Université de Montréal

Access to Care for the Poor Living with Chronic Disease in India

An Analysis of Selected National Health Policies

par

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Résumé

Cette recherche sur les barrières à l'accès pour les pauvres atteints de maladies chroniques en Inde a trois objectifs : 1) évaluer si les buts, les objectifs, les instruments et la population visée, tels qu'ils sont formulés dans les politiques nationales actuelles de santé en Inde, permettent de répondre aux principales barrières à l'accès pour les pauvres atteints de maladies chroniques; 2) évaluer les types de leviers et les instruments identifiés par les politiques nationales de santé en Inde pour éliminer ces barrières à l'accès; 3) et évaluer si ces politiques se sont améliorées avec le temps à l'égard de l'offre de soins à la population pour les maladies chroniques et plus spécifiquement chez les pauvres.

En utilisant le *Framework Approach* de Ritchie et Spencer (1993), une analyse qualitative de contenu a été complétée avec des politiques nationales de santé indiennes. Pour commencer, un cadre conceptuel sur les barrières à l'accès aux soins pour les pauvres atteints de maladies chroniques en Inde a été créé à partir d'une revue de la littérature scientifique. Par la suite, les politiques ont été échantillonnées en Inde en 2009. Un cadre thématique et un index ont été générés afin de construire les outils d'analyse et codifier le contenu. Finalement, les analyses ont été effectuées en utilisant cet index, en plus de *chartes*, de *maps*, d'une grille de questions et d'études de cas. L'analyse a tété effectuée en comparant les barrières à l'accès qui avaient été originalement identifiées dans le cadre thématique avec celles identifiées par l'analyse de contenu de chaque politique.

Cette recherche met en évidence que les politiques nationales de santé indiennes s'attaquent à un certain nombre de barrières à l'accès pour les pauvres, notamment en ce qui a trait à l'amélioration des services de santé dans le secteur public, l'amélioration des connaissances de la population et l'augmentation de certaines interventions sur les maladies chroniques. D'un autre côté, les barrières à l'accès reliées aux coûts du traitement des maladies chroniques, le fait que les soins de santé primaires ne soient pas abordables pour beaucoup d'individus et la capacité des gens de payer sont, parmi les barrières à l'accès identifiées dans le cadre thématique, celles qui ont reçu le moins d'attention. De plus, lorsque l'on observe le temps de formulation de chaque politique, il semble que les efforts pour augmenter les interventions et l'offre de soins pour les maladies chroniques physiques soient plus récents. De plus, les pauvres ne sont pas ciblés par les actions reliées aux maladies chroniques. Le risque de les marginaliser davantage est important avec la transition économique, démographique et épidémiologique qui transforme actuellement le pays et la demande des services de santé

Mots-clés : Accès, politiques de santé, Inde, maladies chroniques, pauvreté

Abstract

This research on the barriers to access chronic disease care for the poor in India has three objectives: 1) to assess whether the goals, objectives, instruments and targeted populations, as formulated in current national health policies in India, address the main barriers to access chronic disease care for the poor; 2) to assess the types of policy levers and instruments identified in current national health policies to address these barriers to access; 3) And to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor.

Using Ritchie and Spencer's framework approach (1993), a qualitative content analysis was completed on selected Indian national health policies. To begin with, a conceptual framework on the barriers to access chronic disease care for the poor in India was generated from a review of the scientific literature. Policy documents were then sampled in India in 2009. A thematic framework and index scheme were generated to build the analysis tools and codify the content. Finally, the analysis was conducted using indexing, charts, maps, questions grids and case studies. It was achieved by comparing the barriers to access identified in the original conceptualization to those identified by the content analysis of each policy.

This research highlights that a number of barriers to access for the poor in India are addressed by national health policies as they relate to upgrading services in the public sector, improving the knowledge of the population and scaling up some interventions for chronic disease care. On the other hand, barriers related to the costs of chronic disease care, the affordability of outpatient services and people's ability to pay for them were the least addressed from the framework that was previously established. Moreover, when looking at the timeline of our sample of policies, it appears that efforts to scale up interventions for physical chronic diseases are more recent. In addition, the poor are not targeted specifically for actions related to chronic disease care. The risk of marginalizing them further is important as economic, demographic and epidemiologic transitions are transforming the country and the demand for health services.

Keywords: Access, health policies, India, chronic diseases, poverty

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List of abbreviations

ASHA	Accredited Social Health Activist
AYUSH	Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy (Department)
CCDC	Center for Chronic Disease Control
CHC	Community Health Center
COPD	Chronic Obstructive Pulmonary Disease
CVD	Cardiovascular Diseases
DALY	Disability per Adjusted Life Years
DG	Dominique Grimard
EMR	Electronic Medical Records
GDP	Gross Domestic Product
HMDG	Health Minister's Discretionary Grant
HR	Human Resources
IEC	Information and Education Campaigns
JFL	Jean-Frédéric Lévesque
MHP	Mental Health Program
NCD	Non-Communicable Disease
NGO	Non-Governmental Organization
NHP-2002	National Health Policy – 2002
NRHM	National Rural Health Mission
NSSO	National Sample Survey Organization
OECD	Organization for Economic Co-operation and Development
PPCDSC	Program for the Prevention and Control of Cardiovascular Diseases and Stroke
PHC	Primary Healthcare Center
PHFI	Public Health Foundation of India
PPP	Public-Private Partnership
RAN	*Rashtriya Arogya Nidhi* (Policy)
Rs	Rupees
TB	Tuberculosis
TRIPS	Trade-Related Aspects of Intellectual Property Rights
WHO	World Health Organization

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1. Introduction

Context and background

In India, the prevalence of chronic diseases such as diabetes and heart diseases has increased in recent years. As in many other developing countries, economic growth, the change in lifestyle, the transformation of living environments due to rapid urbanization, the decline in mortality, population ageing, these are all factors that have contributed to this epidemiologic transition. This increase in chronic diseases also adds up to the already heavy burden of infectious diseases like malaria and tuberculosis, leading to a situation of double burden of communicable and non-communicable diseases.

In India, this transition happens when the performance of the healthcare system is described as very low, especially towards the poor. Public expenditure on health has been historically low and as a consequence the health system is grossly underfunded. The result is a weak public healthcare system, especially for primary care and in rural and isolated regions. On top of this, the majority of health services, in particular outpatient care is delivered by a large, heterogeneous and mainly unregulated private sector. In this system, the poor face a variety of barriers to access. When they choose to consume health services, they mainly receive care from unqualified providers in the private sector. But an important number will often simply choose to forgo treatments and live with untreated morbidities. The characteristics of the Indian health system will be presented in more details in the background section.

Managing chronic diseases represents a challenge in this context. The health system is currently not tuned for this type of care and most providers are not equipped to detect, diagnose and manage these types of diseases. In addition, they also represent an entirely different type of burden for the patients.

Chronic diseases are lifelong diseases that cannot be cured but controlled. They are often categorized in surveys by asking patients if their ailments lasted more than 12 months. They can cause important disabilities to people suffering from complications. Treating these diseases often requires multiple regimens of drugs and complex care. Patients must manage their disease on an everyday basis and healthcare providers must be seen on a regular basis. These are fundamental elements to an optimal control of various chronic diseases. And in the Indian context, where social protection and insurance coverage are low and the majority of payments are out-of-pocket, it can represent an important financial burden. Care becomes more expensive due to its availability

throughout the country and the intensity of treatments. It becomes even more catastrophic[1] in the case of hospitalizations for acute events caused by chronic disease.

Taking this definition, mental disorders can be seen as chronic diseases on the same level as diabetes, cardiovascular diseases or asthma. Many authors have also labeled HIV-AIDS as a chronic disease because of its incurable and lifelong treatments status. The differentiation is made however between communicable and non-communicable diseases. Still, some chronic diseases have also been labeled "lifestyle diseases" as they are consequences of changes brought by urbanization and economic development. Nonetheless, this research focus will be on chronic non-communicable diseases and will include in its perspective the following diseases: diabetes, cardiovascular diseases, chronic respiratory disorders and asthma, musculoskeletal disorders and mental disorders.

The association between poverty and chronic disease is clear. In its 2005 publication entitled *Preventing chronic disease: A vital investment*, the World Health Organization (WHO) has laid out the evidence on the links between poverty and chronic disease. In many countries, the burden of chronic diseases is particularly concentrated among the poor. Poor people are more vulnerable to chronic disease because of their limited freedom of choices in lifestyles and living environments, the psychosocial stresses they are under and their decreased access to health services. Chronic diseases also have the potential to push individuals and their families further into poverty because of the burden of treatments and the health and economic consequences of untreated morbidities. The WHO has thus called for more investments in preventing chronic diseases and has even underlined how it should also be viewed as a poverty reduction strategy.

The links between poverty and chronic diseases have already been established. It is also known that in India the poor face important barriers to access and we also know that the healthcare system is currently not yet tuned for chronic disease care. On the other hand, little is known on the extent to which existing national health policies are planning actions on the various barriers to access that the poor with chronic disease in India can face.

Research question and objectives

For a long period of time, chronic diseases were seen as a problem of the few affluent living in urban centers. In recent years, scientific evidence has started to prove otherwise and recent initiatives were undertaken by the central government of India and its Ministry of Health and Family Welfare. Therefore, this research aims to investigate to what extent current Indian national health policies address the main barriers to access for the poor living with chronic diseases.

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[1] Catastrophic expenditure refers to health spending jeopardizing a household's well-being. It will be defined in the literature review section.

This research was structured with three objectives. The first objective was to assess whether the goals, objectives, instruments and targeted populations, as formulated in current national health policies in India, address the main barriers to access health services for the poor living with chronic diseases. The second objective was to assess the types of policy levers and instruments identified in current national health policies to address the barriers to access in each dimension of access. And the third objective was to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor.

Methods and data

To provide an answer to this research question and meet these objectives, a qualitative content analysis of selected Indian national health policies was completed in 2009. Using the framework approach (Ritchie and Spencer, 1993), this content analysis was based on prior conceptualization of access, health systems functions and the role of policy on access.

These conceptualizations were used for two purposes. First, they served to structure the literature review. Second, they also served to generate a framework of the problem under study (i.e. the barriers to access to the poor with chronic disease in India). This framework was fed with elements from the literature review. This framework served to build the analysis tools. These tools include: an index to codify the content, a policy map to structure the codified content and the question grid to analyze the content. Finally, case studies were used to synthesize the findings and transpose them into a clear and manageable size.

The sampling of policy documents was achieved using a purposive strategy and was conducted in New Delhi, India, from January to April 2009. The sampling was completed during a research internship at the Public Health Foundation of India and Center for Chronic Disease Control, two private non-profit research organizations. The sampling strategy was executed by triangulating information from official reports and key informants. In the end, the policy documents were collected either directly from the government websites or through the same key informants. The final sample was composed of the National Health Policy 2002, the Rashtriya Arogya Nidhi (formerly the National Illness Assistance Fund), the Health Minister's Discretionary Grant, the National Rural Health Mission, the Mental Health Program for the 10th development plan, and the newest Pilot Program for the Prevention and Control of Diabetes, Cardiovascular diseases and Stroke.

