC provides to a population of 30,000 (in plains) and 20,000 (hilly/tribal area) and has a staff of 15 (1 medical officer and 14 supporting staff). Assuming we take one such PHC out of the 211, and in that, one day in the week mostly prior to the NCD clinic, around 200 patients (depending upon the footfall at the PHC, NCD prevalence in the catchment population their health seeking behavior) will be advised to get the following tests done. After recording demographic data, the entire population is screened for type 2 diabetes using:

Test	**Cut off for pre-diabetics**	**Specifications**
Fasting Plasma Glucose	**Normal= <100mg/ dL** **Pre-diabetics=100-125mg/ dL** **Diabetics= ≥126 mg/dL**	Fasting is defined as no caloric intake for 6-8 hours
2-hr Plasma Glucose after Oral Glucose Tolerance Test.	**Normal= <140mg/ dL** **Pre-diabetics=140-199mg/ dL** **Diabetics= ≥200 mg/dL**	using a glucose load containing the equivalent of 75g of anhydrous glucose dissolved in water.

*Hemoglobin A1C (HbA1C)	**Normal= 4-5.6%** **Pre-diabetics= 5.7-6.4%** **Diabetics= ≥6.5%**	Performed at laboratory level and gives the average level of glucose in blood for past 3 months.
Random Plasma Glucose (RPG)	**Normal= 79-160mg/Dl** **Pre-diabetics=160-2 mg/dL** **Diabetics=>/equal to 200mg/dL**	By finger prick and the value varies depending on the time of last meal.

1. Risk assessment questionnaire: asking for signs of diabetes (such as thirst, polyuria etc.), any known family history of diabetes or other chronic condition
2. Biochemical tests: There are 4 options of screening:

   ***HbA1C is not performed at PCH level in the current scenario.**
3. Combination: to assess risk of diabetes by questionnaire followed by blood glucose measurement and if a certain score is reached, combination testing becomes resource intensive hence improve performance. Example, measuring fasting blood glucose and HbA1c at the same time.

1. **Cost of human resources for a day:** Existing staffing at PHC as per IPHS standards:

1. MO's- AYUSH/MBBS
2. Pharmacist
3. (3) Staff nurse/ANM
4. health worker (female)
5. male health assistant

6. female health assistant
7. laboratory technician
8. data entry operator
9. (2) multi-skilled Group D worker
10. (3) class IV workers.

NDR model proposes screening of pre-diabetics and diabetics and data entry at the PHC level which would require additional staff time of 1 medical officer, who would examine the patient. Data entry into the MIS could be either managed by the existing staff at the PHC or, a data entry specialist could be recruited, 1 / 2 nursing staff, 1 / 2 laboratory technician who would perform the investigations on the instructions of the MO.

The annual cost of running a PHC in Punjab is 3-6 lacs INR (42). The additional cost of HR for NDR to the PHC would include the additional staff time of the medical officer and the compensation for a trained data entry operator. Cost of recruiting and training the data entry operators would be an initial/one-time expense.

2. **Cost of other resources –**

Following pie chart and table shows the resource allocation for various operations done at PHC level

