



India's Healthcare System

– Overview and Quality Improvements

Despite earnest efforts by the government, India's healthcare system faces substantial challenges in providing care to its citizens. This report is focused on systematic healthcare improvements based on measurements within the healthcare system, including clinical outcomes indicators and disease registries in India. It is part of the Swedish Agency for Growth Policy Analysis' Health Measurement Project in which quality measurements in healthcare have been studied in a number of countries.

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Foreword

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Summary

India has a population of 1.2 billion people, whereof three quarters live in rural areas. Parts of India have a topology that makes access difficult and travel time-consuming. Nearly 400 million people in India live on less than 1.25 USD (PPP) per day, and 44 percent of all children are malnourished and the infant and women mortality rates are still unacceptably high despite earnest efforts by the government. Strong economic growth in the last decades has fuelled migration from rural to urban areas.

Against this backdrop the challenges that India's healthcare system faces in providing care to its citizens are substantial. There is a rise in infectious diseases as well as in non-communicable diseases, giving India's healthcare a double burden to combat. At the same time India's public spending on health is extremely low. In 2009 it amounted to just 1.1 per cent of GDP. If public funds, private funds and external flows are combined, the total health expenditure amounts to 4.1 per cent of GDP. With a capacity crunch in the public healthcare system, patients have become dependent on private healthcare providers who currently treat 78 per cent of outpatients and 60 per cent inpatients. Further, with an underdeveloped healthcare insurance system high out-of-pocket expenditures for healthcare result, which can be prohibitive for access to care or drive people into poverty. To mitigate this undesirable situation, India's government plans to increase public health investment from 1.1 per cent to 2–3 per cent of GDP over the next five years.

However, already in 2005 the Government launched the National Rural Health Mission (NRHM), a health programme in mission mode to improve the health system and the health status of the people, especially for those who live in the rural areas, and provide universal access to equitable, affordable, and quality healthcare. As a component of NRHM, measurement and reporting of clinical output and performance indicators has been employed from the sub-district and are regularly reported and aggregated through increasing administrative levels up to the national level. This data enables the state and national health ministries to plan programmes and evaluate their impact.

The main trends in the debate on healthcare have focused on major legislative gaps, lack of uniform standards for healthcare leading to the current fragmented and uncontrolled nature of the private sector and ineffective implementation in the public sector. Experts have pointed out that the government needs to adopt a broader healthcare approach, while at the same time taking measures to achieve additional progress in seven prioritised target areas. Based on this, one of the healthcare priorities in the next five years will be to focus all existing national health programmes under the umbrella of the NRHM and extend its reach to urban areas.

Over the last 30 years an extensive national cancer registry has developed, which includes both population- and hospital-based disease registries. Current developments include an expansion of hospital-based cancer registries to look at patterns of care and survival, bringing in more details on cancer cases affecting three sites; breast, head & neck, and cervix. The process of establishing a national stroke registry has recently been initiated and plans exist for future national diabetes and cardiovascular disease registries.

A chronic kidney disease registry is functioning under the Indian Society of Nephrology; some 50–60 000 cases are described in the registry, but no follow-up of the patients is made, which reduces the value of the collected data. Recently, a 3-year grant from a gov-

ernmental funding agency has allowed a multi-centric study to begin to establish the prevalence of CKD in India.

Recent changes in the legislation governing transplants in India and a commitment from the government to fund an improved transplant registry are interesting.

In a study by the Cardiological Society of India–Kerala Chapter (CSI-K) an extensive registry was constructed containing presentation, management, and in-hospital outcomes of 25 748 Acute Coronary Syndrome patients across 125 hospitals throughout Kerala. The resulting findings and recommendations are currently being integrated in a quality-improvement programme that will be rolled out shortly under the auspices of the Centre for Chronic Disease Control (CCDC). The CCDC also runs translational research projects investigating the benefits of low-cost handheld units for clinical decision support and registry submission. The role of other players in the Indian Health Management Information System (HMIS), like the Central Bureau of Health Intelligence and the Statistics Division of the Department of Health and Family Welfare is also being discussed.

There is no significant debate in India relating to patients' integrity vis-à-vis disease registries, or other modes of collection and use of personal clinical data and legislation in this area is not yet in place. The public discourse is rather focused on how to overcome the capacity deficit in the public health system, which leads to challenges of access. However, other challenges exist in data collection within the healthcare system; the absence of a unique personal identifier, the lack of human resources within the public healthcare system, and the absence of parts of the legislative framework that could ensure better coverage and consistency in data collected.

There is evidence that data collected in the healthcare system, be it disease surveillance, clinical outcome and performance monitoring or disease registries, have come to good use in policy formulation and quality improvement in the healthcare system.

Under the NRHM, the process of performance-based monitoring was initiated emphasizing 'accountability' by way of engaging various stakeholders including the end-users. The Ministry of Health and Family Welfare rewards states for better performance under the NRHM, based on the health outcome indicators. Incentives in terms of additional allocation and disincentives in terms of budget cuts are also part of the national government directives to the states for the NRHM planning process. Several state governments also have incentives in terms of honouring better-performing districts based on specific parameters.

The processes for health measurement will get a major boost in India's 12th Five-Year Plan (2012–2017) as it proposes a composite Health Information System (HIS) that would incorporate and strengthen many of the important components discussed in this report.

Sammanfattning

Indien har en befolkning på 1,2 miljarder människor, varav tre fjärdedelar lever på landsbygden. Delar av Indien har en topologi som gör vissa områden svårtillgängliga och resor tidskrävande. Nästan 400 miljoner människor i Indien lever på mindre än 1,25 USD (köpkraftsjusterat) per dag, 44 procent av alla barn är undernärda, spädbarns- och mödradödligheten är fortfarande oacceptabelt hög trots uppriktiga ansträngningar från regeringen. Kraftig ekonomisk tillväxt de senaste decennierna har lett till migration från landsbygden till städerna.

Mot den bakgrunden är utmaningarna, som Indiens sjuk- och hälsovårdssystem möter i att förse medborgarna med vård, omfattande. Smittsamma, såväl som icke-smittsamma sjukdomar ökar vilket ger Indiens hälsosystem en dubbel börda att bekämpa. Samtidigt är Indiens utlägg på sjuk- och hälsovård extremt låg. 2009 omfattade den bara 1,1 procent av BNP. Om offentliga, privata och externa medel räknas samman, så uppgår de totala sjuk- och hälsovårdsutläggerna till 4,1 procent av BNP. På grund av kapacitetsbrist i det offentliga systemet så har patienterna blivit beroende av privata vårdgivare som för närvarande behandlar 78 procent av öppenvårdspatienterna och 60 procent av slutenvårdspatienterna. Eftersom hälsoförsäkringssystemet är underutvecklat leder det till höga individuella utgifter för sjuk- och hälsovård, vilket kan hindra tillgången till vård eller driva människor i fattigdom. För att dämpa denna oönskade situation planerar Indiens regering att öka investeringarna i det offentliga sjuk- och hälsovårdssystemet från 1,1 procent till 2–3 procent av BNP, de närmaste fem åren.

Redan 2005 lanserade regeringen den nationella hälsomissionen för landsbygden (National Rural Health Mission (NRHM)), ett hälsoprogram i uppdragsform (mission mode) för att förbättra sjuk- och hälsovårdssystemet och förbättra befolkningens hälsostatus, särskilt för de som bor på landsbygden, och erbjuda universell tillgång till skälig, prisvärd kvalitetsvård. Som en komponent under NRHM har mätning och rapportering av kliniskt utfall och prestationsindikatorer införts; från sub-distriktsnivå rapporteras detta regelbundet och aggregeras genom stigande administrativa nivåer ända upp till nationell nivå. Den här informationen hjälper delstaternas, och centralregeringens, sjuk- och hälsovårdsministerium att planera program och utvärdera deras effekter.

Huvudtrenden i debatten om sjuk- och hälsovård har fokuserat på stora brister i lagstiftningen, bristen på enhetliga hälsostandarder som leder till den nuvarande fragmenterade och okontrollerade strukturen inom den privata sektorn samt ineffektiv implementering inom den offentliga sektorn. Experter har föreslagit att regeringen bör anamma ett bredare angreppssätt inom sjuk- och hälsovårdsområdet och samtidigt vidta åtgärder för att åstadkomma ytterligare framsteg inom sju prioriterade områden. Baserat på detta, kommer en av prioriteterna inom sjuk- och hälsovård de närmsta fem åren vara att fokusera på befintliga nationella sjuk- och hälsovårdsprogram under NRHM och utöka dess räckvidd även till städerna.

Under de senaste 30 åren har ett omfattande nationellt cancerregister utvecklats, som inbegriper såväl populations- som sjukhusbaserade kvalitetsregister. Pågående utveckling inkluderar en utökning av de sjukhusbaserade cancerregistren för att bedöma behandlingsmönster och överlevnad. En större mängd detaljer samlas in från de cancerfall där bröst, huvud och nacke och livmoderhals drabbats. Processen att etablera ett nationellt stroke-

gister har nyligen initierats och det finns planer för framtida kvalitetsregister för diabetes och kardiovaskulära sjukdomar.

Ett kvalitetsregister för kronisk njursvikt drivs under det indiska sällskapet för nefrologi, med ca 50–60 000 fall beskrivna i registret. Ingen uppföljning görs vilket reducerar värdet av den insamlade informationen. Nyligen har ett 3-årigt anslag beviljats från en offentlig forskningsfinansiär vilket möjliggör uppstarten av en multicentrumstudie för att fastställa förekomsten av kronisk njursvikt i Indien.

En intressant utveckling är en nyligen förändrad lagstiftning rörande transplantationer och åtföljande utfästelse från regeringen att finansiera ett förbättrat transplantationsregister.

Inom en studie utförd av Indiens kardiologiska sällskap, Kerala-avdelningen, utvecklades ett omfattande register innehållande patientpresentation, behandling samt utfall för patienterna så länge de varit kvar på sjukhuset. Studien omfattade 25 748 patienter med akut kranskärlssjukdom intagna på något av de medverkande 125 sjukhusen i Kerala. Resultaten och rekommendationerna från studien håller för närvarande på att integreras i ett program för kvalitetsförbättring som kommer att rullas ut under överinseende av Centre for Chronic Disease Control (CCDC). CCDC driver också translationsforskning för att undersöka fördelarna med att arbeta med handhållna enheter till låg kostnad, som används för kliniskt beslutsstöd och inmatning av data till register. Rollen av andra aktörer inom det indiska hälsoinformations-systemet (Indian Health Management Information System (HMIS)), som centrala byrån för hälsounderrättelser och statistikdivisionen vid ministeriet, diskuteras också.

Det förekommer ingen påtaglig debatt i Indien angående patienternas integritet i förhållande till kvalitetsregister, eller andra sätta att samla in och använda personliga kliniska data. Det finns i dagsläget inte heller någon lagstiftning på plats inom det här området. Den offentliga debatten handlar snarare om hur man ska få bukt med kapacitetsbristen i det offentliga sjuk- och hälsovårdssystemet, ett problem som leder till stora utmaningar vad gäller förmågan att tillhandahålla vård. Det finns dock andra utmaningar när det gäller datainsamling inom sjuk- och hälsovårdssystemet; avsaknaden av ett unikt personnummer, brist på personal inom det offentliga sjuk- och hälsovårdssystemet samt avsaknad av delar av det legala ramverket som skulle kunna säkerställa bättre täckning och överenskommelse i den insamlade informationen.

Det finns bevis för att information insamlad i sjuk- och hälsovårdssystemet, oavsett om det gäller sjukdomsbevakning, kliniskt utfall och prestationsövervakning eller kvalitetsregister, har kommit till god användning inom policyformulering och kvalitetsförbättring inom sjuk- och hälsovårdssystemet.

Under NRHM infördes processen för prestationsbaserad övervakning för att betona ”ansvar” genom att engagera intressenter, inklusive slutanvändarna (patienterna). Ministeriet belönar delstater som har presterat bättre under NRHM, baserat på indikatorerna för kliniskt utfall. Incitament i form av extra tilldelning av medel och motsatsen, budgetnerskärningar, är del av den nationella regeringens direktiv till delstaterna för planeringsprocessen för NRHM. Flera delstater har också infört incitament för att belöna distrikt som har bättre prestation, baserat på specifika parametrar.

Processen för hälsomätningar kommer att få ett uppsving under den 12e femårsplanen (2012-2017) eftersom planen föreslår att ett sammansatt hälsoinformationssystem ska införas, vilket skulle stärka många av de komponenter som diskuteras i denna rapport.

1 Introduction to the Healthcare System

1.1 Overview

India has traditionally been a rural, agrarian economy. Nearly three quarters of the population, currently 1.2 billion, still live in rural areas. However, India's thriving economy is raising average income levels, driving rapid urbanization, creating an expanding middle class and increasing awareness of health insurance. More women are entering the workforce that further boosts the purchasing power of Indian households. However, nearly 400 million people in India live on less than 1.25 USD (PPP) per day¹, and 44 per cent of all children are malnourished² and the infant and women mortality rates are still unacceptably high despite earnest efforts by the government.