Structure

This research is divided into nine sections. Following this introduction, the background section presents the context of study. The characteristics of poverty in India are described and relevant numbers are presented. It is followed by a description of the Indian health system. This description begins by a brief overview of historical developments and policies and ends with a description of its current characteristics with regards to governance and legislation, financing, structure and resources and utilization. The background section ends with a description of the epidemiological transition and the current burden of disease. The origins and main characteristics of the epidemiological transition are overviewed along with a presentation of the current disease burden. Figures on the prevalence of risk factors and various chronic diseases are presented.

In the third section, the literature pertaining to the research problem is reviewed. For each dimension of access (acceptability and ability to seek care, geographic and organizational availability and ability to reach, affordability and ability to pay, and adequacy and ability to benefit), the main barriers identified by the literature are reviewed. The mechanisms of the government response to chronic diseases are also presented. The literature review ends with the gap in knowledge.

In the fourth section, the research question and objectives are presented, along with a summary of the methods and the conceptualizations that were used to meet each objective. The fifth section is the methodology. This section starts with the presentation and review of the main concepts. The concept of access and the concept of health system functions are presented, as well as the role of policy on access. The concepts structuring this research are presented here because they are the basis on which the analysis tools were generated. Following this, the research method is described. Qualitative content analysis and policy analysis are presented first, and then the framework approach itself is described. Each step of the framework approach is described separately: sampling, familiarization, index scheme, indexing, charting and mapping, analysis, and the validity and reliability precautions. The limits and strengths of the research design are then presented. The methodology section ends with a summary of the research question, objectives and related methods. In section seven, the sample is described.

The results are presented in section eight in the form of a scientific article. A synthesis of the literature review and background, the methods and the sampling description are also present in the article. The results themselves are divided into two sections. The first two objectives and their related results are presented first and are detailed by dimension of access. A separate result section is laid out for the third objective on time of formulation and addressing chronic disease care and poverty. A short discussion of the results is provided with the article, as well as a conclusion. There is a separate reference section for the article and the relevant figures and result tables are

subsequently provided in this section. Section nine is for additional results on policy instruments and the level of government priority they translate.

Section ten is the discussion of the results. Taking the objectives altogether, the results are discussed around specific themes that have emerged from the analyses. In this section, the significance and implication of the results are discussed first as they relate to primary care. The central role of primary care for chronic disease management is recognized in the literature and reforming that sector represents a challenge not only for developing countries like India but for industrialized nations as well. Therefore, the focus of primary care was selected to discuss the main results. The central role of primary care is described first. The discussion on primary care and national health policies is then divided into financial barriers to access primary care, the availability and adequacy of primary care, ability to travel, the private sector and regulation, and health literacy and self-management. The discussion ends on the interaction of poverty and chronic diseases and what it implies for national health policies and other sectors.

Section eleven is the conclusion. It begins with a brief overview of the context of this research and main findings. Then, for each study objective, the main conclusions and their significance are summarized. The main key messages and conclusions are also summarized below.

Key Messages

The results of this research can be summarized in six key messages. First, Indian national health policies have not associated poverty with chronic disease. When addressing chronic disease, health policies have not targeted the poor specifically, they have not recognized how the poor are more vulnerable to them and how these diseases can contribute to poverty. Many health problems affect the poor in India and for a long period of time chronic diseases were not at the forefront of these problems. However, as the epidemiological transition goes further, future health policies will have to start addressing this association more thoroughly.

Second, financial barriers to access regular outpatient and chronic disease care for the poor are not prioritized by Indian national health policies. Financial barriers related to the costs of chronic disease care and the burden these costs can represent to the poor were not addressed. And neither were financial barriers to access outpatient care. What current national health policies aim for is to promote and encourage community and private insurance. However, many open questions remain on their plan of action towards market failures and insurance products. Especially in the perspective that risk pooling is a challenge in a country with high levels of poverty and employment in the informal sector. Another major challenge for the future will also be to design insurance products for the needs of poor individuals with chronic disease.

Third, the necessity to better regulate public and private services is also not fully prioritized by Indian national health policies. Even though the necessity to ensure quality care is acknowledged, it remains stated as an objective in itself and little planning is actually provided. The poor consume the majority of their health services, especially primary care services, in the private sector. The care they get is often of poor quality and provided by unqualified practitioners of both modern and traditional medicine. The environment of regulation has been repeatedly described as inadequate in the literature. How the government will better regulate the quality, the quantity and the pricing system remains an open question.

Fourth, abilities to access are not the dimensions of access on which national health policies plan most of their actions. When barriers are addressed, the focus is on the system and what can be changed about it. The abilities of the poor in accessing health services are not discussed in health policies at the national level. In particular, the poor's ability to travel, the modes of transportation they rely on and the interaction of traveling and costs remain to be fully addressed.

Fifth, Indian national health policies have not paid attention to the role of self-management for chronic disease. Chronic disease entails a certain degree of self-management for individuals on a day-to-day basis. For this self-management to be a success a regular contact with a primary care provider equipped to give the necessary support and information is a necessity. In its efforts to strengthen primary care across the country and to better equip providers at all levels of the system to detect and manage chronic disease, national health policies do not approach self-management specifically.

And sixth, primary care can play a central role in chronic disease management and Indian national health policies have not laid out a plan of action in this direction. In national health policies, primary care is seen as a key to more equity in access for the poor. At the same time, planning to increase capacities for mental and physical chronic disease at all levels of care is made. How primary care will be transformed to meet the requirements for better chronic disease management in the public and the private sector remains to be addressed. So far, the government focus is mainly on increasing investment, raising more resources, upgrading existing centers and increasing their physical availability across the country. The central role of primary care for chronic disease management should mark the road for future policies.

2. Poverty, Chronic Diseases and India's Healthcare System

In this section, background information is provided on poverty, chronic diseases and the healthcare system in India. This information is presented to provide the context for this research. Following a brief overall description of India, poverty in this country is described and estimates are presented. Furthermore, figures are presented on the current disease burden and epidemiologic and demographic transitions currently unfolding in India.

2.1. Poverty and Chronic Diseases in India

An Overview of India

India is a country with great geographic, political and cultural diversity. Located in South Asia, it is the 7th largest and 2nd most populous country in the world. Ruled by England during the colonial era from the 18th to the 20th century, India – "the Jewel of the British crown" – gained its independence in 1947 after years of protestations and unrest.

India is a federal constitutional democratic republic based on a Westminster style parliament system with a legal (English common law), a legislative and an executive branch. In its constitution, India describes itself as a sovereign, socialist, secular and democratic country. The dominant national parties are the Indian National Congress and the Bharatiya Janata Party that are followed by regional parties. The country is divided into 28 states and 7 union territories, which are further divided into districts. Each state of India also has its own parliament and legislative structure. The development level of the different states of the country varies greatly, with some states experiencing unprecedented economic growth and increased opportunities, while some regions, most notably Kashmir and the North-Eastern States, experience poor governance, as well as civil and religious unrests and conflicts (Peters 2002).

India is very culturally and geographically diverse. The nation's capital is New Delhi. Hindi is the only language spoken by more than 10% of the population. There are as many languages as there are ethnicities and regions. The central government recognizes a total of 22 regional languages. English has thus been selected as a subsidiary official language in an effort to harmonize and facilitate communications. India is also religiously diverse, with a population constituted of 80.5% Hindus, 13.4% Muslims, 2.3% Christians, 1.9% Sikhs, 0.8% Jains, and 0.4% Buddhist (Government of India 2001). These are the principal religions in India. The Hindus have also been historically ruled by a rigid system of social stratification, the castes, in which people remain for their entire life (Oxford Reference). The geography is also varied with some regions located in wet and dry tropical settings while others are dominated by deserts or the high mountains

the Himalayas. Seasons are driven by the annual monsoons. This invariably results in major floods for certain regions which cut them off from the rest of the country during consecutive months.

Urbanization rates vary across the country with 42.43% of the population residing in urban centers in the state of Maharashtra to only 12.90% in Assam (Government of India 2001). Furthermore, the states of India do not have the same population density. For example, states like West Bengal (903 per km²) and Uttar Pradesh (690 per km²) are more densely populated than Rajasthan (165 per km²) (Government of India 2001). Hence, the population of India is not distributed evenly.

The country has enjoyed a period of unprecedented growth in the last decades, toppled with a 9% GDP growth in 2007 (World Bank 2009b). Major changes have also transformed the economy, with agriculture going from 30.5% of GDP in 1988 to 17.5% in 2008, while the industrial sector went from 26.2% to 28.8%, and the service industry from 43.4% to 53.7% (World Bank 2009b). Urbanization and industrialization rates have constantly been increasing in the past decades. India also has one of the largest armies in the world and has also recently become a nuclear power. Notwithstanding these major developments, the country is still struggling with disparities, poverty and even poor governance in some areas. As it will be demonstrated later, spending on health has been historically low compared to other sectors. Life expectancy is still at 64 for the whole country, infant mortality rate is at 52 per 1000, child malnutrition affects 44% of the under 5 population, and only 66% of the population is literate (World Bank 2009b).

In addition, development opportunities have not been shared equally between the states of India. States in the southern and western regions have experienced more economic growth and industrialization than the states of the northern and eastern regions (Peters et al. 2002; Kurian 2007). For example, Gujarat, Karnataka, Maharashtra and Tamil Nadu are among the most developed states in the country and it is where economic activities and private investments have been the most active. On the other hand, Assam, Orissa, Rajasthan and Uttar Pradesh are labeled as backward and characterized by poverty, worst social and health indicators compared to most other states, poor governance and even social and political instability in some cases. Almost half of India's poor and a third of the population are concentrated in the states of Uttar Pradesh, Madhya Pradesh and Bihar (Kapur Mehta et al. 2003). This variation is illustrated in table 1.

Table 2.1: State-Wise Percentage of Population below Poverty Line (2004-2005)

State	Rural (%)	Urban (%)	Combined (%)
Assam	22.3	3.3	19.7
Gujarat	19.1	13.0	16.8
Karnataka	20.8	32.6	25.0
Maharashtra	29.6	32.2	30.7
Orissa	46.8	44.3	46.4
Rajasthan	18.7	32.9	22.1
Tamil Nadu	22.8	22.2	22.5
Uttar Pradesh	33.4	30.6	32.8

Source: Government of India 2007 (Based on URP-Consumption method).
Note: Variation in percentage in function of development, but also population density and urbanization rates.

Poverty in India

As stated earlier, India has experienced important economic growth in the past decades which has unleashed various social and economic transformations occurring at a rapid pace (industrialization, urbanization, increased literacy, etc.). These transformations have brought important changes in the health and well-being of the entire population. However, this development process has been uneven within the population and across different states. Wealth and opportunities are not distributed equally.