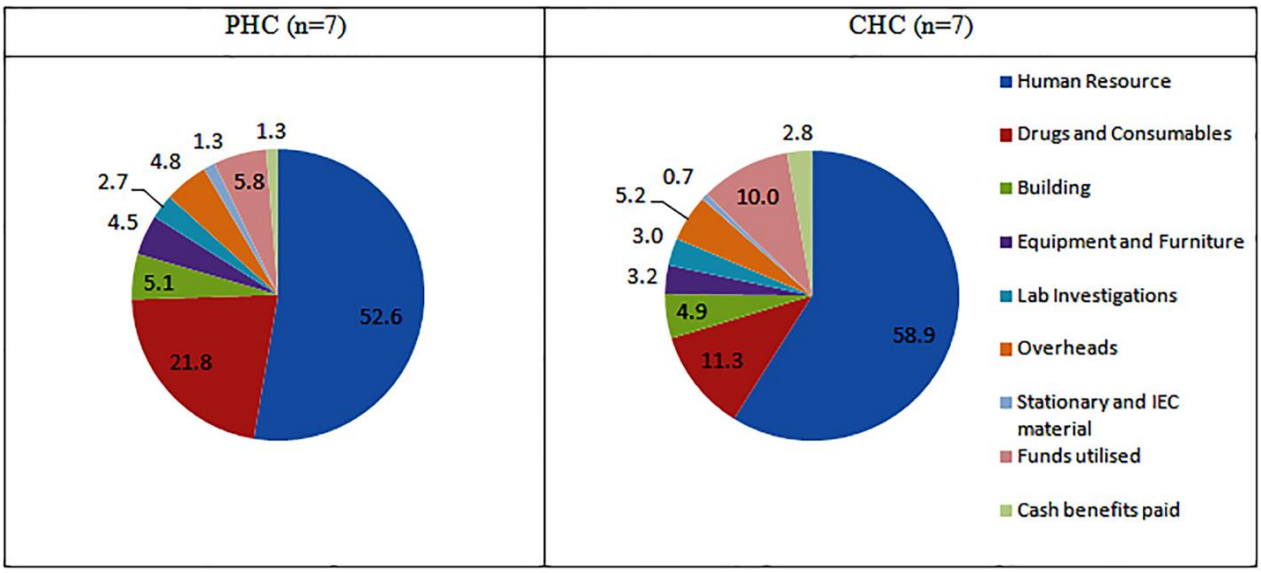


Figure 4: resource allocation at PHC in North India

Annual Cost	PHC(n = 7)			CHC(n = 7)		
	Mean Cost (INR)	95% Confidence interval		Mean (INR)	95% Confidence Interval	
		Lower limit	Upper limit		Lower limit	Upper limit
Human Resource	4,744,379	3,476,203	6,307,073	15,866,007	13,578,670	17,885,743
Drugs	1,704,385	994,367	2,526,073	2,496,358	927,868	4,295,269
Equipment	247,282	148,652	352,471	565,052	404,688	754,073
Consumables	264,583	167,970	346,540	549,970	225,287	1,017,283
Capital	457,188	281,941	660,228	1,328,387	880,384	1,875,420
Furniture	154,716	83,307	232,584	289,995	209,681	376,852
Lab investigations	244,834	59,643	446,964	815,065	447,783	1,200,162
Overheads	436,967	229,080	669,263	1,391,977	627,172	2,642,428
Stationary	80,127	10,303	189,155	150,259	31,765	297,474
IEC material	34,413	20,219	55,883	34,452	20,731	43,939
Funds utilized	525,004	226,601	825,106	2,685,085	1,393,984	4,061,792
Cash benefits paid	117,672	73,429	165,743	744,474	503,954	979,520
Total Annual Cost	8,858,520	7,365,630	10,294,065	26,917,082	22,225,159	32,290,100

doi:10.1371/journal.pone.0160986.t002

Table 4: resource allocation at PHC in North India

The data above gives a clear picture that the major portion of the financial resources are allocated to the human resource, which no doubt, is the important pillar of health industry but since NDR in India would focus on screening of patients for diabetes, this model seeks for greater resource allocations to laboratories/lab investigations.

Cost of diagnostic test lab results/ or any other method of diagnosis outside the public health system

According to a report published in The Times of India in 2015, "the average monthly expense for a diabetic comes to be anywhere between Rs3000 to Rs8000 per month. This cost could further be broken into consultation cost which would be anything between Rs700-1000, regular lab tests for Rs500-1000 and the medicine and insulin cost will be around Rs6000. For an individual, the estimated cost of routine care treatments ranges between Rs35000 to Rs75000 per annum (Lifespan data) depending on whether they are on oral drugs only or on insulin too.'' Curative cure of diabetes is expensive as compared to preventive care which involves life style changes such as losing weight, including healthier food items in the diet and increasing physical activity. This is behavior change which needs high will power and bare minimum financial backing. NDR data will provide enough evidence for physicians and policy makers to give more importance to these preventive measures (43).