Healthcare is one of India's largest service sectors. The Indian healthcare sector can be viewed as a glass half empty or a glass half full. The challenges the sector faces are substantial, from the need to reduce mortality rates, improve physical infrastructure, necessity to provide health insurance, ensuring availability of trained medical personnel etc. There has been a rise in both communicable/infectious diseases and non-communicable diseases, including chronic diseases. While ailments such as poliomyelitis³, leprosy, and neonatal tetanus will soon be eliminated, some infectious diseases once thought to be under control, for example dengue fever, viral hepatitis, tuberculosis, malaria, and pneumonia have returned in force or have developed a stubborn resistance to drugs.

Text box 1.

- Literacy Rates:
M 82 % & F 65 %
- Sex Ratio: 940 / 1000
- Fertility Rate: 2.6
- IMR: 47 / 1000
- MMR: 230 / 100,000
- Life Expectancy 69.9 years (2009 est.)

Source: Census of India, 2011

As Indians live more affluent lives and adopt unhealthy diets that are high in fat and sugar, the country is experiencing a rapidly rising trend in non-communicable diseases / lifestyle diseases such as hypertension, cancer, and diabetes that is expected to grow at a faster rate than infectious diseases.⁴ In addition, the growing elderly population will place an enormous burden on India's healthcare systems and services.

There are considerable shortages of hospital beds and trained medical staff such as doctors and nurses, and as a result public accessibility is reduced. There is also a considerable rural-urban imbalance in which accessibility is significantly lower in rural compared to urban areas.⁵ Women are under-represented in the healthcare workforce.⁶

The health needs of the country are enormous and the financial resources and managerial capacity available to meet them, even on the most optimistic projections, fall somewhat

¹ World Bank data from 2010, USD (PPP), available at:

<http://data.worldbank.org/indicator/SI.POV.DDAY/countries>

² "India at a glance", World Bank, available at: http://devdata.worldbank.org/AAG/ind_aag.pdf

³ Krista Mahr, "How India Fought Polio – And won", TIME, 13 January 2013, available at:

<http://world.time.com/2013/01/13/how-india-fought-polio-and-won/>

⁴ Rajan & Prabhakaran, "Non-Communicable Diseases in India: Transition, Burden of Disease and Risk Factors – A Short Story", *India Health Best*, 6(1), June 2012. Available at: http://phfi.org/images/pdf/policy-notes/Policy_1.pdf. Last accessed 4 April 2013.

⁵ Report of the Steering Committee on Health for the 12th Five Year Plan, Health Division, Planning Commission, February 2012, p. 44, available online at:

http://planningcommission.nic.in/aboutus/committee/strgrp12/str_health0203.pdf, accessed 11 Dec. 2012

⁶ Rao et al (2011). *Human Resources for Health in India*, *the Lancet*: 377: 587–598

short. India's National Health Policy, 2002⁷ had to make hard choices between various priorities and operational options. It does not claim to be a road-map for meeting all the health needs of the populace of the country. Furthermore, it has to be recognised that such health needs are also dynamic, as threats in the area of public health keep changing over time. The policy, while being holistic, focuses on the need for enhanced funding and an organisational restructuring in order to facilitate more equitable access to the health facilities. Also, the policy is focused on those diseases which are principally contributing to the disease burden. This is not to say that other items contributing to the disease burden of the country will be ignored; but only that the resources, and also the principal focus of the public health administration, will recognise certain relative priorities. The policy aims to achieve an acceptable standard of good health among the general population of the country and has set goals to be achieved by the year 2015. However, from a global perspective India's public spending on health is extremely low. In 2009 it amounted to just 1.1 per cent of GDP.⁸ Further, public spending across states also reveals wide variations.⁹

The total health expenditure (combining public funds, private funds and external flows) during this period equalled 4.1 per cent of GDP.¹⁰ The 12th five-year plan (2012–17) aims to increase the public health investment from 1.1 per cent to 2–3 per cent of GDP.

1.2 Structure and Organisation

Under the Indian Constitution, health is a state subject. Each state therefore has its own healthcare delivery system in which both public and private (for profit as well as non-profit) actors operate. While states are responsible for the functioning of their respective healthcare systems, certain responsibilities also fall on the federal (Central) government, namely aspects of policy-making, planning, guiding, assisting, evaluating and coordinating the work of various provincial health authorities and providing funding to implement national programmes.

The organisation at the national level consists of the Union Ministry of Health and Family Welfare (MoHFW). In each State, the organisation is under the State Department of Health and Family Welfare that is headed by a State Minister and with a Secretariat under the charge of the Secretary/Commissioner (Health and Family Welfare) belonging to the cadre of Indian Administrative Service (IAS). The Indian systems of medicine consist of both Allopathy and AYUSH (Ayurveda, Yoga, Unani, Siddha and Homeopathy).

Each regional/zonal set-up covers 3–5 districts and acts under authority delegated by the State Directorate of Health Services. The district level structure of health services is a middle level management organisation and it is a link between the State and regional structure on one side and the peripheral level structures such as Primary Healthcare (PHC) and Sub-Centre on the other.

⁷ *The National Health Policy, 2002 is available online at:*

http://www.mohfw.nic.in/NRHM/Documents/National_Health_policy_2002.pdf

⁸ *Report of the Steering Committee on Health for the 12th Five Year Plan, Health Division, Planning Commission, February 2012, p. 7, available online at:*

http://planningcommission.nic.in/aboutus/committee/strgrp12/str_health0203.pdf

⁹ *High Level Expert Group Report on Universal Health Coverage for India, 2011, p. 98, available online at:*

http://planningcommission.nic.in/reports/genrep/rep_uhc0812.pdf, accessed 2012-12-19

¹⁰ *Report of the Steering Committee on Health for the 12th Five Year Plan, Health Division, Planning Commission, February 2012, p. 7, available online at:*

http://planningcommission.nic.in/aboutus/committee/strgrp12/str_health0203.pdf

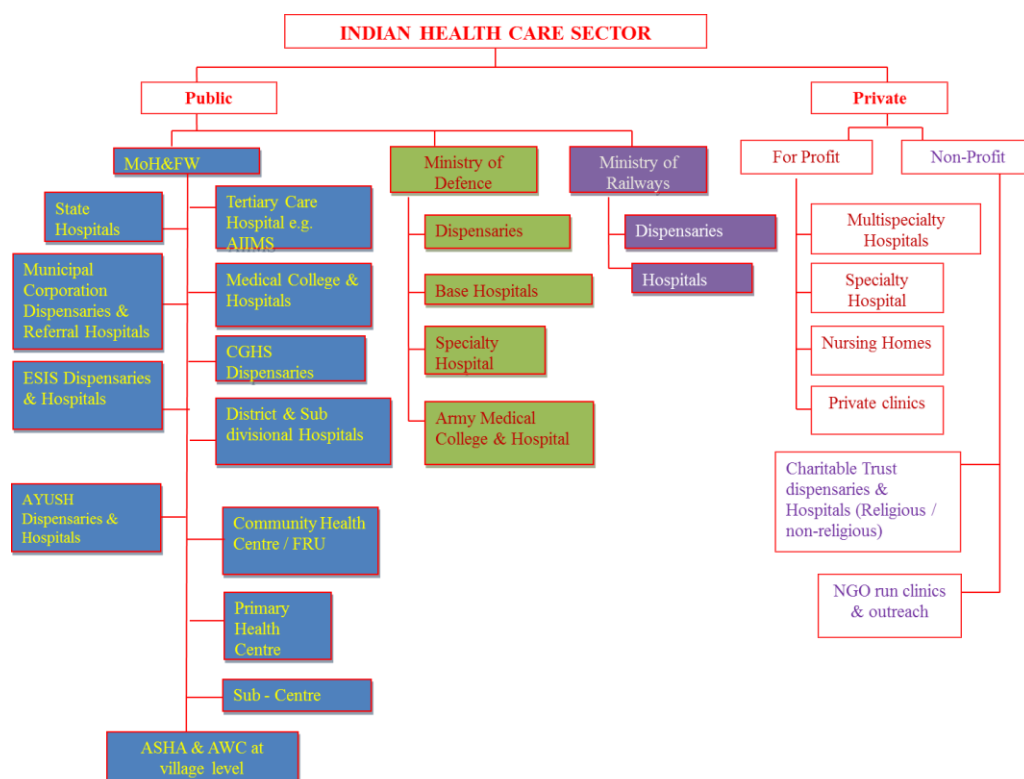


Figure 1: India's healthcare system is characterised by multiple systems of medicine, mixed ownership patterns and different kinds of delivery structures. Public sector ownership is divided between Central & State governments, municipals and Panchayats (local governments). The facilities include teaching hospitals, secondary level hospitals, first-level referral hospitals (community health centres/rural hospitals), dispensaries; primary health centres, sub-centres, and health posts. Also included are public facilities for selected occupational groups like organised work force (Employees State Insurance Scheme), defence, government employees (Central Government Health Scheme – CGHS), railways, post and telegraph and mines among others. The private sector (for profit/not for profit) is the dominant sector and services range from 1000+ bed hospitals to even 2-bed facilities).

Text box 2. Health Infrastructure (public sector)

Rural areas (3-tier system)	Population Norms		Numbers
	Plain Areas	Hilly / Tribal Areas	
Sub-Centres (SCs)	5 000	3 000	147 000
Primary Healthcare Centres (PHCs)	30 000	20 000	23 500
Community Health Centres (CHCs)	120 000	80 000	4 500
Urban areas			
Hospitals			12 700

The healthcare infrastructure in India includes levels (*Text box 2*), that include primary,

secondary or tertiary healthcare providers. The providers of healthcare at these different levels include both public and private actors, but there is an increasing dependence on private providers. The primary level includes village teams, Sub-centres (SCs) and Primary Health Centres (PHCs). The Community Health Centres (CHCs) and Sub-district Hospitals make up the secondary level, and the District Hospitals and Medical Colleges are at the tertiary level.

1.3 National Rural Health Mission

The National Rural Health Mission (NRHM), launched in 2005, is the first health programme in a “*Mission Mode*” to improve the health system and the health status of the people, especially for those who live in the rural areas, and provide universal access to equitable, affordable and quality healthcare which is accountable and at the same time responsive to the needs of the people. The programme is a comprehensive package of promotive, preventive, curative and rehabilitative services to be delivered to the community through a process of inter-sectorial co-ordination with other service departments and active community participation. Various national programmes like immunisation, tuberculosis control, leprosy elimination, cancer control etc. have been integrated under the NRHM programme that also addresses the social determinants of health and delivery of the same with the active participation of Panchayat Raj Institutions (local governance) for its sustainability. The programme will help achieve goals set under the National Health Policy and the Millennium Development Goals. It also seeks to revitalise and integrate local health traditions of medicine (Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy: AYUSH) into the public health system. Health is for the first time being seen as a component of development package.

The NRHM sought to increase public spending on health, reduce regional imbalances in health infrastructure, pool resources, integrate various organisational structures and vertical national programmes, decentralise and achieve district management of health programmes, and turn community health centres into functional hospitals meeting certain standards. The NRHM has a special focus on rural areas in 18 States which have weak public health indicators and/or weak infrastructure.

At the village level the government has promoted the concept of having an accredited female social health activist (ASHA) in order to facilitate household access to healthcare. Village Health Committees of the Panchayat Raj are responsible for putting in place Village Health Plans. The NRHM also calls for the preparation and implementation of an inter-sectorial District Health Plan prepared by the District Health Mission. Such a plan should include provisions for drinking water, sanitation, hygiene and nutrition.

The NRHM also has provisions for capacity building aimed at strengthening the National, State and District Health Missions, for example through data collection, assessment and review for evidence-based planning, monitoring and supervision.

The institutional design of the National Rural Health Mission includes a number of entities at different levels – village, district, state and central (See Appendix). In consultation with the Mission Steering Group, it is up to each State to choose state-specific models.

1.4 Health Insurance

Health Insurance in India is in its infancy. There are several insurance schemes operated by the Central and State governments, such as the Rashtriya Swasthya Bima Yojana (RSBY) which targets Below Poverty Line (BPL) families, the Employees’ State Insurance Scheme (ESIS) and the Central Government Health Scheme (CGHS). There are also public and

private insurance companies as well as several community-based organisations. An estimated 300 million people are believed to be covered by health insurance in India. Of these, approximately 243 million are covered by different forms of government-sponsored insurance schemes while approximately 55 million rely on commercial insurers.¹¹

The RSBY offers an example in which the State governments, through a bidding process, select a public or private insurance company to provide health insurance for the target group. Under the scheme, the beneficiaries also have the freedom to choose between participating public or private hospitals when deciding where to receive healthcare. Experience from the functioning of the RSBY shows that insurance companies, especially in the private sector, have been successful at controlling costs (fraud control for example), managing customer complaints, and tracking the costs and the quality of the services provided by participating hospitals. However, despite this fact, in the ongoing debate about how to organise the Government of India's planned Universal Health Coverage scheme, it has been suggested that the purchases of all healthcare services be managed either by the Central or State governments through the respective Department of Health or by other government agencies, and not by insurance companies or other independent agencies.¹²

1.5 Growing Private Sector

The National Health Policy welcomes the participation of the private sector in all areas of health activities. The policy also encourages the setting up of private insurance instruments for increasing the scope of the coverage of the secondary and tertiary sector under private health insurance packages.