Today, India has 35% of the world's poor and 40% of the world's illiterate (Kurian 2007). Between 1983 and 2005 the proportion of poverty at the national level has decreased from 45% to 28% (Kurian 2007). However, this reduction is the subject of debate over the changes in measurement methods (Kapur Mehta et al. 2003). In spite of this important reduction, a significant proportion of the population remains below the poverty line or not too far from it. The World Bank (2009a) and the Government of India (2007) have estimated poverty at 28.6 % in 2000 and at 27.5% in 2004-05.

Variations in poverty are also observed between rural and urban regions. Rural areas comprise the majority of the country's poor (Kurian 2007). Officially, poverty in rural and urban areas has been estimated at 28.3% and 25.7% respectively (Government of India 2007). Economic growth is stagnant in rural regions: the population depends on agriculture or informal employment and few social and economic infrastructures are available (Kurian 2007). The same author states that industrialization, economic growth and most service infrastructures are concentrated in urban centers. On the other hand, rapid urbanization throughout the country has also resulted in large proportions of the poor migrating towards city in search of economic opportunities. As a consequence of rapid and unplanned urbanization, Kurian (2007) also highlights that good

proportions of the poor live in different urban slums throughout the country and their economic production is concentrated in the informal sector as well. In both rural and urban settings, the living environment is not favoring the poor, where:

> "Rural poverty can be associated with isolation, lack of roads, poor infrastructures and limited institutional presence while urban poverty is generally associated with poor quality housing, overcrowded, unsanitary slum settlements, ill-health related to spread of infectious diseases, exposure to environmental hazards and fear of eviction from illegal squatter settlements." (p.505) (Kapur Mehta et al. 2003).

Hence, it has to be understood that while some people live closer to service infrastructures, the majority of the population is located in rural and remote areas. And this affects planning and the way health services have to be provided throughout the country. Victims of rapid and unplanned regulation, the urban poor are also particularly underserved and are living in unhealthy environments (Peters et al. 2002).

The lower castes of the Hindu religion (scheduled castes, *Dalits* or untouchables)[2] and various tribes (scheduled tribes) scattered in the country have historically been poor and vulnerable (Nayar 2007; Radhakrishna et al. 2004; Subramanian et al. 2006). Furthermore, the Muslim community is also more vulnerable and represents in many instances a socio-economically disadvantaged group (Alam 2008).

Notwithstanding the abolition of "untouchability" by the Indian constitution and the provision of special rights to scheduled castes and tribes, disparities compared to the general population continue to affect these groups. Even though tribes account for only 8% of the population they have more than double the share of poor and illiterate at the national level (Kurian 2007). Poverty, illiteracy and ill-health also remain critical among the lower castes compared to the rest of the population (Kurian 2007; Peters et al. 2002). However, it is also important to note that religious disparities are also changing with economic and social transitions.

Moreover, gender, employment and age in India also influence economic disparities and vice versa. Gender disparities can be seen in the demographic imbalance existing in India and the unequal opportunities women have within their families and in poor communities (Kurian 2007). Gender gaps in health status, literacy and employment opportunities are important (Kapur Mehta et al. 2003; Kurian 2007).

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[2] Oxford reference is defining scheduled castes as "The other official name given in India to the caste considered 'untouchable' in orthodox Hindu scriptures and practice, officially regarded as socially disadvantaged". The untouchables are: "a member of the lowest-caste Hindu group, with whom contact is traditionally held to defile members of higher castes."

Households living in poverty are also concentrated among casual agricultural labor and in informal employment or self-employment (Kapur Mehta et al. 2003; Sundaram et al. 2004). Most members of the lower castes in urban center are casual workers and tribes are overwhelmingly surviving on pre-agricultural modes of subsistence (Kapur Mehta et al. 2003). Livelihood and employment are important factors that are influencing access to health services as most insurance schemes in India are provided with public sector employment and private companies (Peters et al. 2002). Overall, employment in the formal sector of the economy remains very limited, going from 4.10% and 4.58% in Uttar Pradesh and Madhya Pradesh to 7.99% and 8.78% in Karnataka and Maharashtra (Gupta 2005). The poor in India hold fewer assets and are largely dependent on their human and social capital for their livelihood (Kapur Mehta et al. 2003).

Finally, old age in India is another important aspect of poverty. For Kapur Mehta et al. (2003) in settings where resources are already meager, the elderly can suffer disproportionally from economic insecurity. The elderly are a vulnerable and economically dependent group in India; and as much as 40% of them live below the poverty line (Purohit 2003). Moreover, these authors also state that social protection schemes aimed at the elderly and old age pensions in India are underdeveloped and underfunded as well.

Consequently, poverty in India is complex and disparities are not only based on income, but also on gender, religion, age and employment. All these characteristics influence the experience of poverty and ultimately the experience of accessing health services. However, in this research, access is studied through the concept of poverty in a more general perspective. What is important to retain here is that poverty is multidimensional and influences survival chances, employment, environment, social exclusion and social conditions, as well as lack of assets (credit, literacy, land, etc.) (Kapur Mehta et al. 2003).

The Epidemiological and Demographic Transitions in India

India is currently undergoing epidemiological and demographic transitions that have been triggered by economic and social changes. Chronic diseases have proximal and distant risk factors from early to adult life, undernutrition during pregnancy and infant years, and a mix of genetic risk factors, modifiable lifestyle risk factors and risk from the living environment (Miranda et al. 2008; Reddy 2002). Economic growth, increased income, rapid urbanization, changes in living environments and the faster pace of these transformations are among the causes of this transition that are cited in the literature (Abegunde et al. 2007;Ajay et al. 2008;Anand et al. 2007;Goyal et al.

Scheduled tribes are “an indigenous people officially regarded as socially disadvantaged” (Oxford Reference 2010).

2006;Jindal 2007;Joshi et al. 2006;Mathavan et al. 2009;Prabhakaran et al. 2007;Ramachandran et al. 2008c;Reddy 2004;Reddy 2003;Reddy et al. 2005). The resulting changes in lifestyles have contributed to shift the burden of disease towards chronic non-communicable diseases (Peters et al. 2002; Reddy 2002; Reddy 2004). In developing countries like India these transitions are happening at a much faster pace (Karthikeyan et al. 2007; Miranda et al. 2008; Reddy 2004).

Furthermore, decreased mortality and fertility have caused a gradual change in the country's age structure (Peters et al. 2002). The population in India is aging and this trend is projected to increase in the future. A 38% increase in the 60+ age group was observed during the 1991 to 2001 period (Purohit 2003). And this group is projected to outnumber the 0-14 years old by 2019 (Chatterji et al. 2008). Moreover, the demographic transition also propels the epidemiologic transition as chronic diseases and multiple morbidities increase with age (Chatterji et al. 2008; Purohit 2003).

However, these transitions have not been happening at the same rate across the country. Some states are still mainly preoccupied with communicable diseases and high fertility and mortality rates; while others are more advanced in these transitions with lower mortality and fertility rates and an increase in the prevalence of non-communicable diseases (Peters et al. 2002). States like Kerala and Tamil Nadu are more advanced in these transitions, states like Maharashtra and Karnataka are in a more middle transition phase while states like Orissa, Rajasthan and Uttar Pradesh are in the low to very early transition phase (Peters et al. 2002). One study using data from the NSSO has estimated the risk of chronic diseases at 43% in Kerala, compared to 21% in Bihar and 35% for all India (Dilip 2007).

The Burden of Disease in India

Therefore, the burden of disease in India has been changing during the last two decades and the list of diseases that has been causing the most mortality and morbidity in India is now composed of both communicable and non-communicable diseases. The country now has to deal with the rising burden of chronic non-communicable diseases on top of infectious diseases that already threaten the well-being of the poor (Peters et al. 2002). Cardiovascular diseases and depression in India are now among the top 10 diseases causing the most mortality and disabilities (Peters et al. 2002; Reddy 2007a). In table 3 and 4, this double burden of communicable and non-communicable diseases for India is presented and in table 4 specifically it can be seen that they are projected to increase by 2015.

Table 2.2: Top Ten Causes of Deaths in 1998 as Percentages of Mortality

	1998
Ischemic heart disease	15.8
Acute lower respiratory infections	10.4
Diarrheal diseases	7.6
Cerebrovascular disease	6.0
Tuberculosis	4.5
Road traffic injury	2.3
Measles	2.0
HIV/AIDS	1.9
Tetanus	1.8
Chronic obstructive pulmonary disease	1.6

Source: Peters et al. 2002 (WHO 1999)

Table 2.3: Disease Burden in India per 100 000 in 2005 and Projections for 2015

	2005	2015
Diarrheal Diseases episodes/yr	760	880
Mental Health	650	800
Maternal Mortality /100000 births	440	NA
COPD and Asthma	405.20 (2001)	596.36
Diabetes	310	460
Cardiovascular Diseases	290 (2000)	640
Blindness	141.07 (2000)	129.96
Tuberculosis	85 (2000)	N/A
IMR/1000 live births	63(2002)	53.14
HIV/AIDS	51 (2004)	190

Source: Report of the National Commission of Macro-Economics and Health 2005
Note: Diseases ordered in decreasing burden in 2005

This double burden of disease has great consequences for a developing country like India (Peters et al. 2002). Some authors argue that infectious diseases cause more mortality and morbidity. However, more and more studies dispute this and claim that chronic non-communicable diseases are now more important causes (Mishra 2005; Peters et al. 2002). Boutayeb (2006) argues that developing countries are more severely affected by the increasing prevalence of chronic disease because of the rapid pace of the transition, the double disease burden with infectious diseases and the fact that these challenges must be faced with fewer resources.

Prevalence of Specific Risk Factors and Chronic Diseases

In the literature, current prevalence estimates confirm the important burden of chronic non-communicable diseases in India. It has been estimated that 80% of the 35 million deaths caused worldwide by chronic diseases in 2005 were happening in developing countries like India (Strong et

al. 2005). More precisely, chronic diseases in India are now accounting for 53% of all deaths and 44% of Disability per Adjusted Life Years (DALY) (Ramaraj et al. 2008; Reddy et al. 2005).

India has the largest diabetic population in the world and the nation-wide prevalence was already estimated at 12.1% in 2000 (Bjork et al. 2003; Kapur 2007; Ramachandran et al. 2007). In a multicentric study, diabetes prevalence was estimated at 3.1%, 3.2% and 7.3% in rural, peri-urban/slums and urban areas respectively (Mohan et al. 2008). One study in the city of Chennai has even reported an increase in the prevalence of diabetes from 13.9% to 18.6% over a six year period (Ramachandran et al. 2008c). And its prevalence is reported to reach as much as 21.1% in a high income sample from Lucknow, Uttar Pradesh (Boddula et al. 2008).

The prevalence of cardiovascular diseases is at 3-4% and 8-10% in rural and urban areas respectively (Goyal et al. 2006). In rural Andra Pradesh, the prevalence of self-reported cardiovascular disease and angina is 2.5% and 1.1% (Chow et al. 2007). Cardiovascular diseases in 2005 were already among the leading causes of all deaths at 29% (Reddy 2007a). This is also well illustrated in table 2 with Ischemic heart disease being at the top of the ten diseases causing the most mortality in 1998.