Challenges for India to form NDR

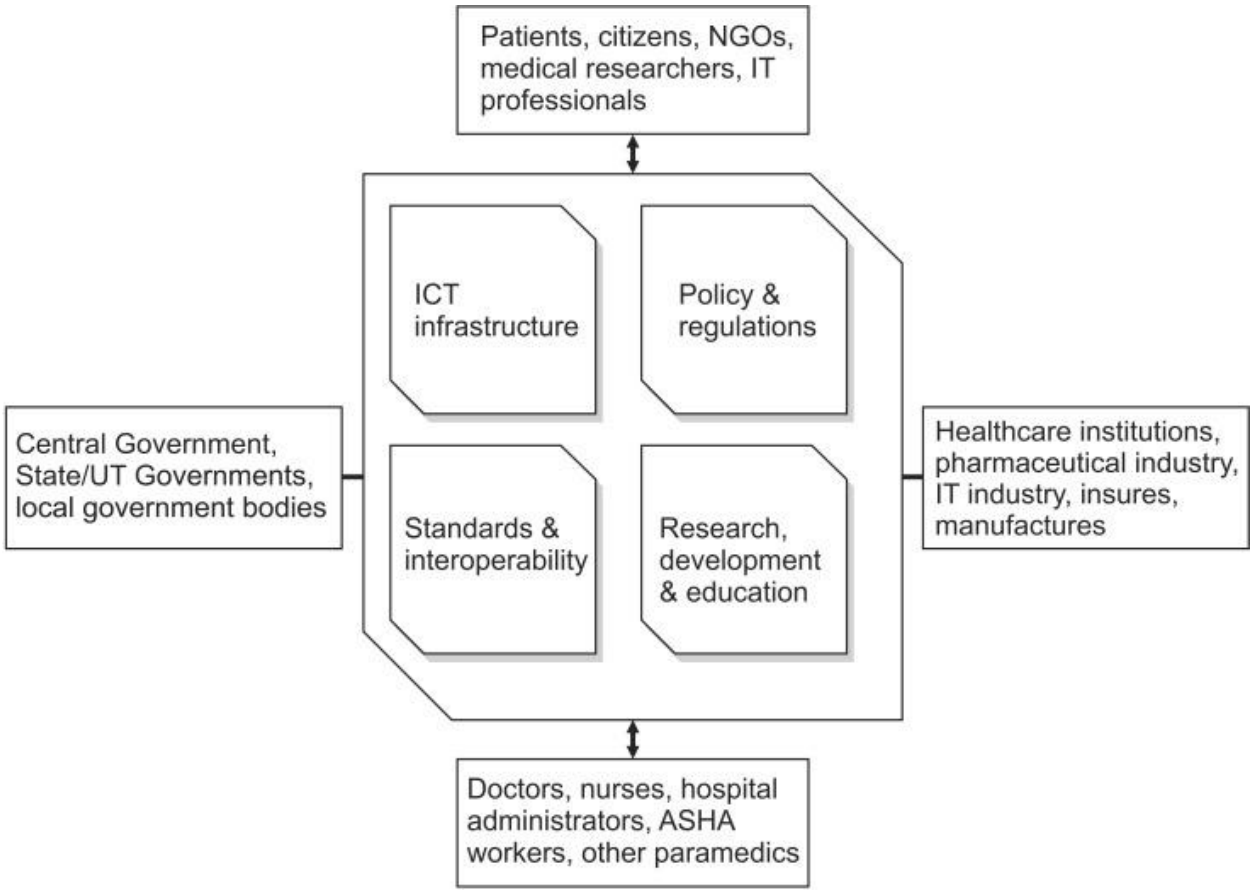
Srivastava S.K a PhD from IIT Kharagpur, in one of his papers on *Adoption of electronic health records: A Roadmap for India* (44), listed the challenges a India would face in developing and successful adoption of EHR which requires coordinated efforts from all the stake holder in four major areas (listed below), gave list of activities to be performed in these areas by giving substantial evidence from countries like England, Germany, New Zealand, Korea and the IT hub of the world, United States, which adopted EHR in a robust manner, over the period of time and developing technology.

According to *Srivastava*, the four major areas where the above-mentioned countries made efforts are:

1. ICT infrastructure
2. Policy and regulations
3. Standards and interoperability
4. Research, development and education.

The figure below shows these four broad components in the development of EHR and the table right below, lists the set of activities to be performed in each of these areas.

Figure5: The essential components for developing EHR: **source (44)**



Component	Activities
1. ICT infrastructure	Creation of basic ICT infrastructure Creation of national secure health net Creation of storage and exchange infrastructure Use of free and open-source software Use of personal health record system
2. Policy & regulations	National health IT policy Protection of privacy Sharing of health information Use of health information Liability for technical failures
3. Standards & interoperability	Establishment of agency for health IT standards Use of unique patient identity Conformation testing facility Support for adoption of standards Guidelines for health IT solutions
4. Research, development & education	Research & development in health IT Human resource development Development of online courseware Dissemination of best practices International collaboration

Table 5: Set of activities to be performed under the components (44)