Today India is experiencing a growing reliance on private healthcare providers who currently treat 78 per cent of outpatients and 60 per cent of inpatients. Private healthcare providers include everything from private hospitals that promote medical tourism by offering world-class services to foreign clients and Indians who can afford it, to private doctors with little medical knowledge or formal training at the other end of the extreme.¹³

Furthermore, the strength of the private sector is illustrated by the fact that it controls 80 per cent of doctors, 26 per cent of nurses, 49 per cent of beds and 78 per cent of ambulatory services.¹⁴ Private actors are now present in all areas of healthcare, including health financing, education, as well as equipment manufacturing and services. The heavy increase in private healthcare providers can be viewed as a result of lacking quality care offered by public providers, shortages of doctors and overcrowding at public healthcare facilities.¹⁵ This subsequently results in about 72 per cent of out-of-pocket expenses that are directed at medicines and put significant pressure on the individual.¹⁶ It is not uncommon that some are driven below the poverty line due to the costs they incur in order to access healthcare services.

¹¹ Report of the Steering Committee on Health for the 12th Five Year Plan, Health Division, Planning Commission, February 2012, p. 23, available online at:

http://planningcommission.nic.in/aboutus/committee/strgrp12/str_health0203.pdf, accessed 11 Dec. 2012

¹² High Level Expert Group Report on Universal Health Coverage for India, 2011, p. 111–113, available online at: http://planningcommission.nic.in/reports/genrep/rep_uhc0812.pdf, accessed 19 Dec. 2012

¹³ Kumar et al (2011). *Financing Healthcare for All: Challenges and Opportunities*, *the Lancet*:377:688–679

¹⁴ Report of the Steering Committee on Health for the 12th Five Year Plan, Health Division, Planning Commission, February 2012, p. 15, available online at:

http://planningcommission.nic.in/aboutus/committee/strgrp12/str_health0203.pdf, accessed 11 Dec. 2012

¹⁵ See for example A.Z. Jilani, G.S. Azhar, N.Z. Jilani, A.A. Siddiqui: *Private providers of Healthcare in India: A policy analysis*. *The Internet Journal of Third World Medicine*. 2009 Volume 8

¹⁶ High Level Expert Group Report on Universal Health Coverage for India, 2011, p. 97–98, available online at: http://planningcommission.nic.in/reports/genrep/rep_uhc0812.pdf, accessed 19 Dec. 2012

2 Discussions on and Initiatives for Increased Quality and Follow-up in Healthcare

2.1 Main Trends in the Healthcare Debate

In recent years, issues of assessing the quality and availability of healthcare have been examined by various government-appointed expert groups.¹⁷ Such reviews have pointed to the occurrence of major legislative gaps and highlighted the fragmented and uncontrolled nature of private sector healthcare delivery systems.¹⁸ Ineffective implementation, lack of rules, lack of uniform standards, and non-coverage of laboratories or diagnostic centres are some of the issues that need to be corrected.¹⁹ Also information about the number, role, nature, structure, functioning and quality of care in private hospitals remains inadequate.²⁰ With no national regulations regarding provider standards and healthcare treatment protocols in place, over-diagnosis, over-treatment, and maltreatment are common.²¹

2.2 Legislative Reforms

The Government has attempted to define standards for healthcare facilities through legislation such as the Clinical Establishment Act, the National Accreditation Board for Hospitals and Healthcare Providers (NABH) and the Indian Public Health Standards (IPHS). Despite these efforts, there is no single authority and unified system in place to ensure that people have access to appropriate and cost-effective care. As health is a State-responsibility, these issues are left for them to manage.

2.3 Need to Adopt Broader Healthcare Approach

In its 11th Five Year Plan, the central government had outlined seven measurable targets that were to be achieved. The targets focused on Infant Mortality Rate (IMR), Maternal Mortality Ratio (MMR), Total Fertility Rate (TFR), under-nutrition among children, anaemia among women and girls, provision of clean drinking water for all, and improving the child sex ratio for age group 0–6 years. While there have been improvements in many of these areas much more needs to be done. A review of the health indicator IMR for example shows that Uttar Pradesh, Madhya Pradesh and Odisha (Orissa) continue to underachieve.²²

Experts have pointed out that in the 12th Plan the government needs to adopt a broader healthcare approach, while at the same time taking measures to achieve additional progress

¹⁷ See for example the High Level Expert Group Report on Universal Health Coverage for India, 2011, available online at: http://planningcommission.nic.in/reports/genrep/rep_uhc0812.pdf

¹⁸ Report on the Working Group on Clinical Establishments, Professional Services Regulation and Accreditation of Health Care Infrastructure for the 11th Five-Year Plan, Planning Commission, 2006, p. 4, available online at: http://planningcommission.nic.in/aboutus/committee/wrkgrp11/wg11_hclinic.pdf, accessed 14 Dec. 2012

¹⁹ Report of the Steering Committee on Health for the 12th Five Year Plan, Health Division, Planning Commission, February 2012, p. 58, available online at: http://planningcommission.nic.in/aboutus/committee/strgrp12/str_health0203.pdf, accessed 11 Dec. 2012

²⁰ Report on the Working Group on Clinical Establishments, Professional Services Regulation and Accreditation of Health Care Infrastructure for the 11th Five-Year Plan, Planning Commission, 2006, p. 8, available online at: http://planningcommission.nic.in/aboutus/committee/wrkgrp11/wg11_hclinic.pdf, accessed 14 Dec. 2012

²¹ Kumar et al (2011), *Financing Healthcare for All: Challenges and Opportunities*, the Lancet; 377: 668–679

²² High Level Expert Group Report on Universal Health Coverage for India, 2011, p. 183, available online at: http://planningcommission.nic.in/reports/genrep/rep_uhc0812.pdf

in the seven target areas mentioned above. Based on this, one of the healthcare priorities in the 12th Five Year Plan will be to focus all existing national health programmes under the umbrella of the National Rural Health Mission.²³

2.4 Calls for Management and Institutional Reforms

In order to improve the quality of healthcare much focus has been directed at issues of infrastructure. Examples are the numbers of health workers available and the number of hospitals available. As mentioned above, the Indian healthcare system suffers from severe shortages of manpower and this problem needs to be addressed in order to achieve the stated objectives. In addition to strengthening the training of health workers and expanding their numbers, there have been proposals aimed at management and institutional reforms. For example, it has been suggested that in order to strengthen the public sector and allow it to function as a promoter, provider, contractor, regulator, and steward of healthcare, and facilitate quality assessment and quality assurance, there is a need to establish a Public Health Service Cadre at centre and state levels, that would comprise public health professionals with multidisciplinary education. This new group of professionals would be responsible for all public health functions, with the aim to improve the functioning of the health system by enhancing the efficacy, efficiency and effectiveness of healthcare delivery. They would have roles in the public health system, starting at the block level and going up to the state and national level.

Similarly, a specialised state level Health Systems Management Cadre has been suggested. Professionals in this group should be given responsibility for managing public sector service provision as well as the contracted-in private sector. Quality assessment and quality assurance for health facilities will be a major function. These health system managers should take over many of the administrative responsibilities in areas such as IT, finance, human resources, planning, and communication that are currently performed by medical personnel.²⁴

The Government has also been advised to establish a National Health Regulatory and Development Authority (NHRDA) tasked with regulating and monitoring public and private healthcare providers. The authority would also be responsible for developing ethical standards for healthcare delivery and the accreditation of healthcare providers and linked to similar state-level institutions.

In addition, three sub-units have been suggested:

- The **System Support Unit** which should develop treatment guidelines, management protocols, and quality assurance methods.
- The **National Health and Medical Facilities Accreditation Unit** (NHMFAU) which should be responsible for the mandatory accreditation of allopathic and AYUSH healthcare providers in the private and public sectors, as well as for all health and medical facilities. This unit should be linked with similar state-level agencies.

²³ *Faster, Sustainable and more Inclusive Growth: an Approach to the Twelfth Five Year Plan*, Planning Commission, October 2011, p. 87-88, available online at:

http://planningcommission.nic.in/plans/planrel/12appdrft/approach_12plan.pdf, accessed 14 Dec. 2012

²⁴ See for example the *High Level Expert Group Report on Universal Health Coverage for India*, 2011, p. 31, available online at: http://planningcommission.nic.in/reports/genrep/rep_uhc0812.pdf

- The National Authority should also include a **Health System and Evaluation Unit** tasked with evaluating the performance of public and private health services at all levels.²⁵

²⁵ See for example the High Level Expert Group Report on Universal Health Coverage for India, 2011, p. 31, available online at: http://planningcommission.nic.in/reports/genrep/rep_uhc0812.pdf

3 Information Systems and Registers

Quality and effectiveness/efficiency is measured within the Indian Public Health System and has been emphasised from the country's 9th five year plan (1997–2002) onwards and gained momentum during the NRHM.²⁶ The NRHM envisaged developing a comprehensive healthcare model by merging family welfare and healthcare services that were earlier separate wings. Standards and norms to ensure quality were also given due importance by the ministry.

3.1 Assessment of Service Delivery

Before the NRHM, the overarching principles of measurements remained restricted to quantitative assessment of service delivery in the primary healthcare system of the government through the **Health Management Information System (HMIS)**²⁷ for administrative purposes. The HMIS data is used at various administrative levels to monitor the Primary Healthcare programme at both sub-district and national level on a monthly basis.

A web-based Health MIS (HMIS) portal is available²⁸ to facilitate data capturing at District level. The HMIS portal has led to faster flow of information from the district level and about 98 per cent of the districts have been reporting monthly data since 2009–10. The HMIS portal is now being rolled out to capture information at the facility level.

3.2 Registration of Births and Deaths

India conducts a national census every 10 years.²⁹ In-between, the estimation of vital statistics is based on the **Sample Registration System (SRS)**. The SRS is a large-scale demographic survey conducted in India to provide reliable annual estimates of birth rate, death rate and other fertility and mortality indicators at the national and sub-national levels (states and rural/urban). The registration of births and deaths began on a voluntary basis and there was no uniformity in statistical returns, resulting in both under-registration and incomplete coverage. In order to unify the Civil Registration activities, the Registration of Births & Deaths Act, 1969 was enacted. Despite the registration of births and deaths being compulsory under the statute, the level of registration has continued to be far from satisfactory in several States/Union Territories (UTs). With a view to generating reliable and continuous data on these indicators, the Office of Registrar General, India, initiated the scheme of sample registration of births and deaths in India popularly known as Sample Registration System (SRS) in 1964–65 on a pilot basis and full-scale from 1969–70. The SRS has since then been providing data on a regular basis.³⁰ Annual SRS bulletins are also published.³¹ The survey currently encompasses 1.1 million households and a population of 6 million in almost 7000 sample units across India.

²⁶ http://www.mohfw.nic.in/NRHM/Task_grp/Mission_Document.pdf

²⁷ In India, the information flow is organised from the sub district facility level (of Sub Centres and Primary Health Centres) to the Block which represents the first level of aggregation. From there, reports flow to the district, then state and finally to the national level, and at each stage an aggregation is carried out.

²⁸ <https://nrhm-mis.nic.in/>

²⁹ <http://www.censusindia.gov.in>

³⁰ <http://www.censusindia.gov.in/2011-Common/srs.html>

³¹ <http://www.nrhm-mis.nic.in/PublicPeriodicReports.aspx>

3.3 Disease Surveillance

One of the important initiatives of the MoHFW was the introduction of the **Integrated Disease Surveillance Project (IDSP)**³² in 2004 that allowed tracking and organisation of emergency responses to locally endemic communicable diseases. The quality of reporting has significantly improved over a period of time. The IDSP has recently included non-communicable diseases. However, this initiative has yet to be developed to the extent that the information can be used for monitoring purposes.

The IDSP was launched with World Bank assistance in November 2004 to detect and respond to disease outbreaks quickly. State Surveillance Units (SSU) and District Surveillance Units (DSU) were established in all states and UTs (35) and districts (640) across India. A Central Surveillance Unit (CSU) was established and integrated in the National Centre for Disease Control (NCDC), New Delhi (see 3.12).