The prevalence of musculoskeletal (MSK) pain and joint problems in rural and urban areas respectively is 14.1% and 19.5% for the general population and reaches as much as 28.4% and 23.2% among the elderly (Joshi et al. 2009; Purohit 2003). The prevalence of asthma and chronic respiratory problems in India is estimated between 2.4%-3.5% and 10.5% (Aggarwal et al. 2006; Jindal 2007).

Psychiatric morbidities are affecting 58.2 individuals per 1000 population (National Human Right Commission 2008). One author also argues that the pattern of mental morbidity is changing. In rural West Bengal, the prevalence of depression went from 49.93 per 1000 population in 1972 to 73.97 per 1000 population in 1992 (Nandi et al. 2000a). Similarly, in a prevalence study of common mental disorders found in a primary care center in Tamil Nadu, depression took 83.8% of the 33.9% cases detected (Pothen et al. 2003).

Furthermore, the increasing prevalence of physical chronic diseases also contributes to the increased prevalence of some mental disorders as comorbidities (Math et al. 2007; Moussavi et al. 2007). Interactions between mental and physical health increases the risks and burden of certain conditions (Prince et al. 2007). Mental disorders can increase the rate of certain health conditions. The prevalence of some risk factors such as smoking or poor diet is often higher among people suffering from mental disorders. Diseases such as depression often have other biological effects on physical health. Likewise, mental and physical non-communicable diseases often share risk factors. Inversely some physical diseases can also increase the risk of mental disorders by affecting the brain (i.e. diabetes), by imposing a psychological burden on people or increasing the

risk of depression when disabilities arise. Finally, the comorbidity of mental and physical chronic disease can also affect the outcome of treatments because of delayed health-seeking or lowered adherence to treatments.

The prevalence, incidence and mortality figures presented above show the magnitude of the burden of chronic disease in India. Even if states are at different levels of the transition, chronic diseases are on the rise everywhere and affect every segment of the population. If chronic diseases are predominantly diagnosed in wealthier and urban settings, poor segments and rural areas are not spared (Bjork et al. 2003; Goyal et al. 2006; Joshi et al. 2006; Mishra 2005; Reddy 2007a).

The poor are exposed to non-communicable disease risk factors and due to their lower education, higher psychosocial stresses and limited choices with regards to nutrition and life-styles and access to health services, **they are more vulnerable to chronic diseases** (WHO 2005). They live in poor communities and unhealthy environments that expose them to adverse risks. Some studies have demonstrated that risk factors, like physical inactivity, hypertension and the use of tobacco are widely prevalent among the poor and rural inhabitants in India (Ajay et al. 2008; Anand et al. 2007; Joshi et al. 2006; Reddy et al. 2007a; Reddy et al. 2005). Wealthier and more educated individuals tend to be affected first by changes in lifestyles, but they will also be the first to modify their behavior (Beaglehole et al. 2007b; Reddy 2002; Reddy et al. 2007b; WHO 2005). Studies have recently started to observe in India an inverse socio-economic gradient of risk factors, with, for example, a higher prevalence of tobacco use and hypertension among lower socio-economic groups (Ajay et al. 2008; Reddy et al. 2007a). However, changes are still transitory in India and another study among physicians in Madurai has reported a high prevalence of the metabolic syndrome and risk factors in this better educated and higher socio-economic group (Mathavan et al. 2009). Nonetheless, in table 4 is presented the prevalence of various chronic diseases among the poor in a representative sample of the Indian population from the World Health Survey.

Table 2.4: The Prevalence of Selected Chronic Diseases among the Poor (%)

Arthritis	Angina	Asthma	Depression	Diabetes
13.80	6.13	6.23	9.11	1.00

Source: Vulnerability and Inequalities in Health in South Asia: Analysis of the World Health Survey (Levesque et al. 2010)
Note: Percentage of poor individuals with chronic disease / total population
Note: Arthritis, angina, asthma and depression include self-reported cases and self-reported symptoms; diabetes is only composed of self-reported cases.

Finally, chronic diseases in India are not only affecting the elderly but are also affecting the active population (Reddy 2002). It is estimated that each year chronic diseases take 8 million lives in Asia specifically among the 30 to 69 years old (Jha et al. 2007). And as in other developing

countries a high proportion of cardiovascular events and deaths in India occur before the age of 70 (Abegunde et al. 2007; Karthikeyan et al. 2007; Reddy 2004).

2.2. India's Healthcare System

In this section, elements from the historical development of India's healthcare system are presented first. Then the governance and legislation, financing, structure and resources of India's health system are described.

Historical development of India's healthcare system

India inherited a health system from the colonial era but has also a tradition of alternative systems of medicine dating back to previous millennia. Still, during the pre and post independence era, efforts have been made to invest in healthcare. A few authors have explored the historical development of the Indian health system.

Since the independence in 1947, different developments have contributed to shape the way health services are valued and organized today. Universal access and health for all have been promoted by India's various governments, along with the protection of the poor and enhancement of living standards (Banerjee et al. 2008; Banerji 2005; Gupta 2005). However, according to these authors, their promises were never fulfilled.

In 1946, the Bhore committee produced a report that had become a reference at the time. This was the first detailed planning for a national system of health services, focused on primary care, population health and universal access (Banerji 2004; Duggal 2005; Peters et al. 2002). This document was the first deliberate attempt by the newly sovereign Indian government to plan and structure the health system, taking into account the needs of the whole population. However, for some authors, promises of universal access and recommendations from this report have never been fully implemented (Banerji 2004; Duggal 2005).

However, it was not before 1983 that the first real formal national health policy was formulated (Duggal 2005). Before this, health was managed with other sectors, with the central development plan of the government and by recommendations from various expert comities. Recognizing the need for a national policy, the central government formulated in 1983 the first national health policy with goals and objectives set for the year 2000.

Nonetheless, during its developmentalist period, India made investments in education and health (aiming to provide basic, maternal and child health services, health information, referral and national disease programs) (Qadeer 2000; Banerji 2004). By 1956, these authors highlight that

investments were made to develop a network of primary, community and district health centers and that in 1978 India became a signatory and strong advocate for the Alma Ata convention.

By the 80's, it was said that India had an extensive healthcare structure with an important network of primary health centers. However, for Qadeer (2000) and Banerji (2004) this functioning system existed and still mostly exists on paper. Public infrastructures since their beginning have been inadequately staffed and equipped and have had outreach problems. This remains true in the current context.

In the 80's, the process of development changed and for Qadeer (2000) it had become growth-centered, focused on urban regions and a "trickle-down" view of development. Major shifts in priorities and investments occurred during this period. Furthermore, in Qadeer's opinion, structural adjustment policies, donor driven priorities and the private sector started to shape the health agenda as much and if not more than the Indian government itself. As stated by this author, the World Bank and the International Monetary Fund (IMF) were not only advocating for a reduction in government expenditure, but influencing the priorities of health programs. Family planning and population control, base on Malthusian theory[3], thus became a central priority for the government, who also shifted investments accordingly (Banerji 2004; Qadeer 2000).

Duggal (2007) has also demonstrated how the health sector budget had diminished over the years following the structural adjustment policies initiated in the 80's. This was happening as well in other social sectors. Furthermore, following reforms introduced in the 90's, user fees were introduced or increased in different regions of the country.

Finally, the private sector's role in the provision of health services also increased over the years. As it will be detailed later, the largely unregulated private sector started to play an important role in the delivery of health services throughout the country (Qadeer 2000). For this author, encouraged by different states and nurtured in the mixed Indian economy, the private sector grew stronger over the years to become an important actor. On the other hand, Peters et al. (2002) also state that the private sector has been largely neglected by local and central governments and must be better integrated.

The result of these past developments is the inefficient public healthcare system existing today and the neglect of past commitments towards access. The National Health Policy of 1983 was the first attempt to revive universal access, but again this ideal was not fully implemented (Duggal

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[3] "Of, pertaining to or characteristic of the English economist and clergyman Thomas Robert Malthus (1766–1834), especially the population control advocated by him Malthus was a pioneer of the science of political economy and is known for his theory, as expressed in *Essay on Population* (**1798**), that the rate of increase of the population tends to be out of proportion to the increase of its means of subsistence; controls on population (by sexual abstinence or birth control) are therefore necessary to prevent catastrophe" (Oxford Reference 2010).

2005). Over the years, gaps between political commitments and actual implementation of promises have remained (Banerji 2004).

Governance and Legislation

Today, healthcare in India is a shared responsibility between central and state government. And even though healthcare is officially under state jurisdiction in the constitution, the central government's role in this sector has been predominant. To begin with, the central government plays an important role in financing the health system. It transfers the main budget to each state, which has the responsibility of complementary financing (Bhalotra 2007; Duggal 2007; Krishnan 1999; Mishra 2005). As stated in the constitution, the states also have the responsibility to formulate healthcare policies and to manage their territory's health system (Duggal 2005; Mishra 2005). Furthermore, the central government also formulates and implements a variety of policies and programs at the national level (Duggal 2005; Mishra 2005) and has to provide a national strategic framework, the necessary resources, policies and programs, and specific services at the cross-population level (Qadeer 2000). Notwithstanding the official division of power, the health structure is more elaborate at the center as the central government has been playing a great role in policy and program formulation (Duggal 2005; Peters et al. 2003). Furthermore, even if decentralization is promoted in India, it is more or less implemented and this is especially the case for fiscal decentralization (Duggal et al. 2005).

The central government's role in formulating and implementing health policies however has only started to really take hold in the 1980's with the first National Health Policy (Duggal 2005). Enacted in 1983, its goals were set for the next 17 years. Thus, in 2000, these goals were reviewed and the National Health Policy 2002 was formulated on this basis, with goals set again for 2015. Apart from the National Health Policies, the central government also formulates and develops vertically a variety of financial assistance schemes and disease specific programs (for tuberculosis, leprosy and malaria among other programs) (Duggal 2005;Peters et al. 2002). On mental health, there is no unique policy at the center, as it is integrated into the general National Health Policy (Ganju 2000; Khandelwal et al. 2004). However, even though it is not yet implemented in all states and districts, the National Mental Health Program also serves as the main policy with more detailed planning than what is found in the national policy (Jacob et al. 2007; Khandelwal et al. 2004). Furthermore, if healthcare in India has been described as being neglected and underfunded in general, the mental healthcare system is said to have historically received even lower political will and resources (Ganju 2000; Khandelwal et al. 2004). The mental health program was first formulated in 1982 and is renewed with each five-year development plan and now includes a district level program. And,

among its flagship initiatives on health, the central government has also launched in 2005 the National Rural Health Mission to respond to healthcare gaps in isolated and rural regions (Banerji 2005).