Roadmap for India

Considering the use to information and communication technology (ICT), it has been low for our country in comparison to other countries. There has been steady improvement in use of ICT projects, including electronic patient records, by both public and private sector hospitals in India. Certain corporate hospitals in India, such as Max Health, Apollo, Fortis and Sankara Nethralaya have implemented integrated ICT systems in place, covering all aspects like patient registration

and billing as well as laboratory and clinical data[53]. Though, even in these renowned private hospitals, EMR's are seldom exchanged between hospitals. They remain in the same hospital and are referenced when the patient visits again. So, there is no aggregation of such EMR's at a state/central level which makes it impossible to develop a disease registry. Also, there is no authentic report on the number of patients whose EMR's/EHR's have been generated and stored so far. Pertaining to the 4 broad categories, challenges faced by India are:

1. **ICT infrastructure:**
    a) Lack of basic structure (laptops/desktops) especially at public level hospitals and dispensaries. The number of public health facilities in India are large in India but only tertiary care hospitals have computers and connectivity but then seeking healthcare at these tertiary care hospitals which are mostly private set-ups, have proved to burn a hole in the consumers' pockets. To condense such outlays, it is essential to use open source software systems, mobile devices, and the cloud computing environment. Once connectivity becomes available, cloud-based healthcare delivery can be brought to the village level.
    b) Absence of National secure heath net to exchange health information in a secure reliable way. Most countries have articulated national health IT policies that covers a gamut of issues, such as the way health information is collected and shared. Regulations have been enacted for privacy protection, enabling the exchange of health information for the collection of patient information for use in clinical research and other purposes.

c) Sharing of health information: in the existing EHR in India, only the information related to prescription and discharge summaries are exchanged. The details of treatment and diagnosis are not available.

d) Free and open source software (FOSS): in view of the size of the country which has 75% of outpatients and more than 60% of inpatients being treated in private set-ups, it is essential to an FOSS approach and bring them on-board for using EHR. It should support all major national languages by making even local entrepreneurs capable of providing technical support.

e) Personal health record system (PHR): these can play a significant role in the adoption of EHR as the physician would not create the record from scratch. And with PHR's being available, patients can approach hospitals they have not visited in the past, without worrying about interoperability issue

2. Policy & regulations:

a) National Health IT policy: To promote the implementation of NDR, there is absence of coordinated policy of government along with, lack of clarity in existing policies for Health IT. Several efforts are already being made by the Central Government and State Government towards the use of IT in the healthcare delivery. The policy will ensure that the efforts being made lead to interoperable systems without duplication of effort.

b) Protection of privacy: regulations need to be in place for maintaining patient privacy while using e-health applications and patients need to be guaranteed that the discretion of their health data will not be compromised.

c) Sharing of health information: At present, this does not exist except for the information given in relation to prescriptions and discharge summaries. The details of treatment and diagnosis are not available. Often healthcare providers are not willing to share information for several reasons. Laws are required to ensure that healthcare providers share information electronically in the interest of patients.

d) Use of health information: government needs to collect certain important health information of the individual patients for use in public health decision-making or clinical research. Legislation must provide a mechanism to use clinical information after necessary anonymization.

e) Liability for technical failure: this could be because of arising from malfunction of the system, communication channel, or unavailability of service, which can cause harm to the patient. regulations should specify the responsibilities of stakeholders so that they are aware of their responsibilities and do not suffer for reasons beyond their control.

3. Standards & interoperability:

a) Agency for health IT standards: developing and adoption of EHR is a continuous process to an agency should be given responsibility to update data and system continuously.

f) Use of unique patient identity number: at present, every hospital has its own unique patient identification number which cannot be used at state/center level. For a

national level UID, Aadhaar number given by Unique Identify Authority of India (UIDAI) appears to be the best living example, in knowledge of all.

g) Conformance testing facility: even with prescribed standards in place, often IT products and services developed need to be tested by an agency to verify that these solutions are interoperable.

h) Support for standards adoption: facilities for training need to be in place so that an adequate number of professionals can be trained.

i) Guidelines for health IT solutions: There are many areas where it may not be possible to mandate standards as it may be a hindrance for innovation. In such cases, there is often the possibility of issuing guidelines for the benefit of stakeholders.

4. Research, development and education:

a) R&D in health IT: support is needed in R&D projects on secondary usage of EHR's to support decision making in public health. These projects can reduce the cost of deployment and improve the quality of service.

b) Human resource in health IT: At present, no Indian university offers any master- or doctoral-level degree in this area. Steps need to be taken to start such courses in some of the institutions in the country.

c) Development of online courseware: there is need to start a program, of bachelors or masters level, to develop learning modules in this sphere that can be used by anyone in the country

d) Dissemination of best practice: Though online sharing has to continue on a regular basis, workshops/conferences play their own role where people can discuss matters face to face.

e) International collaboration: as India clearly seems to be lagging behind other nations in this area, collaborations would be beneficial.