The project was extended for 2 years in March 2010. From April 2010 to March 2012, World Bank funds were available to the CSU and SSUs in 9 identified states (Uttarakhand, Rajasthan, Punjab, Maharashtra, Gujarat, Tamil Nadu, Karnataka, Andhra Pradesh and West Bengal) while the remaining 26 states and UTs were funded from the domestic budget. The programme is proposed to continue during the 12th Plan as a Central Sector Scheme under the NRHM with an outlay of INR 8.51 billion (USD 160 million) from the domestic budget only.

During the establishment of the IDSP all State/District Surveillance Teams and Rapid Response Teams (RRT) were trained. An IT network connecting 776 sites in States/District HQ and premier institutes has been established with the help of the National Informatics Centre (NIC) and the Indian Space Research Organisation (ISRO) for data entry, training, video conferencing and outbreak discussion.

Under the project, weekly disease surveillance data on epidemic-prone disease are being collected from reporting units such as sub-centres, primary health centres, community health centres, hospitals including government and private sector hospitals and medical colleges. The data are collected in 'S' (syndromic), 'P' (probable), and 'L' (laboratory verified) formats using standard case definitions. Presently, more than 90 per cent districts report such weekly data through e-mail/portal³³. The weekly data are analysed by the SSUs/DSUs for disease trends. Whenever a rising trend of illnesses is observed, it is investigated by the RRT to diagnose and control the outbreak.

3.4 Periodic Health Surveys

The **National Family Health Survey (NFHS)**, **District Level Household and Facility Survey (DLHS)** and **Annual Health Survey (AHS)** are periodic health surveys.

3.4.1 National Family Health Survey

The **NFHS** captures maternal, child and geriatric health conditions and the effectiveness of public healthcare through sampled population surveys at an interval of 6 years. The NFHS is a large-scale, multi-round survey conducted in a representative sample of households throughout India. Three rounds of surveys have been conducted since the first in 1992–93.

³² <http://idsp.nic.in/>

³³ www.idsp.nic.in

The survey provides state and national information on:

- fertility
- infant and child mortality
- practice of family planning
- maternal and child health
- reproductive health
- nutrition
- anaemia
- utilisation of health and family planning services
- quality of health and family planning services

Each successive round of the NFHS has had two specific goals:

- To provide essential data on health and family welfare required by the MoHFW and other agencies for policy and programme purposes.
- To provide information on important emerging health and family welfare issues.

3.4.2 District Level Household and Facility Survey

The **DLHS** is designed to provide information on family planning, maternal and child health, reproductive health of ever married women and adolescent girls, utilization of maternal and child healthcare services at the district level for India. The third in this series of surveys, DLHS-3, was designed to provide healthcare and utilisation indicators at the district level for the evaluation of the activities under the NRHM.³⁴ DLHS-3 therefore also provides information on new-born care, post-natal care within 48 hours, and role of ASHAs (Accredited Social Health Activist) in enhancing the reproductive and child healthcare and coverage of the safe mother and child scheme, the Janani aur Shishu Suraksha Yojana (JSSY). An important component of DLHS-3 is the integration of Facility Survey of Health Institutions (Sub- Centre, Primary Health Centre, Community Health Centre and District Hospital) accessible to the sampled villages.

3.4.3 Annual Health Survey

Realising the need for the preparation of a comprehensive district health profile with key parameters based on a community set-up, the **AHS** has been designed to yield benchmarks of core and vital health indicators at the district level on fertility and mortality, prevalence of disabilities, injuries, acute and chronic illness and access to healthcare for these morbidities, and access to maternal, child health and family planning services. The objective is to monitor the performance and outcomes of various health interventions by the government at closer intervals through these benchmark indicators. The AHS was conceived during a meeting of the National Commission of Population held in 2005 under the chairmanship of the Prime Minister wherein it was decided that "there should be an Annual Health Survey of all districts which could be published/monitored and compared against benchmarks".³⁵ The AHS is implemented by the Office of Registrar General, India in all the 284 districts

³⁴ <http://www.rchiips.org/>

³⁵ <http://www.censusindia.gov.in/2011-Common/AHSurvey.html>

(as per the 2001 census) in 8 Empowered Action Group States (Bihar, Jharkhand, Uttar Pradesh, Uttarakhand, Madhya Pradesh, Chhattisgarh, Odisha (Orissa) and Rajasthan) and Assam for a three-year period (i.e. a base-line survey followed by two surveys to update the results and see trends) spread over 2010–11 to 2012–13. These nine States, which account for about 48 per cent of the total population, 59 per cent of births, 70 per cent of infant deaths, 75 per cent of under-5 deaths and 62 per cent of maternal deaths in the country, are the high-focus States in view of their relatively higher fertility and mortality. A representative sample of about 20.1 million people and 4.1 million households were covered in 20 694 statistically selected PSUs (census enumeration blocks in the case of urban areas and villages or a segment thereof in rural areas) in these 9 AHS States during baseline and to be followed every year. With the present coverage, the AHS is the largest demographic survey in the world.³⁶

3.5 Health Standards

An important move by the MoHFW was the introduction in 2007 of **Indian Public Health Standards (IPHS)** for various levels of primary and secondary healthcare services. The IPHS are a set of uniform standards envisaged to improve the quality of healthcare delivery in the country. The IPHS documents were revised in 2012³⁷, keeping in view the changing protocols of the existing programmes and introduction of new programmes especially for non-communicable diseases. Flexibility is allowed to suit the diverse needs of the states and regions. These IPHS guidelines will act as the main driver for continuous improvement in quality and serve as the benchmark for assessing the functional status of health facilities. States and UTs are to adopt these IPHS guidelines to strengthen the public healthcare institutions and put in their best efforts to achieve high quality of healthcare across the country.³⁸

Under the NRHM, in 2007 the health ministry, in collaboration with the Armed Force Medical College, Pune and the WHO, initiated a process for developing **Standard Treatment Guidelines (STG)**³⁹ along with cost, for the medical professionals and investigation facilities available at various levels of public healthcare infrastructure in India.

3.6 Accreditation and Certification

Given the disorganised nature of the Indian healthcare sector there is no single government authority in place responsible for compliance monitoring and assessing the quality of the services provided by healthcare actors through regular medical audits. However, an increasing number of hospitals in India are receiving accreditation and certification from national and international bodies such as the National Accreditation Board for Hospitals and Healthcare Providers (NABH)⁴⁰ (see also 3.12), the National Accreditation Board for Testing and Calibration Laboratories (NABL), the Joint Commission International (JCI) and the International Organization for Standardization (ISO).

³⁶ Press Release 16 July 2012, "Subject: Annual Health Survey (AHS) in 8 EAG States and Assam – Release of District Level Factsheet: 2010-11", Office of Registrar General, India, available online at: http://www.censusindia.gov.in/vital_statistics/AHSBulletins/files/Final_Press_Release_DLFS.pdf, accessed 29 Jan. 2013

³⁷ <http://mohfw.nic.in/NRHM/iphs.htm>

³⁸ <http://mohfw.nic.in/NRHM/iphs.htm>

³⁹ <http://mohfw.nic.in/NRHM/STG/Index.htm>

⁴⁰ For list of accredited hospitals (currently 163 in total) see <http://www.nabh.co/main/hospitals/accredited.asp>

Of the 163 hospitals currently NABH-accredited, only 12 are public hospitals.⁴¹ Further, it can be noted that 93 out of the 163 NABH accredited hospitals are located in the metro areas of India's five largest cities⁴² and most of the remaining hospitals in progressive tier II cities⁴³. All JCI Accredited Hospitals in India, listed on the JCI official website, are managed by private healthcare providers, none are public.⁴⁴ Out of the 19 hospitals listed 13 are located in metro areas.

When it comes to ISO certification it is apparent that public hospitals to some extent have been successful in obtaining certification, even outside the metro areas and progressive tier II cities.⁴⁵

3.7 Quality Programmes in the Private Hospital Sector

In addition to receiving accreditation by such accrediting bodies, corporate hospital chains often have additional procedures for assessing quality. **Apollo Healthcare**, for example, launched its own quality assessment programme, Apollo Clinical Excellence (ACE@25 – initially designed to cover 25 hospitals using 25 parameters) in 2008, for the purpose of measuring and improving clinical quality within its hospitals.⁴⁶ The programme uses a balanced scorecard and measures a number of different parameters which are compared to international benchmarks. The hospitals are divided into three groups, A, B and C, depending on their bed strengths, location, and the services offered, and the number of parameters measured varies between the three groups. The programme is currently in place at 32 locations within Apollo and an oversight committee is tasked with reviewing monthly summaries of their respective performance.⁴⁷ Low performance, fluctuations or declining results for any parameter become the focus of the hospital concerned. Some of the parameters covered include: mortality rate, average length of stay, complication rates, healthcare associated infection rates, patient satisfaction with pain management, medication errors, and transplant survival rates. The results for the different parameters are compared to those of well renowned international institutions.⁴⁸ Each hospital within the Apollo Group also manages a comprehensive infection prevention and control programme with the overall purpose of minimizing patients' infection risk.

Max Healthcare has adopted quality initiatives using the so-called Six Sigma methodology, in which Sigma Capability (z-value) is a measure of how well a process is being performed. The logic behind Six Sigma is that all processes include the potential for errors and the key is to reduce the likelihood of such errors. When the number of errors/defects decreases, sigma capability increases. The goal of Six Sigma is to achieve less than 3.4

⁴¹ "Public" refers to government managed hospitals as well as autonomous institutes established by the government (national, state or local level). The remaining 151 NABH accredited hospitals are run by corporations or as not-for-profit organisations set up by actors other than the government.

⁴² Delhi (incl. Gurgaon, Noida & Ghaziabad), Hyderabad, Bangalore, Mumbai (incl. Thane) and Chennai.

⁴³ Indian cities in the range of approximately 1 to 5 million population.

⁴⁴ <http://www.jointcommissioninternational.org/JCI-Accredited-Organisations/>

⁴⁵ Karun Dev Sharma, "Implementing Quality Process in Public Sector Hospitals in India: The Journey Begins", *Indian J Community Med.* 2012 Jul-Sep; 37(3): 150–152. doi10.4103/0970-0218.99909. Accessed 4 April 2013.

⁴⁶ "Apollo pulls up an ACE", *Express Healthcare*, September 2010, available online at: <http://healthcare.financialexpress.com/201009/strategy01.shtml>, cited 19 Feb. 2013

⁴⁷ http://www.apollohospitals.com/about_accreditation.php

⁴⁸ "Apollo pulls up an ACE", *Express Healthcare*, September 2010, available online at: <http://healthcare.financialexpress.com/201009/strategy01.shtml>, cited 2013-02-19

defects per million opportunities.⁴⁹ Based on five guiding principles⁵⁰ – *Define, Measure, Analyse, Improve and Control* – Max Healthcare attempts to enhance process capability when delivering services and achieve cost optimisation.⁵¹

See Appendix 2 for an overview of the corporate hospital chains in India and their quality initiatives.

3.8 National Disease Registries under the NCDIR

The **National Centre for Disease Informatics and Research (NCDIR)**, a wing under the Indian Council of Medical Research (ICMR), is responsible for various disease registries in India.⁵² It works closely with the health ministry, state governments, medical institutions/colleges and other agencies to provide baseline information and establishing data collection (on cancer, stroke, cardiovascular diseases and diabetes) and technical support to design, monitor and evaluate control programmes and activities.

3.8.1 National Cancer Registry Programme

The **National Cancer Registry Programme**⁵³ (NCRP), commenced by the Indian Council of Medical Research (ICMR) under the NCDIR in December 1981, developed a network of cancer registries across the country with an aim to generate reliable data on the magnitude and patterns of cancer, undertake epidemiological studies based on results of registry data, help to design, plan, monitor, and evaluate cancer control activities under the National Cancer Control Programme (NCCP), and develop training programmes in cancer registration and epidemiology.

Three Population Based Cancer Registries (PBCRs)⁵⁴ in Bangalore, Chennai and Mumbai were set up in 1982 and have gradually expanded over the years and as of now there are 27 PBCRs under the NCRP network. There are also five Hospital Based Cancer Registries (HBCRs).⁵⁵ The purpose of the HBCRs is to contribute to patient care by providing readily accessible information on the patients with cancer, the treatment received and its results. The data is also used for clinical research and for epidemiological purposes.⁵⁶

⁴⁹ Breakdown defects per million opportunities: 2 sigma = 308 537; 3 sigma = 67 000; 4 sigma = 6 200; 5 sigma = 533 and 6 sigma = 3.4 defects.

⁵⁰ Define (what is important to the customer?), Measure (how well is the healthcare provider doing, construct process flow), Analyze (analyze the process), Improve (improve the process performance measures – prioritise root causes, innovate pilot solutions, validate the improvement), and Control (control the process gains in order to ensure that the solution is sustained) The scope for the Six Sigma approach in hospital services, as specified by Max Healthcare includes “bed related inpatient functions”, “outpatient related functions”, “diagnostic and treatment functions”, “administrative functions”, “research and teaching functions” and issues regarding “supply chain”.