Finally, as stated earlier, policies since independence have not been translated into real meaningful changes at the national level for some authors. Even with the Alma Alta declarations, the necessary investments were never sufficient to sustain the public system and to provide healthcare to the large vulnerable segments of the population as formulated in health policies (Banerjee et al. 2008; Devadasan 2004b; Sankar et al. 2003). Authors have argued that the main health policies in India are not giving enough attention to issues of access, insurance and social protection (Banerjee et al. 2008; Devadasan 2004b; Gupta 2005; Jayal 1999; Kumar 1999). On the other hand, it is also important to note that access to healthcare is not recognized as a right in the constitution and social protection is based on the concept of essential needs and not on human rights and social justice (Jayal 1999).

Financing

The financing of India's health system is closely linked to some of the main access-related problems. India's health system has been suffering from the diminution of public expenditure imposed by structural adjustments policies (Duggal 2007; Mishra 2005). The government has been allocating only 1% of GDP to the health sector for many years, a proportion lower than the average of developing countries (Duggal 2007; Peters et al. 2002; Sankar et al. 2003). Moreover, it is argued that this low level of public financing is also biased towards the wealthier population (Peters et al. 2002). The mental health budget is integrated in the overall health budget and although its share has increased with the 10th five-year plan, it is also argued to be too low (Khandelwal et al. 2004).

Furthermore, if states receive resources from the center and manage them, financial resources are not distributed equally among them (Peters et al. 2003). In addition, the decreasing healthcare budget has greatly impacted the poorest states and poorer individuals first and foremost (Purohit 2001). With the 2006-2007 budget, public expenditure per capita on health varied from 934 Rs in Goa, 664 Rs in Delhi and 379 Rs in Kerala to 225 Rs in Karnataka, 177Rs in Gujarat and 198 Rs in Maharashtra (299 Rs per capita for all India) (Duggal 2007).

The other part of the financing problem is that 72% of all resources are generated from out-of-pocket payments (Peters et al. 2002). Out-of-pocket payments are a regressive form of financing, particularly in a country with virtually no social protection like India (Devadasan 2004b; Duggal 2007; Peters et al. 2008a; Roy et al. 2007). Social protection is very limited in India. A variety of

public schemes exists for state and central government employees through different ministries and with some public-private partnerships (Gupta 2005; Peters et al. 2002). But, employment in the formal sector is not the rule in India. Some initiatives have been launched towards the unorganized sector but they remain limited in terms of resources made available and coverage (Peters et al. 2002). In 2003, one universal health insurance scheme was launched by the government for families below poverty line but the program is criticized for its management problems and for collecting premiums too low to be efficient (Gupta 2005). Finally, some old age pension initiatives exist but are also very limited in terms of resources and coverage (Purohit 2003).

In all, it is estimated that only 5 to 10% of the Indian population is covered by health insurance of any kind (Indiastat 2009; Peters et al. 2002). Studies have demonstrated that the introduction or amelioration of insurance schemes can not only increase utilization, but also decrease its negative financial impact on households and individuals (De Allegri et al. 2007; Devadasan 2004a; Jutting 2004; Meessen et al. 2006; Ranson 2002; Waters 2000). Of course, insurance schemes have theirs limits in reaching the extremely poor and the unorganized sector. These schemes can have organizational and equity issues. Nonetheless, an overall positive impact is depicted in the literature.

As a consequence of this financing system, the utilization of health services in India is one of the main causes of impoverishment. It is estimated that about 24% of the population will either not use health services or systematically fall into impoverishment when they do (Duggal 2007; Krishnan 1999; Peters et al. 2002). Furthermore, the utilization of health services is also one of the main causes of indebtedness in India (Mishra 2005; Peters et al. 2002).

Structure

In the public sector, services are structured more or less in the same functioning pyramid (Dipankar et al. 2007; Peters et al. 2002). The sub-centers are at the base of the pyramid and offer the most basic health services. These centers are followed by primary centers that each cover 30 000 people and offer curative as well as preventive health and family planning services. Sub-centers and PHC are followed by community health centers that have about 30 beds, general health services and some specialized family planning services. After CHC, there is at the top of the pyramid, the district level city hospitals that have approximately a hundred beds, as well as super-tertiary hospitals in major urban centers.

Primary health centers (PHC) in India are only intended for rural areas and often constitute the only public health facilities in these areas (Duggal 1992). In urban centers, individuals can access, in theory, all the other sources of the pyramid (Duggal 1992). Primary care is not only delivered in

sub-centers and PHC, but also in community health centers and district hospitals (Bajpaj et al. 2004).

There are also specialized mental health hospitals in important urban centers and psychiatric wings in some public hospitals (Ganju 2000; Khandelwal et al. 2004). However, the same authors state that mental health services at the primary care level are still mostly non-existent in India.

Resources and Utilization

Currently, only 20% of all health services are offered in the public sector while 80% are provided in the private sector (Duggal 2007; NSSO 2006; Peters et al. 2002). One of the main findings of the NSSO 60th Round Survey was the predominant use of private services by all income groups in rural and urban settings for both outpatient and inpatient care (NSSO 2006), but it is even more pronounced for outpatient care. However, a slightly greater use of public services was observed in rural regions (NSSO 2006). These figures are listed in table 5. Moreover, for inpatient care, if most users will first make their entry in the private system, many will ultimately move to the public sector as treatments become too expensive (Ramachandran et al. 2007; Levesque et al. 2007). Finally, it is also important to underline that the private sector has also taken its share in the provision of mental health services (Ganju 2000; Khandelwal et al. 2004).

Table 2.5: Utilization of Public and Private Services by Gender, Setting and Source (%)

	Outpatient services				Inpatient services			
	Rural		Urban		Rural		Urban	
	Females	Males	Females	Males	Females	Males	Females	Males
Private	39.8	37.9	42.2	38.6	24.7	30.9	29.5	32.2
Public	11.8	10.5	10	9.2	19.3	22.4	17.9	20.6

Source: NSSO 60th round 2004

Concerning the poor's utilization of health services, the NSSO survey has demonstrated that compared to the rich, they will rely more often on the public sector, especially for inpatient care (NSSO 2006). In their extensive study, Peters et al. have also underlined that the poor rely mainly on the private sector for their outpatient care, but they mostly seek this care from unqualified providers (Peters et al. 2002). However, in a more global perspective, the poor do rely more on public services compared to wealthy individuals (Peters et al. 2002).

More recently, authors have also demonstrated that expenses related to inpatient care have dramatically risen in recent years, especially for the rural poor (Mukherjee et al. 2010). As expenditure on inpatient care keeps rising and the dependence on public hospitals has decreased,

these authors emphasize that the average cost of hospital care has increased everywhere, including in public hospitals and are now above the price of essential food. The combination of rising demand for private inpatient care and rising prices has resulted in a higher financial burden. Even more so, data have demonstrated that the poor in rural areas rely increasingly on contributions and loans to finance inpatient care.

Quality problems in the public sector have allowed the creation of a gap that was filled over the years by the private sector (NSSO 2006; Peters et al. 2002). The private sector is described as a heterogeneous block that includes different kinds of providers of modern allopathic medicine and traditional *Unani*, *Ayurveda* and homeopathic medicine[4] (Bhat 1999; De Costa et al. 2007; Peters et al. 2002). The private sector is mainly constituted of 'for profit' providers, but also includes a variety of voluntary organizations (Bhat 1999). So far, the private sector as a whole remains largely unregulated and this means that services of poor quality are often delivered by unqualified providers (Peters et al. 2002; Peters et al. 2008b).

Human resources and necessary medical supplies are scarce in the public sector. Insufficient training and pay are among the causes cited that explain the scarcity of skilled human resources in rural areas and in the public sector in general (Peters et al. 2002). In absolute terms, India has important numbers of physicians and beds in the public sector but these numbers fall short when making the comparison in per capita with other developing countries. For example, by the end of the 1990s India had 0.2 physicians per 1000 population compared to 0.7 to 1.8 physicians per 1000 population in other low and middle income countries (Peters et al. 2002). Still, even if absolute numbers are high, the per capita distribution is low. Important shortfalls exist everywhere: 17% of nurses and midwives, 28% of doctors and 47% of male multipurpose worker's positions are vacant in public facilities across the country (Peters et al. 2002). Finally, the ratio of beds in rural areas is 15 times lower and primary centers are functioning with only 38% of essential manpower and 31% of essential supplies necessary (Deongokar 2004).

Shortages in rural areas are more pronounced. Most professionals are not attracted by the isolation and poor living conditions of rural regions (Peters et al. 2002). In a survey of public

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[4] Allopathic medicine is: "the treatment of disease by conventional means, i.e. with drugs having effects opposite to the symptoms. Often contrasted with homeopathy";
Unani is: "a system of medicine practiced in parts of India, thought to be derived via medieval Muslim physicians from Byzantine Greece";
Ayurveda is: "the traditional Hindu system of medicine (incorporated in Atharva Veda, the last of the four Vedas), which is based on the idea of balance in bodily systems and uses diet, herbal treatment, and yogic breathing";
And Homeopathy is: "a system of complementary medicine in which ailments are treated by minute doses of natural substances that in larger amounts would produce symptoms of the ailment; often contrasted with allopathy". (Oxford Reference 2010).

facilities in rural Rajasthan for example, absenteeism was recorded 36 to 45% of the time and some sub-centers were closed up to 56% of the time because of this (Banerjee et al. 2008). In addition, most healthcare professionals available in rural areas are unqualified. In a survey of public and private providers in Madhya Pradesh, an imbalance was recorded between rural and urban regions. In this study, 90% of all unqualified doctors identified were located in rural areas (De Costa et al. 2007). Furthermore, a public-private imbalance was also recorded in the same study. Overall, 75.6% of all qualified doctors were working in the private sector and only 59.5% of all beds were found in the public sector (De Costa et al. 2007).

Shortage in the supply of necessary equipments and medicines in the public sector have been deplored. One study has reported that the availability of common essential medicines (WHO core list) in public services was low and ranged from 0% to 30% in six surveyed sites across the country (from 0% in West Bengal, to 12.5% in Karnataka to 30% in Tamil Nadu) (Kotwani et al. 2007). This shortage of manpower and medical supplies in the public sector has given way to a situation where individuals are now forced to buy the necessary tests, equipment and drugs in the private sector to receive care in public facilities (Peters et al. 2002).

Issues in stewardship and the lack of systematically enforced regulation have an impact on prices and quality. The private sector is used even by the poorest because the quality of its services is perceived to be better (Kurian 2007; Peters et al. 2002; Roy et al. 2007). However, quality in the private sector is highly uneven. As mentioned above, some practitioners in allopathic and traditional medicine are qualified and have received a valid training from a recognized institution, while many others have not (Bhat 1999; De Costa et al. 2007; Kumar et al. 2007; Peters et al. 2002). The varying quality of private services is a consequence of the absence of official and systematically enforced regulation (De Costa et al. 2007; Mishra 2005; Peters et al. 2008b). Peters *et al.* argue that the regulatory structure for price, quantity and quality in India is disconnected from reality (Peters et al. 2008b). There are many reports in the private sector of skimping on quality, charging higher prices and providing unnecessary services (Peters et al. 2008b, Das, j. et al. 2007). A structure to ensure the necessary oversight over the Indian health system has been identified as one of the main gaps to be bridged by Peters et al. (2002).