Certain other challenges that the author realized India would face are:

1. Exploding population rate: Sweden has $1/10^{th}$ population as compared to India. Compiling individual data at a national level for this giant number of people is a task in itself.
2. Lack of awareness regarding the importance of screening at the primary level.
3. All resources focused on maternal and child health and then on TB/ HIV Aids: ICMR gets a fund of 600 crores every year out of which major chunk is given away to the RCH, TB/HIV and AIDS program. Considerable amount of funds need to be allocated to NPDCS for the suggested reforms.
4. Behavior and life style change communication: India is a country world renowned for its age-old customs and traditions, which are still very much in existence and people living by them, are not open to any form of change or reform. Diabetes is a disease that can be prevented and managed well with life style modifications. The communication of these changes to the general public is the sphere where health care providers feel a blow. Though we see many people are indulging in healthy activities these days but, they are the ones sprawling the urban sectors of the nation while the ones' in the rural

setting prefer living by the old tradition of eating rich food in order to live healthy. Behavior change communication barrier plays a major role in Diabetes prevention.

Budget allocation: no genius plans would work without financial resources and NDR requires a channeled fund allocation. The Economic Survey of the Government of India 2017 gives a grim picture of persistent underfunding of health sector by the government. It reminds Indians that as a nation the achievement in health outcomes had been a mixed bag. India has done 'reasonably well' in life expectance at birth and 'exceptionally well' in fertility decline, on a global sphere. But when compared to the core indicators at a national level, a week delivery system is seen as the primary reason for poor health outcomes. The survey reported the public funding of health sector as 1.2% of GDP with Central government spending constituting a third of overall government funds. It also reported that The Union Government's allocation to health schemes, in the last five years have witnessed steady decline. The health sector suffered the brunt of under allocation and few other policy changes that were effected on account of implementation of Fourteenth Finance Commission recommendations. Amidst all the criticism, the Union Budget 2017-18 has sought to take action by stepping up allocation from Rs39,888 crores (revised estimate during 2016-17) to Rs48,880 crores, with a nominal rise of 23%. Nearly half of additional funding to Health Ministry is allocated to the Ministry's flagship program - National Health Mission - from Rs22,598 crores during 2016-17 to about Rs27,131 crores in 2017-18. With an ambitious plan outlined by the Union Budget to eliminate Kala-Azar and Filariasis by 2017, Leprosy by 2018 and Measles by 2020, National Urban Mission or Non-communicable diseases

are yet to see light of such ambitious plans in any significant way. Unless substantial public resources are set aside to match disease profile and strengthen health system, targets will tend to be elusive. And such targets need to be aligned with other health related goals.

Conclusion

India houses a large number of people who are shadowed by the engulfing dusk of chronic diseases. With a young demographic dividend suffering from diseases like Diabetes and CVS, it is the responsibility of the government to take that extra must needed step to aid their diagnosis and treatment. With the advent of the Digital India Initiative, Aadhar card and Unique Identification Number (UIN), a digital cloud space is already in place. Just like having a UIN and an Aadhar card has been made a mandate for every Indian national, the MoHFW with the hand holding of GOI can educate Indians regarding the increasing burden of Diabetes and how registering under NDR would put them out of misery of dealing with chronic disease burden. This was done effectively by the state of Goa, which gave the importance of spreading awareness regarding the registry to the locals at par to training the human resource. It has been proved by the examples of Aadhar and UIN that awareness campaigns run at national level had a larger and better impact. As seen from the example of Sweden, a country that pronounced itself a winner in not just combating the prevalence rate of diabetes but also using the data from NDR to study the association of more sever chronic diseases, it is a lesson for India to take the challenge of developing and implementing a national diabetes register which will not only help identify and screen the diabetics and their future but would also help answer India's specific research questions like through one

single data source and help policy makers understand the diseases pattern and burden in a more systematic way only to draft a more comprehensive national health policy.

India is following the demographic transition which Sweden has surpassed, dealing with associated rising trend of NCD's effectively. Take away message for India from this study is that focusing and investing greater proportions of resources on preventive health care for the young population at this hour would prove to be beneficial in the perspective of health and financial aspects for future geriatric population.

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