⁵¹ PowerPoint presentation available online at:

http://www.maxhealthcare.in/aboutus/awards_qualityinitiatives.html

⁵² <http://www.ncdirindia.org/>

⁵³ National Cancer Registry Programme, Indian Council of Medical Research, available online at:

<http://www.ncrpindia.org/index.aspx>

⁵⁴ Population Based Registry = Includes individuals who are residents of the geographical area (to see the disease profile in the population).

⁵⁵ Hospital Based Registry = patients could come from anywhere (the registry serves the purpose to see patient treatment patterns).

HBCRs are located at Kidwai Memorial Institute of Oncology, Bangalore; Cancer Institute (WIA), Chennai; Assam Medical College, Dibrugarh; Tata Memorial Hospital, Mumbai and Regional Cancer Centre, Thiruvananthapuram

⁵⁶ HBCRs website, available at http://www.ncrpindia.org/HBCR_WEBSITE/About_HBCR.aspx

The NCRP, located in Bangalore, is assisted by a Steering and a Monitoring Committee that meets periodically to oversee and guide its functioning. A review meeting is held annually where the principal investigators and staff of the registries present results and participate in the discussions. The meeting is preceded by a workshop.

Cancer registration in India is active and staffs of all registries visit hospitals, pathology laboratories, and all other sources of registration of cancer cases on a routine basis. Death certificates from the municipal corporation units are also scrutinised and information is collected on all cases where cancer is mentioned on the death certificates.

Over the years, the registries and the office of the NCRP have used modern advances in information technology to enter the data and also help in specific activities that involves checking the data, identifying duplicates, and matching mortality and incidence records. Data quality and completeness of coverage, a prime requisite for good cancer registration, is ensured to the best possible extent by the NCRP.

The staff from registries and the NCRP have benefited from short/long term training fellowships from established institutions in developed countries. This has helped the working of the cancer registries and also to evolve epidemiological studies. Reports based on registry data are published regularly and are available on NCRPs website.⁵⁷ Data from the NCRP registries are also regularly published by the International Agency for Research on Cancer – the cancer research arm of the World Health Organisation (WHO), in succeeding volumes of “Cancer Incidence in Five Continents”.⁵⁸

3.8.2 India Cancer Atlas

In 1999, sanctioned by the WHO, work began to develop an atlas of cancer in India. 105 centres participated and electronic data capture allowed the NCRP to map the pattern of cancer incidence in several districts in India. This mapping showed that some districts in the north-east had a significantly higher incidence of cancer.⁵⁹

This set the ball rolling, not only for the addition of more and more PBCRs (described above), but also of better use of electronic technology and improved software (developed at the NCDIR) for use in the registries.

3.8.3 Patterns of Care and Survival Studies

Since 2007, an extension to the HBCRs has been developed in order to more closely monitor patterns of care and survival in three types of cancers: cervix, breast and head & neck. These are leading sites of cancer in India and are amenable to early detection and control measures. By correlating survival to stage and treatment of the cancers, the control activities can be evaluated.

Workshops for each site of cancer were held with the clinical experts to decide what information to collect and a standardised form for reporting was developed. This 12-page form allows collection of much more clinical information than the 4-page core form for the PBCRs and HBCRs.

⁵⁷ http://ncrpindia.org/Annual_Reports.aspx

⁵⁸ <http://ci5.iarc.fr/>

⁵⁹ *DEVELOPMENT OF AN ATLAS OF CANCER IN INDIA - First All India Report: 2001-2002*, available at: http://www.ncrpindia.org/Cancer_Atlas_India/map.aspx

To support the participating centres the NCDIR developed software to help hospital staff to enter required information at registration, before, during and after treatment, as well as at periodic follow-ups. Waiting times for patients from entering the hospital to diagnosis, from diagnosis to commencement of treatment, from commencement of treatment to ending the treatment are recorded.

The biggest challenge has usually been to ensure consistency in follow-ups. The software was therefore developed to regularly send listings of patients that the clinician needs to follow up and automatically send SMS reminders to the patient as well as the treating doctor.

After completion of the treatment, 3-monthly or 6-monthly follow-ups are made. For survival analysis, the patients are followed up for 3–5 years, including 1–2 follow-up visits per year.

The Patterns of Care and Survival Studies Initiative has to date registered 65 000 patients for these three sites of cancer from 17 centres across the country. The initiative aims to account for every new patient with these particular types of cancer at the participating centres, whether they receive treatment or not. As mentioned earlier, the initiative began in 2007 and data from the three first years will be published once 75 per cent follow-ups have been completed.

3.8.4 Punjab Cancer Atlas

Due to higher incidence of cancer in Punjab (state in the North West of India dominated by intensive agriculture), the state health department, in collaboration with the NCDIR, began a project to develop a “Cancer Atlas” covering Punjab and indicating the districts of the state that have the highest percentage of cancer patients vis-à-vis age group and type of cancer. All medical institutions, hospitals, diagnostic centres, pathologists, radiotherapists, oncology-physicians and surgeons across the state were asked to register every cancer case under their treatment or diagnosis. The purpose of setting up this state-wide cancer registry and developing an atlas of cancer cases is to report the incidence and mortality of cancer and to determine survival in cancer patients, in a specified population within a defined geographic area.

3.8.5 Organisation

The NCDIR currently interacts directly with 150 centres (reporting hospitals), and each PBCR interacts with 60–70 centres. The PBCRs are based around the country, and each has a designated principal investigator. The PBCRs’ designated staff actively collect data from their participating centres and then transmit the data electronically to the NCDIR, which has a designated team that coordinates data transfer from the PBCRs.

By comparison, within the Punjab Cancer Atlas each physician or his/her nurse assistant would enter the data directly into the system.

To give an example, in Delhi a team of 8 PBCR staff visit the participating centres and actively collect data (hard copy). There is a better chance of coverage of cases through active data collection. The NCDIR provides the funds, but it is the responsibility of the principal investigator (and his/her institute) to hire and pay the team. Administrative control rests with the hosting institute, not with the NCDIR.

3.8.6 National Stroke Registry

The objectives of setting up a national stroke registry are:

- To generate reliable data on the magnitude and incidence of stroke;
- To know the patterns of care in patients with stroke.

The data collected will be useful for epidemiological, clinical and control research in stroke.

The Research Area Panel on Stroke, consisting of a number of stroke experts from different hospitals in India, recommended in April 2012 the setting up of a national stroke registry and by the end of the year invitations were sent out by the NCDIR to professional categories involved in stroke care at public and private hospitals.⁶⁰ This is an exploratory phase to decide where interest is sufficiently high to set up population- and hospital-based stroke registries across the country

Apart from a clinical diagnosis, stroke requires, an MRI or CT scan – in that respect the disease is somewhat similar to cancer (that requires microscopic diagnosis and in some cases radiologic diagnosis). At least in urban areas, the likelihood would be high that the patients would have a CT or MRI, thus ensuring that the right diagnosis is registered.

3.8.7 Diabetes and Cardiovascular Disease

The NCDIR's first cancer registries are more than 30 years old by now, and as described above a national stroke programme has been initiated, but work to establish registries on diabetes or cardiovascular disease (CVD) has yet to start.

Diabetes and CVD are a bigger challenge than cancer and stroke as advanced imaging techniques are not required for diagnosis. Any number of practitioners could therefore diagnose and treat these conditions and it is thus harder to collect the data and the data may also be somewhat more unreliable.

Note that there is a national diabetes registry for the uncommon form of diabetes in young children, The Neonatal Diabetes and Maturity Onset Diabetes of Young Registry India, which is hosted by a diabetes specialist centre and the Madras Diabetes Research Foundation (MDRF).⁶¹

3.9 Other Disease Registries

3.9.1 Chronic Kidney Disease Registry

In the absence of knowledge on incidence and prevalence of chronic kidney disease (CKD) in India, it was decided that the Indian Society of Nephrology (ISN) would take the lead in forming the Chronic Kidney Disease (CKD) Registry.⁶² The aim of the registry is to establish the prevalence and pattern of diseases, provide demographic and socio-economic information and risk factor analysis and provide an information platform for advocacy, prevention/treatment proposals, and improvement opportunities.

⁶⁰ <http://strokeregistryindia.org/>

⁶¹ <http://neonataldiabetes.in/index.html>

⁶² <http://www.ckdri.org/>

The Registry

Initially, 10–11 nephrologists at major institutions (private/public) contributed data. The registry was supported financially by an educational grant from a pharmaceutical company. The number of contributing centres increased gradually and today 170–180 centres contribute data.

Three years after the registry was set up, a facility for on-line submission of data was opened but a majority of submissions are nonetheless still on hard copy.

The form for data collection was developed to capture the data of a CKD patient at his/her first visit to that hospital. No follow-up data is captured.

Patients are divided into three categories and three forms are used:

- Adult CKD (currently there are 50–60 000 entries in the registry)
- Haemodialysis (very recent)
- Paediatric CKD (small number)

The patients in the registry are representative of the Indian population. They come from all over the country and are rich as well as poor. However, of all people suffering from CKD only a small subset are contained in the registry. This is not only because the registry only covers a small number of hospitals, but also because generally only the most seriously affected patients seek help at hospitals. Globally, it is estimated that 10 per cent of the population suffer from CKD, which would imply 120 million people in India. Affected patients are graded from stage 1 to 5 of CKD. For every patient in stage 5, which corresponds to the end-stage (dialysis/transplant) of CKD, there would be 10 patients in stage 3–4 and 200 patients in stage 1–2 (who will only be picked up if they are investigated). In India, normally only patients at stage 4–5 therefore seek medical care and they represent a small, but seriously affected, subset of all CKD patients.

The major drawback of the registry is that data is only collected once. A typical example (at AIIMS⁶³) is that a patient comes to the department for the first time and is diagnosed as end-stage (5) CKD and advised that he needs a transplant. He will be registered as “stage 5 on medicine”. He will then leave the hospital to decide, arrange finances and find a kidney donor. The registry will reflect that there are a large number of end stage patients on medicine; but this may actually not be a true reflection of matters.

The main output/results generated from the CKD registry are: gender, age group, economic situation, etiological differences, common complication patterns, e.g. diabetes, practice pattern in the form of what medicine is used. The registry publishes an annual report, which is presented at the annual meeting of the ISN.

Multi-Centre Study to Determine the Prevalence of CKD in India

In a new initiative, a multi-centre study comprising nine hospitals located across India has begun with the purpose of determining the **prevalence of CKD** in India. This study has been funded by the ICMR for three years.

⁶³ All India Institute of medical Sciences (AIIMS), New Delhi – a major public teaching hospital.

Lack of Treatment Capacity the Main Challenge for Accessibility

The ISN publishes guidelines for care of CKD patients, based on international research. Except for a nominal admission fee and daily charge the public hospitals do not charge for services and basic medicines, e.g. the public hospitals do not charge for dialysis, but the patient needs to cover the costs of consumables. The same is true for transplants or other surgery; the service is free but consumables need to be paid for by the patient.

However, patients in the Below Poverty Line category (BPL; which constitutes approx. 20 per cent of patients) are expected to be given free medical treatment. In reality, because this number is so huge, resources are not sufficient. The number of dialysis machines and consumables, as well as manpower, is insufficient.

The government is currently developing a programme to establish stand-alone dialysis centres so that it should be possible to provide dialysis at every district level and every medical college. INR 15 billion (USD 280 million) has been budgeted. The government has also devised a programme for training non-nephrology physicians on a 1 year course in dialysis medicine, and expects that they will man the stand-alone dialysis units.

3.9.2 Indian Transplant Registry

Indian Transplant Registry⁶⁴ – The purpose of the National Transplant Registry is to collect transplant-related data from various centres in the country and to collate the data from time to time to determine the number of transplants done in the country, essential demographic data of Indian patients undergoing transplants, the immunosuppressive regimes used by various centres, short/long-term results, complications during management, patient survival after transplants, donor profiles, etc.

The data is to be stored on a secure server and can be accessed by any registered member of the Indian Society of Organ Transplantation (ISOT). The information submitted will be highly confidential with only collated data available for viewing. The site is to be developed in phases and in the first phase, data related to kidney and liver transplants will be captured. For transplants in India (kidney, heart, liver, pancreas, lungs), one may register on the website with essential information and a username and password will be sent within 24 to 48 hours. The registry will help in performing a national audit to understand short/long-term outcomes in the complicated field of transplants.

After a recent change in the legislation⁶⁵ governing transplantations in India the government has decided to introduce a new transplant registry that will be funded by the government. Cases will be followed up. Discussion is ongoing to make it mandatory to report to the registry. The new registry will be under the National Organ and Tissue Transplant Organisation (NOTTO) formed under the MoHFW.