Thus, India's central government has been playing an important role on health, but that commitments and resources have been described in literature as falling short of what is needed. The lack of financial resources and issues about financing, the lack of social protection and insurance, a service delivery dominated by an unregulated private sector, the scarcity of resources and the failing regulatory structure undermine the whole health system as well as the poor's

experience of care. It is in this context that India is currently undergoing epidemiological and demographic transformations that affect the way health services have to be provided and sought.

3. Literature Review

In this section, the scientific literature is reviewed. To begin with, even though the concept of access will be detailed more thoroughly in the methodology section, it is briefly defined here first to structure the review. Then, the barriers to access for the poor living with chronic diseases in India are reviewed for each dimension of access. Finally, an overview of governmental policies addressing chronic diseases is presented, followed by the gap in knowledge

3.1. Poverty and Access

Access is understood in terms of needs and utilization. As defined by Peters et al, "access is related to the timely use of services according to needs (p.162)" (Peters et al. 2008a). Or as stated by Lévesque, "utilization or not according to given needs is the expression of realized or failed access (p.45)" (Lévesque 2006). Furthermore, equity in access is defined as receiving equal services for equal needs (Waters 2000).

Realized access is based on the optimal interaction of a population (demand) with health services (supply) (Lévesque 2006). Between these two poles, multiple barriers can hinder the user's abilities to access or the accessibility of health services (Frenk 1992). On the supply side, the socio-cultural acceptability of services, their geographical and organizational availability, their affordability and their adequacy are the dimensions that characterize the supply side (Lévesque 2006). On the demand side, the individual's abilities to seek care from existing services, to reach health services, to pay for these services and to benefit from the care received affect their power of utilization (Lévesque 2006). In India, the demographic characteristics and socio-economic status of households can influence their abilities in access (Deongokar 2004; Lévesque 2006).

Therefore, it is clear that poverty and access are closely intertwined. Poverty affects people's power to access existing health services. Without the possibility to access health services in times of needs, poverty becomes a determinant of worst health outcomes. Peters *et al.* argue that "absolute levels of income and material deprivation influence people's risk of disease and ability to purchase health services" (Peters et al. 2008a). Quoting Sen, they also wrote that "relative income is important because it translates into capabilities, or what you are able to do with what you have, which is an important factor in accessing health services" (Peters et al. 2008a; Sen 1992). The poor start at a disadvantage point on all the dimensions of access and are constrained in their access by more opportunity costs (Peters et al. 2008a). Overall, a good access to health services without barriers or consequences on one's own living standards is essential (Gilson et al. 2008b; Lévesque 2006).

It was estimated that the 20% poorest in India have twice the mortality and morbidity rate of the wealthiest (Peters et al. 2002). The determinants of worst health outcomes for the poor are located at the individual, household, community, health system and government levels (Wagstaff 2002).

Poor individuals and households are constrained to unhealthy behaviors and inadequate use of health services because they have lower income and fewer assets, and less opportunities and knowledge. Furthermore, social norms and living environment in poor communities affect the health status of individuals. Health services in their communities are often weak institutions of bad quality and this is coupled by their exclusion from health financing and insurance. Supply of other related sectors, such as education, nutrition and sanitation, also affect the worst health outcomes of the poor. Finally, as it will also be demonstrated in the methodology section, health policies also influence the provision of health services and their financing (Wagstaff 2002).

The Indian government has been criticized for not reaching the poor adequately with health services. In India and other developing countries, access is problematic for the poor in these health systems characterized by lack of funding, user fees, lack of adequate social protection and unregulated privatization.

3.2. Barriers to Access for the Poor in India

Major barriers to access already constrain the poor's access in important ways. Chronic diseases do not only create new barriers to access for the poor but also exacerbate existing ones.

Poor individuals suffering from chronic diseases are more susceptible of falling into the "medical poverty trap". As Ramaraj et al. (2008) exemplified for poverty and cardiovascular disease in India, the poor are more susceptible of having untreated morbidity due to lack of access to outpatient services for regular check-ups and health investigations. The poor usually wait for complications before resorting to care which means that the services they now need are greater to treat complications, thus increasing even more the costs of treatments. This often means for households long term impoverishment, coping strategies and the resort to the irrational use of drugs.

Acceptability, Choices and Ability to Seek

Barriers related to the socio-cultural acceptability of services and ability to seek can hinder the poor's access. In addition, knowledge and literacy can also influence people's ability to identify health problems and seek appropriate care.

The acceptability of health services depends on the context where it is evaluated (Peter's et al. 2008a). Acceptability (and the related ability to seek) is the level of concordance that exists between attributes of services and users' socio-cultural norms and beliefs (Lévesque 2006). Gender (both of the provider and the user), beliefs in different systems of medicine and education can all affect access.

To begin with, gender can become a barrier to access for poor women, as much as income (Ensor et al. 2004). In many households and communities around the world it is not considered acceptable for women to travel a distance to reach available care, especially alone (Ensor et al. 2004). In Punjab, one study underlined the unacceptability for women to travel alone to reach care, thus increasing opportunity and direct costs of utilization because of the necessity to accompany them (Booth et al. 1992). In another study in Gujarat, *Purdha*[5] restrictions were also identified as affecting women's possibility to access health services, and these travel constraints also affected the choice of provider (Vissandjee et al. 1997). Furthermore, given these restrictions, it is also found not acceptable for women to consult male doctors or other male professionals. The need for the public sector in India to make services more gender-sensitive is acknowledged in the literature (Peters et al. 2002).

Along the same lines, beliefs in different systems of medicine also affect utilization in India. In many communities, indigenous and traditional providers are the first line of services for outpatient care (Peters et al. 2002). In the Gujarat study, traditional healers were used in 67% of the time (Vissandjee et al. 1997). Short distance, cultural affinity and the influence of extended family were all reported as influencing this utilization (Vissandjee et al. 1997). Women were more likely to use these services in this study because of distance and family pressures. In addition, the use of traditional healers in the same study also decreased with education.

Education and literacy influence the ability to seek appropriate care (Ensor et al. 2004). Education influences the capacity of individuals to produce health, integrate health messages and it serves as a basis for individuals to evaluate their own needs and adopt the best health-seeking strategies (Ensor et al. 2004). In India and other rural regions in developing countries, uneducated individuals have a lower ability to distinguish between qualified and unqualified providers (De Zoysa et al. 1998; Ensor et al. 2004). Furthermore, the poor and less educated, because of issues related to costs, accessibility and availability, sometimes engage in harmful strategies, such as not seeking the care they need or self-medicating for example (Bhatia et al. 2001; De Zoysa et al. 1998; Saradamma et al. 2000).

Health literacy influences health-seeking behaviors and access and it goes further than socio-cultural believes. This is even more the case for physical non-communicable diseases that represents a newer and unfamiliar burden for the poor in India. Mental health literacy is also a major factor at play, where culture does not only affect the choice of providers, but also the explanation given to the origin of disorders (Basu 1990).

Some authors argue that the general lack of knowledge on non-communicable diseases and the lack of awareness among the Indian population on healthy behaviors and the importance to

seek care is a significant barrier to access (Ajay et al. 2008;Beaglehole et al. 2007a;Bjork et al. 2003;Karthikeyan et al. 2007;Mishra et al. 2006;Mohan et al. 2005;Pandian et al. 2007;Ramachandran et al. 2002;Ramachandran et al. 2008a;Ramachandran et al. 2008b;Reddy et al. 2007b). Individuals lack knowledge on what exactly are chronic diseases like diabetes, what are the risk factors and what is required for their optimal control. Currently this is not only the case among the poor, but for the entire population.

In one study in the city of Chennai, authors discovered that knowledge of diabetes in the general population was very low with 25% not even knowing that diabetes existed (Mohan et al. 2005). Furthermore, even among the diagnosed diabetic a very low percentage knew about possible complications of their disease (41%), and the need for control and healthy habits (11.9%) (Mohan et al. 2005). Therefore, even in major cities like Chennai which has a major specialized diabetes hospital, control was not adequate and knowledge of diabetes in the population very low. One study on an industrial sample discovered that the rates of undiagnosed diabetes were important in all socio-economic groups and many individuals were not seeking treatments to control their disease even if care through their employer was free (Ajay et al. 2008). Another study of diabetes in India has also underlined how the majority of patients lack understanding of the need to constantly monitor diabetes and control glycaemia (Bjork et al. 2003). The same authors state that this lack of knowledge might be affecting access to tests and specialists even more than socio-economic status or living in urban centers near health centers (Bjork et al. 2003).

Similarly, some studies have also underlined the lack of knowledge and awareness of stroke symptoms in the Indian population. This lack of knowledge and awareness among patients and their families causes delays in admission to health centers (Das, K. et al. 2007; Pandian et al. 2006b). In a study of asthma, the lack of knowledge and awareness of the disease, its symptoms and its possible complications was also identified as leading to sub-optimal control (Jindal 2007).

Perceived stigma and lack of awareness on mental disorders affect utilization of mental health services in India (National Human Right Commission 2008). Mental health literacy and attitudes can influence the recognition of a mental health problems and health-seeking patterns (Jorm 2000). Utilization of traditional and faith-based healers for mental diseases is important in India. Furthermore, many families will seek care through traditional healers for mental problems and some will be discouraged to seek formal treatment in psychiatric wards and mental hospitals (Ganju 2000; Khandelwal et al. 2004). In many cases, it originates from the explanation people have for these diseases, their difficulty in distinguishing traditional medicines from religious healers or the accessibility of psychiatric care, especially in rural areas (Khandelwal et al. 2004). In a rural Maharashtra study, authors have highlighted that even if disorders were acknowledged by families,

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[5] "the practice in certain Muslim and Hindu societies of screening women from men or strangers by means of a curtain or all

village doctors and community interventions, the inappropriate use of medicines were favored over seeking help from a qualified psychiatrist (Kermode et al. 2009). Even if disorders were recognized, they were often not considered by the study participants as "real illnesses" (Kermode et al. 2009).

Therefore, knowledge and awareness affect utilization of health services in general and for chronic disease specifically. Literacy can affect prompt health-seeking behaviors and the reflex to seek appropriate and regular care. Hence, the poor's knowledge and literacy affect the very beginning of the chain of access. Education is associated to knowledge of diseases, but also to better treatment-seeking behaviors (Reddy et al. 2007b). The health system in India is currently not equipped to deliver knowledge efficiently to patients (Das, K. et al. 2007) on top of the fact that few providers can currently detect and manage these types of diseases.

Availability and Ability to Reach

In general and specifically for chronic disease, problems related to the geographic and organizational availability of health services can represent important barriers to access. Similarly, they also play on the poor's ability to travel in order to reach healthcare facilities. Following the decision to consult a healthcare provider, patients are challenged by availability problems and their ability to reach.