3.9.3 Kerala Acute Coronary Syndrome Registry

Cardiovascular disease (CVD) is the leading cause of death in India leading to premature death, disability, and financial catastrophe due to high out-of pocket expenditures for acute cardiovascular care. The South-Indian state of Kerala has one of the lowest infant mortality

⁶⁴ <http://www.transplantindia.com/>

⁶⁵ The original act from 1994 was amended via a proposal from 2009 moved by the Minister of Health and Family Welfare, the Transplantation of Human Organs (Amendment) Bill (2009). Lok Sabha (lower house of the Indian parliament) passed the amendment on 12 August 2011 and Rajya Sabha (upper house of the Indian parliament) on 26 August 2011. <http://www.igovernment.in/site/transplantation-human-organs-act-be-amended>

rates, the highest literacy rate, and the longest life expectancy of all Indian states and is thus considered to have a more well-developed healthcare system than the other states. This was one reason why Kerala was selected for an investigation in the patient- and hospital-level characteristics in the presentation, management, and outcomes of cardiovascular disease (CVD), including acute coronary syndrome (ACS).⁶⁶

There are limited registry data from India on individuals who experience ACS. The two largest ACS registries in India to date are OASIS-2⁶⁷ (1028 patients; 1999–2000) and CREATE⁶⁸ (20 937 patients; 2001–2005). In both cases, data from a large number of hospitals throughout India was collected.

The Cardiological Society of India–Kerala Chapter (CSI-K) developed a prospective ACS registry to evaluate contemporary trends in the presentation, management, and outcomes of ACS patients in a broad range of registered hospitals and providers in Kerala to evaluate the opportunities for data-driven continuous quality improvement. Presentation, management, and in-hospital outcomes of 25 748 ACS patients across 125 hospitals throughout Kerala were analysed and published. The measured parameters were compared to previous Indian studies as well as international studies. Areas with potential for quality improvement are also discussed.

A quality improvement programme based on the results has been planned and funded and will commence shortly (see below).

3.10 The Centre for Chronic Disease Control is Building Research Capacity in India and Beyond

In order to build research capacity in developing countries, the WHO and the Global Forum for Health Research, together with 14 other organisations set up the Initiative for Cardiovascular Health in Developing Countries (IC Health) in 1999. In India, the Centre for Chronic Disease Control (CCDC) serves as the secretariat (local partner) for IC Health.

The CCDC's mission is to build research capacity and conduct translational research and policy-relevant research in areas of chronic diseases, mainly cardiovascular disease (CVD).

The CCDC has been recognised as a Scientific and Industrial Research Organisation (SIRO) by the Department of Scientific & Industrial Research (DSIR) and the Ministry of Science and Technology, Government of India. It is part of the closely-knit, world-class research collaborative network comprising the Public Health Foundation of India (PHFI), Emory University of USA, the All India Institute of Medical Sciences (AIIMS), the Madras Diabetes Research Foundation (MDRF), and the South Asia Network of Chronic Diseases. Model Surveillance System for CVD in South Asia

An attempt is being made to establish a model surveillance system for CVD in South Asia, and see whether the governments can adapt it if it is successful. The current project is being run in three South Asian cities; Delhi, Chennai, and Karachi. Urban areas were chosen

⁶⁶ Mohanan, P. P. et al. "Presentation, management, and outcomes of 25 748 acute coronary syndrome admissions in Kerala, India: results from the Kerala ACS Registry", *Eur Heart J Advance Access published September 7, 2012*. Available at doi:10.1093/eurheartj/ehs219.

⁶⁷ Prabhakaran D. et al. "Two-year outcomes in patients admitted with non-ST elevation acute coronary syndrome: results of the OASIS registry 1 and 2.", *Indian Heart J* 2005;57:217–225.

⁶⁸ Xavier D. "Treatment and outcomes of acute coronary syndromes in India (CREATE): a prospective analysis of registry data", *Lancet* 2008;371:1435–1442.

(over rural settings) as they have almost double the burden of CVD. This is funded by the National Heart, Lung, and Blood Institute (NHBLI) USA and implemented by the PHFI collaboration.

The work encompasses two components: surveillance and research. A unique cohort model is employed, where some 150 000 individuals (selected by population-based proportionate sampling) in the three cities are phenotyped (for CVD risk factors). The first follow-up has been completed and the second is in progress. The aim of the study is to look at incidence, mortality, and eventually causality. With data on mortality, causality can be determined in terms of the risk factors. An Indian score will be developed that may replace the international scores for risk which have been used hitherto.

In a few years another cross-section survey will be made in the same areas to get the secular trends to see how the risk factors have changed and understand what areas to focus on, e.g. is there an increase in obesity or a decrease in lipids?

3.10.1 Current research portfolio

In addition to the South Asian surveillance system described above, the CCDC is pursuing a number of translational research projects aiming to improve healthcare quality, usually with low-cost solutions in order to make them sustainable in the South Asian setting. Some of the projects are briefly described below.

Low Cost Quality Improvement Programme at Diabetes Clinics

This project, funded by the National Heart, Lung, and Blood Institute (NHBLI) in the USA, aims at evaluating low-cost quality improvement for outpatient care at diabetes clinics. It evaluates the new role of care coordinators, who are non-physician health care workers, and IT-enabled decision support system for disease management, on a tablet or computer. This is a randomised control trial, where the usual care pattern is compared with a care-coordinator enabled programme to see if there is a difference in outcome at the end of five years. Outpatients with diabetes with certain inclusion criteria are included in the study. The patients are in second or tertiary care, largely in tertiary care, and a mix of private and public healthcare providers. The study is being conducted at 10 centres in India and 1 centre in Pakistan.

The decision support system has prompts at periodic times and can send text messages to the patients, e.g. reminding them to come for a scheduled follow-up. When the patients visit the clinic, their data are entered in the decision support system. If it detects something that is not in order, it generates a report, e.g. “the blood sugar level is not under control”. It may suggest new drugs and can even name them. The decision support system has been developed by PHFI and CCDC over a period of two years.

Evaluation of the National Non-Communicable Disease Programme in a 40 000 Cohort

At 6 community health centres in the North-Indian state of Himachal Pradesh, this project aims to mirror the recently introduced National Programme for Prevention of CVD, Diabetes, Stroke and Cancer to see how it performs. The CCDC has developed a mobile-phone based decision support system and an electronic health record used by healthcare workers/nurses. A cohort of 40 000 people is being developed, which is a huge investment as the aim is to follow the cohort for 10 years. The participating individuals must give written consent for the community-based research programme.

Secondary Prevention in Acute Coronary Syndrome Treatment

This project, funded by the NHBLI, is planned but has not yet begun. The project intends to recruit 100 hospitals in Kerala for a step-wise quality-improvement programme according to a check-list programme. It includes shortening door-to-needle time in the emergency ward and training staff for better adherence to treatment guidelines on admittance, treatment, and discharge of patients.

This is a question of low-hanging fruit. People come to the hospital but are not always given the right treatment. Based on the registry study (described in section 3.9.3), there is scope for improvement as nearly 40 per cent of patients do not get the right treatment, even if they come to teaching hospitals. Timed intervention for a group of hospitals is followed for five years. The next group of hospitals will begin 6 months after the initial group of hospitals.

Community-Based Registry of Diabetes

PHFI and CCDC are also developing a community-based registry of diabetes that includes 10 000 patients in two cities; Visakhapatnam in Andhra Pradesh and Sonapat in Haryana. In the study, which is just about to begin, the intention is to screen patients at the community level using a proportionate population-based sampling. To get 10 000 patients it is expected that 100 000 people need to be screened. The 10 000 patients will be followed up on complications. A pharmacy component has been added. Pharmacists will be trained and incentivised to give patients lifestyle instructions when they come to buy their diabetes medicines.

3.10.2 System for Cardiovascular Diseases in Indian Industrial Population

During 2002–2008 an industrial work site intervention programme was run where employees in medium to large companies and their families were included. It involved 10 industries (public and private sector) all across India. The project included the establishment of a morbidity and mortality surveillance system and a survey of cardiovascular disease, diabetes, and other risk factors. The second phase involved the evaluation of a health promotion programme in these industries. The study was endorsed by the WHO and the MoHFW. The CCDC was responsible for coordination, data collection, data management, and data analysis. The project has resulted in 16 publications.⁶⁹

3.11 Organisations/Institutions Involved in Various Healthcare Registries and Health Measurements in India

The important agencies dealing with the Health Management Information System (HMIS) in the Indian Government's Healthcare System are:

The Central Bureau of Health Intelligence (CBHI)⁷⁰ is the health intelligence wing of the Directorate General of Health Services (DGHS). At the national level it is the main organisation which deals with the collection, compilation, analysis and dissemination of information on health conditions in the country, covering various aspects of health including health status, health resources, utilisation of health facilities, etc.

⁶⁹ Reddy, K. S., et al. "Methods for establishing a surveillance system for cardiovascular diseases in Indian industrial populations", *Bulletin of the World Health Organisation*, June 2006, 84(6) and Prabhakaran, D. "Impact of a Worksite Intervention Program on Cardiovascular Risk Factors A Demonstration Project in an Indian Industrial Population", *JACC* 53(18), 2009:1718–28.

⁷⁰ <http://cbhidghs.nic.in/>

CBHI has the following broad objectives:

- Maintain and disseminate the National Health Profile (NHP) of India.
- Maintenance of the Health Sector Policy Reforms Options Database.
- Inventory and GIS Mapping of Government Health Facilities in India.
- Facilitate Capacity Building & Human Resource Development in Health Information System & Medical Records management.
- Need Based Operational Research for Efficient Health Information System as well as use of the Family of International Classification (FIC) in India.
- Review the progress of health sector Millennium Development Goals (MDG) in India.

The CBHI continuously collects data throughout the year (delivered on-line) from states/UTs regarding the number of cases and deaths due to communicable and non-communicable diseases. The CBHI also collects data after the end of each calendar year on public and private establishments – health infrastructure and health human resources. The deadline for the states' health ministries to report data for January to December of the previous year is 15 February.

First, the 640 districts deliver the requested data to the states' health ministries, which compile the district data and pass them on to the CBHI. The CBHI does not publish data continuously, only data compiled in the National Health Profile (NHP) once a year (available in print and online⁷¹). The CBHI validates all data before publishing the compiled lists.

Data is published under six headings in the NHP:

1. Demographic Indicators
2. Socio-Economic Indicators
3. Health Status Indicators
4. Health Finance Indicators
5. Human Resources in Health Sector
6. Health Infrastructure

HS-PROD⁷² is a database for health sector reforms being developed by the CBHI. Currently it contains more than 260 reform options from a varied range of fields and stakeholders like the State/UT governments, development partners, and NGOs. The idea is to spread best practices and innovations in health services management across India.

The CBHI has created a database of government health facilities, educational institutions, training centres, and other healthcare establishments in India using a geographical information system (GIS). The database contains the exact location of each of the 116 types of government healthcare facilities. By displaying the data on maps this becomes a useful tool in health planning. Eventually, the information will be provided to patients on-line to enhance accessibility, giving them for example instant knowledge of the nearest health centre, hospital, blood bank, etc. and the specific facility's capacity, opening hours, etc.

⁷¹ National Health Profile of India is available at <http://www.cbhidghs.nic.in/index1.asp?linkid=267>

⁷² www.hsprodindia.nic.in

The Statistics Division of the Department of Health and Family Welfare is responsible for the Health Management Information System (see 3.1) and facilitates the flow of physical and financial performance from the district level to the state HQ and the centre using a web-based HMIS interface. They are involved in concurrent evaluation of the NRHM and the organisation of surveys. The division is organised into a computer unit, a demography unit, a performance monitoring and evaluation unit, and an impact monitoring unit. The impact monitoring unit has a field evaluation unit and a concurrent evaluation unit. As there is a greater thrust in the Reproductive and Child Health (RCH) programme, continuous funding is assured for its surveys and studies. The staffs are exposed to statistical techniques and survey methodologies. It brings out various publications periodically such as monthly bulletins on family welfare statistics and a yearbook on family welfare programmes in India.

3.12 Other players beyond the HMIS

The Office of the Registrar General and Census Commissioner under Ministry of Home Affairs, Government of India is responsible for the Sample Registration System (SRS) – India conducts census operations once every ten years. In-between, the estimates of vital statistics are based on the Sample Registration System, which was described in section 3.2.

The National Centre for Disease Control (NCDC)⁷³ is under the administrative control of the Director General of Health Services, MoHFW. In view of the drastic reduction achieved in the incidence of malaria under the National Malaria Eradication Programme (NMEP), the Government of India decided to reorganise and expand the activities of the institute to cover other communicable diseases as well.

The NCDC has recently developed a partnership with the US Center for Disease Control and Prevention's (CDC) Global Disease Detection (GDD) Programme in order to establish a GDD regional centre in India.

NCDC was established to function as a national centre of excellence for control of communicable diseases. The function of the institute also includes various areas of training and research using a multi-disciplinary integrated approach. The institute is also expected to provide expertise to the States/UTs on rapid health assessment and laboratory-based diagnostic services. Surveillance of communicable diseases and outbreak investigation also forms an indispensable part of its activities (see 3.3). The institute has its headquarters in Delhi and has 8 out-stations across the country.

There are several technical divisions at the headquarters of the institute, i.e. the Centre for Epidemiology and Parasitic Diseases (Dept. of Epidemiology and Dept. of Parasitic Disease), the Division of Microbiology, the Division of Zoonosis, the Centre for HIV/AIDS and related diseases, the Centre for Medical Entomology and Vector Management, the Division of Malariology and Coordination, and the Division of Biochemistry and Biotechnology. Each division has several sections and laboratories dealing with different communicable diseases. The institute has a 24/7 Disease Monitoring Cell to respond to enquiries related to disease outbreak.

The International Institute for Population Sciences (IIPS)⁷⁴ is a deemed university located in the city of Mumbai, Maharashtra, India and was started in 1956 under the joint

⁷³ <http://www.nicd.nic.in/>

⁷⁴ <http://www.iipsindia.org/>

sponsorship of Sir Dorabji Tata Trust, the Government of India, and the United Nations. It has established itself as the premier Institute for training and research in population studies for developing countries in the Asia and Pacific region. Besides teaching and research activities, the Institute also provides consultancy to the government and non-government organisations and other academic institutions. The MoHFW used the services of IIPS as the nodal agency responsible for coordinating the NFHS and the DLHS.

The National Accreditation Board for Hospitals & Healthcare Providers (NABH)⁷⁵ is a constituent board of the Quality Council of India, set up to establish and operate accreditation programmes for healthcare organisations (see 3.6). The board is structured to cater to much desired needs of consumers and to set benchmarks for progress of health industry. The board while being supported by all stakeholders including industry, consumers, government, has full functional autonomy in its operations.

The Disease Management Association of India (DMAI)⁷⁶, which also goes by the title of The Population Health Improvement Alliance, was formed by executives from the global healthcare industry to gather all healthcare stakeholders onto one platform. The DMAI has been successful in establishing an intellectual pool of top healthcare executives to become an enabler in building a robust healthcare system in India. The DMAI is building the knowledge pool to contribute and convert 'Ideas' into 'Reality' for healthcare in India. The DMAI is the only non-profit-making organisation focused on population health improvement in India. Among several other initiatives, the DMAI is working on creating a central disease registry for chronic patients across India.

⁷⁵ <http://www.nabh.co/main/index.asp>

⁷⁶ <http://www.dmai.org.in/content/about-dmai>

4 Conditions

There is no significant debate in India relating to patient's integrity vis-à-vis disease registries, or other modes of collection and use of personal clinical data and legislation in this area is not yet in place. The absence of debate on personal integrity may be connected to the general under-capacity in the public health system, leading to access problems and a greater concern among individuals and society at large to solve the capacity crunch in India's public health system first. Secondly, a significant proportion of the population is not well educated and may therefore not consider confidentiality of patient data an issue.

However, other challenges exist in data collection within the healthcare system. The absence of a unique identifier, the lack of human resources within the public healthcare system and the absence of parts of the legislative framework that could ensure better coverage and consistency in data collected. These problems are discussed below, with reference to systems and actors described in the previous section.

4.1 Challenges for national registries

4.1.1 Unique identifier missing

The PBCRs are taken up in English (not local languages). The NCRP uses a standard code form for many of the entries, used across all the registries. All staff have been trained and manuals developed. The aim is to keep the quality of the registry data at international standard.

In the handling of data from the PBCRs regular quality checks, according to the international agencies for research on cancer under the WHO are employed. However, the main focus is on duplicate elimination. As India does not yet have a unique personal identifier. One patient could go to a lab and then go to a consultation, and finally to the treating hospital, generating three data sets submitted to the PBCR. The system software is developed to be able to identify these three data sets as belonging to the same individual. The duplicate checks software will detect any permutation of "first name", "middle name", and "last name" and put it up as a potential duplicate. The software will also detect the phonetics in case the same name is spelled differently. Actually, names are classified and divided into 4–5 different zones as North Indian names are different from South Indian names or East Indian names. Potential duplicates are sent back to the district registries for guidance. As can be imagined from the above, duplication detection and deletion is a major exercise.

The Government of India has initiated a process to provide each citizen with a unique identification number (Aadhaar number). The process of providing Aadhaar Numbers to citizens began in 2010 and as of March 2013 300 million numbers have been assigned (25 per cent of the population). One of the future uses of the Aadhaar might be to create "healthcare and patient record databases".

Incidence data under the NCRP is fairly good, but coverage is a challenge. The 27 PBCRs cover 7.45 per cent of the Indian population. They represent 16 States and one Union Territory (UT). The remaining 15 States and 5 UTs are still not covered, although there is pressure from the MoHFW and the concerned states to be included, with their own PBCRs. Within this 7.45 per cent of India's population, 70–80 per cent of those who get cancer will be registered in one of the 27 PBCRs. Although there is a commitment from the hospitals that are participating, there are logistical issues that reduce the "coverage number".

4.1.2 State Legislation Needed to Make Cancer a Reportable Disease

Generally NCRP has a good collaboration with the hospitals/centres, but cancer is not yet a compulsory reportable disease. The NCRP and the MoHFW have tried to persuade several states to make it compulsory, but this has not happened yet, with the exception of Punjab (where a documented higher incidence of cancer than the Indian average had moved the state government to make reporting of cancer cases compulsory). In other states, there may be issues in the medical community due to lack of awareness or other priorities within the healthcare system.

4.1.3 Staff Shortage Affects Reporting

Healthcare providers are all very busy, particularly considering the high patient burden at most clinics, so they would like to have a simpler mechanism for reporting or separate personnel to do this work. In addition, if they provide the data, they would like to have something in return, if not money. These are some of the issues that the NCDIR is trying to address through further development of its software. The aim is to be able to provide participating healthcare providers with the results of their patients, what their survival is and a comparison of the provider's own patients' survival to others. The reluctance at some hospitals (to spend time reporting cancer cases) is not dependent on whether it is a private or a government hospital. However, in general the government hospitals have many cases waiting and they therefore need additional staff to record the data that the registries request. To some extent the NCDIR provides this, but more can be done.

4.2 Challenges in Performance Data Collection

When it comes to clinical and performance data collection and analysis the situation has improved under the NRHM, but it is mainly the public healthcare system that contributes. There is no legal mandate for private actors to provide this type of data (although they are mandated to report communicable diseases to the IDSP). In 2010, the Central government passed the Clinical Establishment Act, which also mandates private actors to provide clinical and performance data. However, this central legislation must first be approved by each state assembly.

Seven states have already approved the new legislation and the National Health Minister is pressing the other 28 states/UTs to approve the legislation.

Under the new legislation private practitioners would need to report how many patients they are seeing and what disease they have.

5 Use of Data

A few examples of how the measured data is used and what impact it has in policy formulation are given below.

5.1 Use of Registry Data

5.1.1 NCDIR's National Cancer Registries

The NCRP has made significant impact after 30 years of existence and a growing coverage by newly started PBCRs and HBCRs and a number of resulting publications; particularly noteworthy the tri-annual reports on the PBCRs and HBCRs as well as trend reports going all the way back to 1982. The collected knowledge has played a paramount role in the design of the National Cancer Control Programme launched by the MoHFW. Further, the registry data has also provided the rationale behind the current Tobacco Legislation.

5.1.2 Punjab Cancer Atlas

Initial data from the Punjab Cancer Atlas showed that on average the number of cancer patients in Punjab (90 cancer patients per 100 000 population) is higher than the national average (80 per 100 000). Further, numbers in some regions are far higher (up to 136 per 100 000 in the worst affected district). The Punjab state government has voiced concerns that the high incidence of cancer may be connected to excessive use of pesticides in affected areas.⁷⁷ The state government had already earlier decided to ban the manufacture, import and use of carcinogenic pesticides. It has also made arrangements for educating the farmers on their healthcare and the judicious use of pesticides. Further, the government has also decided to provide medical care, financial assistance, and setting up of super-speciality hospitals for treatment and prevention of cancer in the affected districts.⁷⁸

5.1.3 National Health Profile

The National Health Profile (NHP), collated by the CBHI, is published every year (in July/August for the preceding calendar year). It contains a wide range of health-related data from the whole country, collected by a number of organisations, and is used as a planning tool by the MoHFW for health planning and monitoring of the entire health sector. It is also used as a planning tool by the Government's Planning Commission, thus the Health section in the 5-year plan is based on data from the NHP. Further, the NHP is also referred to in parliament when questions relating to health are being answered by responsible ministers. So, clearly the health-related data compiled in the NHP is essential for policymaking. In addition it is used by researchers and medical colleges, etc.

5.2 Non-Government Players

5.2.1 Chronic Kidney Disease Registry

The initial aim of setting up the CKD registry was to be able to influence the policy formulation, but the experience has been that policy makers are not paying so much attention to professionals, as in a western setting. Matters have improved lately and more attention is

⁷⁷ "Punjab's cancer cases exceed national average", *Times of India*, 29 January 2013.

⁷⁸ "Punjab bans pesticide causing cancer", *The Hindu*, 23 April 2012.

paid to the results generated by the registry and the recommendations for quality improvements have been derived from the data. A multi-centre study is now commencing across the country to establish the prevalence of CKD in India and it must be expected that this will further expand the information available and may thus be helpful to obtain stronger impact on policy formulation.

5.2.2 Centre for Chronic Disease Control

The CCDC has used its experience to influence policy development⁷⁹, but public policy has many stakeholders and many people are involved in the process. For example, the National Programme for Prevention of CVD, Diabetes, Stroke and Cancer has taken 8–9 years to develop and gone through several cycles. The CCDC has interacted with policy-makers at several stages and given input to the process of policy development.

One of the studies mentioned in section 3.10.1, the industrial population study, led to a number of health recommendations that have been put to further use by the MoHFW and other organisations, such as the CBHI for example, as a basis for health-promotion advertisements on TV.

PHFI and CCDC are also active in building capacity in policy development. A funding programme for health leadership (for senior physicians) exists, through which they can visit Emory University in the USA for three weeks of intensive training in policy development. On their return they are invited to contribute with their new skills to the institutions where they are working.

Another way that the CCDC has tried to influence the policy process is to point at the economic consequences, on the individual as well as on the state level.

The CCDC also contributed to an economic impact study in four countries, looking at heart attack/stroke patients and their families (in India (Kerala), Tanzania, Argentina, and China). In India out of pocket expenditure is about 80 per cent. Two thirds of patients in the study needed to employ distress financing. Catastrophic health expenditure (more than 40 per cent of the sustainable level) was observed in almost half of patient cases. This has proved to be an important advocacy document vis-à-vis the government. In another study macroeconomic effects of CVD in 5 countries were discussed in terms of what 1 per cent or 3 per cent reduction in CVD entails for economic growth.

5.3 Incentives under the National Rural Health Mission

Under the NRHM, the process of performance-based monitoring has been initiated emphasising ‘accountability’ by way of engaging various stakeholders including the end-users. The MoHFW rewards states for better performance under the NRHM, based on the health outcome indicators. Incentives in terms of additional allocation and disincentives in terms of budget cuts are also part of the national government directives to the states for the NRHM planning process (See Appendix 3). Several state governments also have incentives in terms of honouring better performing districts based on specific parameters.

The NRHM mother and child care scheme (JSSY) which is centrally funded, provides incentives in the form of cash assistance to pregnant women and community volunteers (ASHA), for antenatal care during the pregnancy period, institutional care during delivery

⁷⁹ For example, see Rajan & Prabhakaran, “Non-Communicable Diseases in India: Transition, Burden of Disease and Risk Factors – A Short Story”, *India Health Beat*, 6(1), June 2012. Available at: http://phfi.org/images/pdf/policy-notes/Policy_1.pdf. Last accessed 4 April 2013.

and the immediate post-partum period in the public health centre. These performance indicators are reported on a monthly basis. The objective behind this scheme is to reduce overall maternal and infant mortality and to increase the frequency of institutional deliveries for poor families. Incentives are also provided to recruit and retain medical and paramedical professionals to provide services in public health facilities that are situated in remote and difficult areas.

6 Discussion

The massive public health service in India has all positive intentions and examples of attempted efforts towards building a provider and patient-friendly public healthcare system. The possibilities lie in building up a comprehensive mechanism to improve quality of health services in the primary healthcare system, but achieving the same in tertiary healthcare is a daunting task due to the presence of diverse stakeholders organising the services. Ensuring accountability of service providers through medico-legal instruments, that are agreed upon and implemented along with standardised protocols, as well as continuously enhancing consumer awareness at all levels about their rights to quality healthcare, may improve the current status.