At the outset, availability is defined in both geographical and organizational aspects. Availability is the level of medical supply per population or within a geographical area or organizational structure (Kruk et al. 2008). In India, services in the public sector are perceived to be of poorer quality not essentially for the medical staff's clinical skills, but more basically because of problems related to the availability of medical professionals, equipments, treatments and medicines and the fact that the use of these services still involves many costs (Peters et al. 2002, Lévesque et al. 2007). Also, distance and utilization have a negative relationship: utilization generally diminishes as distance increases (Bashshur et al. 1971; Peters et al. 2008a; Shengelia et al. 2003). Furthermore, in poor, remote and isolated communities, communications are often difficult as roads are often impracticable and sometimes completely shut down with season changes (Peters et al. 2002). Hence, traveling toward a health center and supplying these regions are important challenges (Peters et al. 2002).

As it is the case in most countries, health services in India are more concentrated in urban areas (Peters et al. 2002). This is the case even though the majority of the population of India lives in rural regions. Furthermore, some authors have argued that rural and isolated regions in India are

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enveloping clothes" (Oxford Reference 2010).

particularly under-covered. The density of services and availability of qualified health professionals is much lower compared with urban centers (Banerjee et al. 2008; Mishra 2005; Peters et al. 2002).

Various studies have highlighted distance as an important barrier to access in rural areas and even in some urban communities. For the NSSO (2006), the fact that the proportion of people getting treated for ailments is much better in urban setting is an illustration of the impact of the geographic availability of health centers. In that survey, 12% of rural respondents said they did not seek care for minor ailments because there were no medical facilities available in their community. In a study in rural Orissa, physical access to health services has been shown to be restricted by distance and communications (Ager et al. 2005). In this study, the only care available near the community was private and public facilities were located hours away from the village. On top of this, the principal ways to reach these health centers were driving a bull cart, riding a bicycle or walking. Moreover, communications are even completely disrupted during the monsoon season. In poor urban communities, distance is also a self-reported reason for untreated morbidity. Even though health services are concentrated in urban centers, they are not necessarily accessible to the poor in slums neighborhood. In a study of health services utilization in two poor slums of Mumbai, 50.6% of the respondents that lived in a slum at the outskirt of the city and 12.5% of the respondents that lived in a slum at the center of the city said they did not go for treatment in municipal facilities because they were located too far away from their home (Yesudian 1999). As it was seen earlier, primary care centers in India are intended for rural regions. In reality, the lack of primary health services in urban areas has been suggested as a factor that affects the poor's access in urban centers(Duggal 1992, Lévesque 2006). The poor cannot afford private care or higher levels of services.

Hence, availability barriers also affect the poor in their choice of providers. As it was stated before, the poor use private services more predominantly for their outpatient care. One reason motivating this choice is the availability of private services and the shorter distance needed to reach these facilities (Peters et al. 2002). However, even if they are often perceived as offering services of better quality, private providers located in poor communities are often unqualified or poorly qualified (Peters et al. 2002). Peters et al. have reported that in 1998, 44% of respondents to a national survey said they used private services because of their availability near their community (Peters et al. 2002).

As it was detailed earlier, the shortage of qualified human resources is critical in the public health system. In rural areas, the availability of skilled and motivated human resources is preoccupying (Banerjee et al. 2008; Peters et al. 2002). Many primary care and sub-centers in rural regions even remain completely vacant of medical personnel (Bajpai & Goyal 2004). The exodus of educated and qualified workers is a problem everywhere but affects first and foremost rural and isolated regions (Mishra 2005). The availability of qualified providers is an important barrier to

access (Peters et al. 2002). If you can reach infrastructures where there are either no doctors or unqualified ones, full access is not realized. Rural doctors are mostly trained in traditional medicine, but a majority also practices allopathic medicine, giving drugs and injections for which they did not receive appropriate training (Kumar et al. 2007). The majority of qualified traditional providers are located in private solo practice in urban centers, while untrained traditional healers, traditional birth attendants and healing priests are mainly based in rural areas (Peters et al. 2002).

In addition, throughout the system, capacities for the detection and management of chronic disease are low. Some state-subsidized care and private high-tech centers offer acute care and long term quality treatments for chronic disease, but these facilities are located in important urban centers (Reddy et al. 2005). Moreover, primary and secondary centers in rural areas and towns are not equipped to offer this type of care (Reddy et al. 2005). Hence, services available are mainly accessible to affluent individuals, being located in urban centers and offered by a few highly qualified (and expensive) private providers (Ramaraj et al. 2008). In rural areas, primary care services are especially ill-equipped to manage these diseases for detection, referral, health promotion and follow-ups (Joshi et al. 2006).

Furthermore, one important element in acute interventions for some chronic diseases is emergency care (Karthikeyan et al. 2007; Pandian et al. 2007). A rapid access to emergency services for acute events is critical in some cases and only a few institutions are able to offer this kind of care in India (some public but mainly private ones) (Peters et al. 2002). Most cities do not have an integrated ambulance and emergency service and thus most individuals use other types of transportation, which cause delays in interventions (Ramaraj et al. 2008). In a study of stroke care in India (Pandian et al. 2006a), authors found that 59% of patients arrived late at the medical facility and that living in a 10km radius from the hospital was one factor favoring early arrival. Moreover, modes of transportation to facilities varied from 7% in cycle rickshaw[6] and 10% in auto rickshaw to 12% ambulance, 22% taxi and 49% personal car.

In addition, the mental health system in India, as in most developing countries, is described as lacking qualified human resources and to offer services that resemble more detention than therapy (Ganju 2000; Khandelwal et al. 2004). Moreover, one study has reported that there are more psychiatric beds in the sole city of New York than in all India (Ganju 2000). Another report also confirms the shortage of mental health professionals and facilities as affecting utilization (National Human Right Commission 2008). Similarly, the geographic distribution of mental health facilities also varies across settings (Ganju 2000). Capacities exist in cities where mental health clinics, hospitals and qualified professionals are located, but few of them are located in rural areas (Khandelwal et al. 2004). One study of mental health in rural Maharashtra has underlined how the

[6] Cycle rickshaw: “a light two-wheeled passenger vehicle drawn by one or more people, chiefly used in Asian countries” and Auto rickshaw: (in the Indian subcontinent) a motorized, three-wheeled rickshaw for public hire (Oxford 2010).

inaccessibility of psychiatrist and the need for patients to travel in distance to reach professional care is a barrier to access (Kermode et al. 2009).

Hence, chronic disease exacerbates problems of availability and ability to reach that already influence the poor's access. Capacities for the detection and management of chronic disease are scarce and specialized services are concentrated in few settings and providers.

Moreover, other factors linked to availability, acceptability, adequacy and affordability are intertwined with barriers related to the individual's ability to reach. Traveling to health centers can increase the indirect costs of treatments, while it might also be perceived as necessary in order to reach services of better quality (Ensor et al. 2004; Peters et al. 2008a; Yesudian 1999). Also, gender discrimination can affect poor women's utilization of services as it is often not socially acceptable for women to travel alone (Ensor et al. 2004).

Affordability and Ability to Pay

Once the needs are perceived, the provider selected and the health facility is reached, barriers related to the affordability of these services and ability to pay can still affect the poor's access. Direct and informal payments, combined to the indirect and opportunity costs associated with utilization can hinder the poor's ability to pay for health services (Peters et al. 2008a).

It is important to highlight how willingness and ability to pay are two different concepts. Health purchases might be done notwithstanding actual ability to pay and it can put living standards in jeopardy (Russell 1996). Catastrophic expenditure is related to the capacity of payments and in the absence of it, individuals are forced to cut down on other essential services, go into indebtedness or other coping strategies in order to pay for care (Kawabata et al. 2002;Peters et al. 2008a;Wagstaff et al. 2003;Xu et al. 2003). More technically, catastrophic expenditure is also defined as healthcare spending equal to or greater than 40% of a household's income (remaining after subsistence needs are met) (Xu et al. 2003). On the other hand, this phenomenon is only observed if there is actual use of healthcare services and many poor household often simply choose to forgo treatments because they cannot afford it (Kawabata et al. 2002).

Here, it is also important to understand the difference between direct costs of health services and indirect costs resulting from utilization (Russell 1996, 2004). The importance of costs is such that even if services are free in theory, direct and indirect costs can arise from the purchase of drugs or transportation and influence the decision of poor individuals to use health services and the type of provider to see (Banerjee et al. 2008;Bhatia et al. 2001;Levesque et al. 2007;Peters et al. 2002). Indirect and opportunity costs also includes losses in productivity or income due to illness or taking care of a family member (Russell 2004). In many developing countries, selling assets to pay for healthcare can also result in a loss of future productivity and income when, for example, farming

tools, animals or land are sold to pay for healthcare bills (Khan 2005;Roy et al. 2007;Russell 1996;Russell 2004).

In India, the poor will either bear financial consequences after using health services or go into different coping strategies to avoid this burden. In the last decades, India has witnessed an increase in the use of private services, out-of-pocket payments and indebtedness, as well as self-reports of avoiding utilization because of costs (Duggal 2007). As underlined earlier, out-of-pocket payments and the lack of insurance and social protection explain in part why many financial consequences can result from the use of health services in India. This situation results in households being pushed into or further into poverty after consuming health services (Peters et al. 2002; Van Doorslaer and al. 2005). In order to pay for services, some individuals in India will go into financial distress, delay the use of health services or not adhere completely to their prescribed treatments (Devadasan 2004b; Peters et al. 2002; Roy et al. 2007; Van Doorslaer and al. 2005).

In theory, care is free for the poor in the public sector, but because of problems related to the organizational availability of supplies, they often bear the costs related to the purchase of necessary medicines and supplies (Ager et al. 2005, Levesque et al. 2007). The availability of medicines in the public sector is problematic and most individuals have to purchase them in the private sector where their costs are higher (Kotwani et al. 2007). Even if they exist in theory, free care is often not implemented effectively (Bhatia et al. 2001) These approaches do not always account for indirect costs, informal payments and opportunity costs related to the utilization of public services (Bhatia et al. 2001;Dror et al. 2008;Peters et al. 2002).

Various studies have underlined the importance of costs on access. One Indian study examined the costs of health services and illness in five resource-poor settings (Dror et al. 2008). In this study, the median cost of illness represented, on average, 73% of a household's monthly income and up to 780% of the income of the 10% of households that are the most exposed to illness and care. In the same study, it was found that direct costs were more important on a ratio of 67:30, with hospitalization being costlier and drugs constituting the greater share of total costs. Costs in this study were also increasing with private health services utilization.

The poor in India are less likely to seek care when ill and more likely to resort to unqualified outpatient providers because of financial constraints (Peters et al. 2002). Also, inability to pay and lack of insurance decrease their odds of hospitalization and force them to borrow money when they have to (Peters et al. 2002). In the NSSO survey of 1995-96, as much as 24% of the poorest reported not using care at all when in need (Gupta 2003). The NSSO 2004 reported that 28% of rural respondents and 20% of urban respondents gave financial restraints as a reason for untreated morbidity (with untreated morbidity being at 18% and 11% in rural and urban areas) (NSSO 2006). In the same way, in rural Orissa costs associated to utilization represent an important barrier and

many individuals have reported not using services, selling assets or delaying utilization until enough money has been saved (Ager et al. 2005).