During the 11th five-year plan period a number of measures were tried to improve quality of care. This was based on an understanding that even with available inputs, at the level of the hospital there were many management steps that could improve quality of care. Patient satisfaction often related to the dignity with which they were treated and to basic amenities in the hospitals. The most widespread approach to quality in the 11th plan period was the creation of quality assurance committees that would use a checklist to monitor for quality gaps. With few exceptions, this approach did not sustain or gain the necessary importance it needed nor have measurable impacts. They were indistinguishable from routine monitoring. The major reason for this was lack of adequate professional set-up of quality assurance cells at state and district levels.⁸⁰

For sustainability of quality in the service provision it was essential that states should have their own quality assurance mechanism. A number of hospitals were taken up for NABH in a number of states; Kerala, Gujarat, Madhya Pradesh, to name a few. However, most never got accredited and the high degree of inputs needed to get NABH and to sustain such an accreditation was prohibitive. Another approach which was piloted by the National Health Systems Resource Centre (NHSRC)⁸¹ built on the ISO system, adding 24 state government-NHSRC specified mandatory processes which were to be audited. Currently over 100 facilities are certified and another 500 are in the pipeline.

The process of health registries will get a major boost in the 12th Plan (2012–2017) as it proposes a composite Health Information System (HIS)⁸² that would incorporate the following:

1. Universal registration of births, deaths and cause of death. Maternal and infant death reviews.
2. Nutritional surveillance, particularly among women in the reproductive age group and children under six years of age.
3. Disease surveillance based on reporting by service providers and clinical laboratories (public and private) to detect and act on disease outbreaks and epidemics.

⁸⁰ *Report of the Working Group on National Rural Health Mission (NRHM) for the Twelfth Five Year Plan (2012-2017)*, available at: http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG_INRHM.pdf, last accessed on 4 April 2013.

⁸¹ http://nhsrindia.org/quality_page.php

⁸² http://planningcommission.nic.in/aboutus/committee/wrkgrp12/health/WG_INRHM.pdf, last accessed 4 April 2013.

4. Out-patient and in-patient information through Electronic Medical Records (EMR) to reduce response time in emergencies and improve general hospital administration.
5. Data on Human Resources within the public and private health system
6. Financial management in the public health system to streamline resource allocation and transfers, and accounting and payments to facilities, providers and beneficiaries. Ultimately, it would enable timely compilation of the National Health Accounts on an annual basis.
7. A national repository of teaching modules, case records for different medical conditions in textual and audio-visual formats for use by teaching faculty, students and practitioners for Continuing Medical Education.
8. Tele-medicine and consultation support to doctors at primary and secondary facilities from specialists at tertiary centres.
9. Nation-wide registries of clinical establishments, manufacturing units, drug-testing laboratories, licensed drugs and approved clinical trials to support regulatory functions of Government.
10. Access of public to their own health information and medical records, while preserving confidentiality of data.
11. Programme Monitoring support for National Health Programmes to help identify programme gaps.

Further, the 12th plan should encourage quality certification of public hospitals. One type of certification involves certification of quality of care in terms of the input standards – infrastructure, human resources, drugs and equipment, and the outputs in terms of the packages of services available. This certification ensures that the hospital lives up to the Indian Public Health Standards. Another form of certification relates to the organisation of work and processes central to providing ethical, efficient and effective quality care. Such certification is relatively independent of the level of inputs. It only certifies that there is a quality management system in place that ensures the best quality of outputs for the level of inputs currently available. Quality certification should not remain limited to standards of infrastructure but it should have thrust on comprehensive in-house quality assurance for both infrastructural and service delivery. A good quality service delivery should be first certified by district and State quality assurance cells/committees before any third party certification.

The 12th plan envisages that every district would announce as part of its five year strategic district plan, the package of services each facility would guarantee such that taken together the district health system would ensure universal access to good quality of comprehensive Reproductive and Child Health (RCH) services, emergency care and trauma related services, infectious diseases management and chronic disease management. Such a district plan would become the instrument to be used for programme audit by the government and for social audit and community monitoring purposes.

One of the most important areas where persistence and quality is needed is in the state level institutions of management and governance. Governance institutions need to function as good governance and need to have the necessary separation from management functions. The governing boards of the State and District Health Societies and Rogi Kalyan

Samitis⁸³ must perform different functions from the executive committees. The programme management units must function as secretariats of the executive committees.

An accountability framework needs to be built with clearly defined responsibilities for all officers at all levels. Involvement of communities should be strengthened to ensure that the accountability framework is implemented effectively. The principles of good governance are to be emphasised and practices such as the display of expenditures on the district and state websites on a monthly basis could be mandated to ensure transparency in the 12th Plan.

One direction of change would be to integrate the various steps undertaken by the Ministry of Health and Family Welfare over different periods into one integrated 'National Health Survey' with a periodicity of three years. Meanwhile, programme evaluation of specific strategies would be continued using appropriate methodologies to assess the contribution of each programme to the overall goals.

⁸³ Rogi Kalyan Samiti (Patient Welfare Committee) - <http://www.mohfw.nic.in/NRHM/RKS.htm>

7 List of People Interviewed

Dr. A. Nandakumar, Director-in-Charge, National Centre for Disease Informatics and Research, Indian Council of Medical Research, Bangalore

Dr. Sanjay K. Agarwal, Professor & Head of the Department of Nephrology, All India Institute of Medical Sciences, and Convener for the Chronic Kidney Disease Registry of India. Member of Core Group National Organ and Tissue Transplant Organisation (NOTTO).

Dr. B. N. Dhanya Kumar, Director of Health & Family Welfare Services, Government of Karnataka

Dr. Pradeep Saxena, Director of the Central Bureau of Health Intelligence, Ministry of Health & Family Welfare

Dr. D. Prabhakarab, Executive Director of the Centre for Chronic Disease Control

8 Appendix

Appendix 1: Institutional design of the National Rural Health Mission

Levels	Entities	Members	Functions
Village	Village Health & Sanitation Samiti (local government body)	Panchayat representatives, ASHA and community health volunteers	Rogi Kalyan Samiti manages public hospitals.
District	District Health Mission	District Health Head as Convener, all relevant departments, NGOs, private professionals etc.	Controls, guides and manages all public health institutions in district CHCs, PHCs & SCs.
State	State Health Mission	Chaired by State Chief Minister, Co-chaired by State Health Minister, Convener State Health Secretary and representatives from relevant departments, NGOs and private professionals.	
Central	National Mission Steering Group	Chaired by Union Minister for Health & Family Welfare. Includes Deputy Chairman of Planning Commission, Ministers of Panchayati Raj, Rural Development, Human Resource Development and public health professionals.	Provides policy support and guidance to the Mission.
	Empowered Programme Committee serving as Executive Body of the Mission	Chaired by Secretary, Health & Family Welfare.	
	Standing Mentoring Group		Guides and oversees the implementation of ASHA initiatives.
	Task Groups		Selected for time-bound tasks.

Appendix 2: Corporate Hospital Chains in India

Hospital	Number of hospitals in India	Capacity (number of beds)	Patient Volume	Accreditation	Additional Quality Initiatives
Apollo Hospitals Enterprise Limited	49 hospitals across the country (36 owned, including subsidiaries, joint ventures and associates. 13 managed or franchised)	7987 beds	In patient admissions 2011-12: over 280 000. Out patient volumes 2011-12: Over 2 500 000.	7 hospitals have received accreditation by the Joint Commission International (JCI) USA and 5 hospitals by the National Accreditation Board for Hospitals & Healthcare Providers (NABH) (Annual Report 2012). 1 hospital has been accredited by the National Accreditation Board for Testing and Calibration Laboratories (NABL). 1 hospital has been awarded an ISO 9002 certification.	Apollo Clinical Excellence - ACE@25. Balanced scorecard used to measure parameters such as mortality rate, average length of stay, complication rates, healthcare associated infection rates, patient satisfaction with pain management, medication errors, and transplant survival rates.
Fortis Healthcare (India) Limited	30 hospitals across India (21 wholly or partially owned, operations and management agreement for remaining 9)	6290 beds	Not specified	4 hospitals have received accreditation by the Joint Commission International (JCI) and 12 hospitals by the National Accreditation Board for Hospital & Healthcare Providers (NABH) (Annual Report 2010-2011). 8 hospitals have been accredited by the National Accreditation Board for Testing and Calibration Laboratories (NABL)	No details of clinical quality initiatives spanning across multiple Fortis hospitals. An Initiative aimed at streamlining non-clinical processes (Fortis Operating System - FOS) is in place in 13 hospitals. Individual hospitals have introduced their own quality enhancing initiatives. Fortis Escort Heart Institute, New Delhi, for example received the Asian Hospital Management Excellence Award 2011 for "Reducing Surgical Site Infections In Cardiac Surgery Patients".
Manipal Hospitals (part of Manipal Education and Medical Group)	15 hospitals (Karnataka, Tamil Nadu, Goa, Andhra Pradesh)	unspecified	Not specified	1 hospital has received accreditation with the National Accreditation Board for Hospital & Healthcare Providers (NABH) and 1 laboratory has received accreditation by the National Accreditation Board for Testing and Calibration Laboratories (NABL) and its blood bank has received accreditation by the NABH for Blood Banks. 2 hospitals are ISO 9001:2008 certified.	No details concerning quality initiatives provided.
Max Healthcare (owned by Max India)	12 hospitals (in Delhi-NCR, Punjab and Uttarakhand)	1900 beds	Patient base: approx 1.4 million (no separation between in patient/out patient)	2 hospitals have received accreditation by the National Accreditation Board for Hospital & Healthcare Providers (NABH). Max Healthcare's blood bank has received accreditation by the NABH Accreditation for Blood Banks. 5 hospitals are ISO 9001:2000 certified, and 1 hospital is ISO 14001:2004 certified.	Six Sigma Methodology to achieve process quality and cost optimization (Basic principle: Define, Measure, Analyze, Improve and Control).
CARE Hospitals	12 hospitals (Andhra Pradesh, Chhattisgarh, Maharashtra, Gujarat, Odisha)	1600 beds	450 000 out patients per year/ 30 000 in patient admissions	1 Laboratory has received accreditation by the National Accreditation Board for Testing and Calibration Laboratories (NABL)	No details provided regarding quality initiatives. However, according to CARE Hospitals clinical and procedural outcomes are on par with US norms.
Global Hospitals India	8 hospitals (Andhra Pradesh, Maharashtra, Karnataka, Tamil Nadu)	> 2000 beds	Not specified	1 hospital has received accreditation with the National Accreditation Board for Hospital & Healthcare Providers (NABH).	No additional details provided regarding quality initiatives.
Columbia Asia	7 hospitals (Karnataka, West Bengal, Delhi-NCR, Maharashtra, Uttar Pradesh, Punjab)	unspecified	Not specified	4 hospitals have received accreditation with the National Accreditation Board for Hospital & Healthcare Providers (NABH) and 3 laboratories have received accreditation by the National Accreditation Board for Testing and Calibration Laboratories (NABL).	No details of quality initiatives provided. Columbia Asia website simply notes "Monitoring of quality indicators, incident reports, patient feedback and various mock drills for disaster/emergency situations." without providing any additional details.

Appendix 3: Key conditionalities and incentive

NRHM PIP Guideline 2013–14

The key conditionalities were agreed and enforced during 2012–13 and will remain applicable in 2013–14:

- Rational and equitable deployment⁸⁴ of human resources with the highest priority given to high-focus districts and delivery points.
- Facility-wise performance audit and corrective action based on the results thereof.
- Non-compliance with either of the above conditionalities may lead to a reduction in outlay of up to 7.5 per cent and non-compliance with both results in a reduction of up to 15 per cent.
- Gaps in implementation of JSSK (mother and child scheme) may lead to a reduction in outlay of up to 10 per cent.
- Continued support under NRHM for 2nd auxiliary nurse-midwife (ANM) would be dependent on improvement on antenatal care (ANC) coverage and immunisation as reflected in maternal and child tracking system (MCTS).
- Vaccines, logistics and other operational costs would also be calculable on the basis of MCTS data.

Initiatives in the following areas would draw additional allocations by way of incentivisation of performance:

- Responsiveness, transparency and accountability (up to 8 per cent of the outlay).
- Quality assurance (up to 3 per cent of the outlay).
- Inter-sectorial convergence (up to 3 per cent of the outlay).
- Recording of vital events including strengthening of civil registration of births and deaths (up to 2 per cent of the outlay).
- Creation of a public health cadre (by states which do not have it already) (up to 10 per cent of the outlay).
- Policy and systems to provide free generic medicines to all in public health facilities (up to 5 per cent of the outlay).

⁸⁴ Rational and equitable deployment would include posting of staff on the basis of case load, posting of specialists in teams (e.g. Gynaecologist and Anaesthetist together), posting of doctors trained in Emergency Obstetric Care/Life Saving Anaesthetic Skills for Emergency Obstetric Care (LSAS) trained doctors in First Referral Units (FRUs), optimal utilisation of specialists in FRUs and above and filling up vacancies in high focus/remote areas.

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- conduct analyses and evaluations that contribute to removing barriers to growth
- conduct system evaluations that facilitate prioritisation and efficiency enhancement of the emphasis and design of growth policy
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