This situation of economic vulnerability towards access is similar to what the literature describes in other countries. In many developing countries, user fees, costs and the poor's inability to pay have all been described as having similar consequences on access and living standards (Ensor et al. 1996; Khan 2005; Leive et al. 2008; Van Damme et al. 2004; Wagstaff et al. 2003; Xu et al. 2003).

Accordingly, the fact that services for chronic diseases are less available and more expensive consequently makes them even more unaffordable to the poor. Chronic disease care in India is available from a few specialized private providers that offer technology intensive services that are too expensive for the majority of the population (Reddy 2003).

In the study on the cost of illness in five resource-poor settings, chronic illnesses represented an important financial burden. Even though they accounted for 18.5% of the total disease burden, they made up for 32% of all costs (Dror et al. 2008). Hospitalizations and drugs associated with chronic illness episodes increased the costs of treatments substantially (Dror et al. 2008). Compared with acute diseases, chronic illnesses increased the direct, indirect and total costs of disease in these poor Indian communities (Dror et al. 2008).

Furthermore, the multiple regimens of medicine that chronic diseases often impose increase the usual financial burden of treatments (Mendis et al. 2007). Moreover, in many developing countries, chronic disease medicines are not widely available, even in generic form and most people do not have the ability to pay for them (Mendis et al. 2007). In India, these drugs are also very expensive (Reddy et al. 2005). One study estimated the affordability of asthma medicines in different states of India. They estimated the cost of basic inhalers to represent 1.6 to 2.3 days of wages for the lowest paid government employee (Kotwani 2009). Essential asthma medicines are thus unaffordable to the majority of the population who works in the informal and agricultural sectors. The price of asthma medicine in this study also varied between states and types providers. While availability was sometimes better in the private sector, procurement prices were also higher.

Chronic diseases are also associated to more episodes of hospitalization and longer stays which can also increase the financial burden (Levesque et al. 2007). Hospitalizations due to complications have a major impact on costs and represent an important burden for individuals and households (Bjork et al. 2003). Due to the importance of costs associated with inpatient care, more patients will turn to the public sector when affected by chronic diseases (Levesque et al. 2007).

Direct costs of regular visits to a healthcare provider, of inpatient care when complications occur, of medicines, lab tests and consumables, as well as indirect costs and the possible loss of income mean that there is a higher financial burden associated to chronic diseases. Especially when taking into account that chronic diseases are treated on the long term and necessitate close

follow ups by professionals. This is disastrous for the poor in most developing countries for whom regular contacts with health services can mean catastrophic costs for the rest of their lives (Russell 2004).

Studies on the cost of diabetes in India have highlighted the high costs associated with regular care, follow-ups and treatments, and their increase in the case of complications requiring inpatient care and surgical interventions (Kapur 2007; Ramachandran et al. 2008a; Tharkar et al. 2009). One study has also demonstrated an increase in expenditure on diabetes over time in India and the fact that co-morbidities increase the risks of complications and the costs of treatments (Tharkar et al. 2009).

In addition, if insurance coverage is generally low in India, it is even lower among individuals with mental health problems (National Human Right Commission 2008). Insurance is an important factor in encouraging patients to seek and adhere to treatments, as well as financially protect households (National Human Right Commission 2008). Mentally ill patients have specific needs and disabilities and also suffer disproportionally from physical diseases due to stress, behaviors and a general incapacity to take care of themselves (National Human Right Commission 2008). One author confirms that schizophrenia is a costly disease to treat, as families have to bear most of the costs of services, drugs and travel, and the usual loss of income of the ill family member or the loss of income of those taking care of him (Grover et al. 2005).

In the end, barriers to access related to affordability are also related to the individual's purchasing power in a context of chronic disease care (Reddy 2003). For some authors, the solution resides in a change in health financing mechanism, social protection and private insurance (Reddy 2003). Even in a country like Sri Lanka, with free and universal access to public services, barriers to access arise due to the costs of chronic disease care, like it is the case for diabetes care (Perera et al. 2007).

Adequacy and Ability to Benefit

Ultimately, when health services are reached, consumed and paid for, access is only realized if these services were effective. Accessing useless, poor or ineffective health services is not access. In the literature, the low level of public expenditure on health is recognized as one of the main causes for the poor quality of public services (Peters et al. 2002). Quality is increasingly being studied in relation to access (Campbell et al. 2000; Lévesque 2006; Peters et al. 2008a; Shengelia et al. 2005). Frenk (1992) has underlined that when studying access, a restrained or a larger scope can be adopted. A restrained scope on access is understood as receiving health services or not. On the other hand, in a larger scope, access is realized if the care received is effective as well.

Quality must be found in both interpersonal and clinical services and it also implies that these services are acceptable, available and affordable as well (Frenk 1992; Lévesque 2006). Quality of clinical care is about making the right diagnosis given certain symptoms, choosing the appropriate course of treatment and using the correct clinical guidelines (Hegelian et al. 2005). Therefore, quality means accessing services that are effective (Campbell et al. 2000). Campbell et al. define access at the individual level as: "whether individuals can access the health structures and processes of care which they need, and whether the care received is effective (p.1614).

Perceived quality affects health-seeking behaviors (Shengelia et al. 2005). In general, individuals cannot assess the technical quality of providers, but will rather judge the quality of interpersonal services (Shengelia et al. 2005). Many authors have confirmed quality's influence on the decision to use services and the choice of facility in India and other developing countries (Akin et al. 1999; Andaleeb 2001; Dipankar et al. 2007; Peters et al. 2008a).

As stated earlier, the private sector is used even by the poorest in India because the quality of its services is perceived to be better (Kurian 2007; Peters et al. 2002; Roy et al. 2007). However, the poor usually consume health services from unqualified providers which means that quality of care is an important issue (Peters et al. 2002). The majority of the poor live in rural areas where the majority of providers are unqualified (De Costa et al. 2007). Unqualified providers often administer medicines for which they did not receive the necessary training and they contribute to the problems of ill health and drug resistance among the poor (Kumar et al. 2007; Peters et al. 2002).

In a study of utilization in rural Orissa, respondents have confirmed that the reputation of a provider influenced their decision to seek care (Ager et al. 2005). Some respondents have declared that they usually wait for positive reports of a provider before using health services or even going extra distance to reach a provider with a good reputation. Similarly, in two urban slums of Mumbai 67.5% and 31.4% of respondents did not seek care in municipal services because of their opening hours, 8.3% and 6.3% because of unavailable medicines, 2.9% and 3.0% because they did not perceived the doctors to be good and 2.7% and 2.4% because of the quality of interpersonal services in these facilities (Yesudian 1999).

In their study on the poor's utilization of health services in urban Chennai, Ergler et al. (2010) affirm that availability of health services at walking distance is necessary but not sufficient to explain patterns of utilization. In their qualitative study, they found out that most individuals sought care in the private sector because of their perceived entitlement for care. Many thought that using private services was appropriate for certain specific ailments including chronic diseases. They also said that care was of better quality and the money spent in the private sector led to a faster recovery and a quick return to productive economic activities. Furthermore, for some respondents, the opening hours and proximity of private providers mean they are the only real choices available. Free and

nearby facilities were used as a last resort choice. The phenomenon of bypassing public services or closer services is indicative of quality problems (Akin et al. 1999).

Furthermore, the introduction of user fees in developing countries, if unaccompanied by any changes in the quality of services, represents an interaction of barriers to access (Haddad et al. 1995; Haddad et al. 2006). An evaluation of a World Bank funded project in Uttar Pradesh illustrates this point (Dipankar et al. 2007). The project group was exposed to an increase in user fees and quality investments in their local health facilities, while the control group was only exposed to an increase in user fees. What was observed is a diminution of utilization in the control group but an increase in the project group. Hence, these authors have concluded that improvements in quality can offset the impact of user fees on utilization.

Quality problems in public facilities and unqualified private providers are critical in India and illustrate the need to improve the regulatory structure. Poor regulation is associated to a poor governance of health services (Peters et al. 2008b). While the government of India currently undertakes important initiatives in the right direction, the same authors state that the regulation and accountability environment is disconnected from reality.

Overall, chronic disease care in India is currently inadequate. The scarcity and unequal distribution of facilities equipped for this type of care and the fact that most professionals do not have the capacity to detect and manage chronic diseases using appropriate guidelines represent major barriers to access. In general, for an early detection of chronic disease regular contacts with a provider is necessary, especially to sustain patients in managing their own disease (Beran et al. 2005;Bjork et al. 2003;Ramachandran et al. 2008a;Ramachandran et al. 2008b;Ramaraj et al. 2008). Applying guidelines and treatment protocols and an efficient system of patient files are necessary to ensure the follow-ups of chronically ill patients (Ramachandran et al. 2007). These are important pre-requisites to sustain the motivation of the patients (Coleman et al. 1998). Even if a regular contact with a source of care is possible, some studies have outlined that many health professionals in India are not qualified to detect and treat chronic diseases, particularly in primary and secondary centers (Bjork et al. 2003;Karthikeyan et al. 2007;Ramachandran et al. 2008a;Ramaraj et al. 2008;Reddy et al. 2005). One study on general practitioners' knowledge of childhood asthma reported that most were aware of treatments, but lacked adequate knowledge of symptomatology to detect cases (Gautam et al. 2008).

Various studies on the quality of diabetes care in India have emphasized this fact. One study has underlined how medical professionals lacked comprehension of the need to monitor and follow-up diabetic patients to ensure optimal control of the disease (Bjork et al. 2003). Similarly, in the city of Chennai, one study has reported that even if 97% of its samples of diabetic patients were being treated, optimal control was achieved in only 30% of cases (Ramachandran et al. 2008b).

Treatments were inadequate in most settings and the prevalence of risk factors in diagnosed diabetic patients was high (Ramachandran et al. 2008b). Hence, treatment of diabetes in this city was not adequate as important risk factors and complications were detected in this sample of diabetic patients (Ramachandran et al. 2008b). Overall, the burden of complications due to diabetes is high in India (Joshi et al. 2008). Some authors have even estimated that in India there is more money spent on the treatments of complications caused by diabetes than for the control of disease itself (Bjork et al. 2003; Ramachandran et al. 2007). There is a lack of standardization in laboratory techniques for the monitoring of diabetes and no consensus over guidelines (Joshi et al. 2008). Moreover, necessary follow-up visits are not standard practice and healthcare professionals are not adequately equipped to maintain the motivation of asymptomatic patients (Joshi et al. 2008). They also don't provide self-management education.

In the same way, the difficulty for physicians to diagnose asthma and distinguish it from other respiratory problems (such as COPD and TB) in primary care centers was also highlighted in the literature (Gautam et al. 2008; Jindal 2007). Moreover, facilities in rural primary care centers and even in public secondary centers located in towns and cities are also described as being inadequately equipped to treat cardiovascular diseases (especially for acute interventions) (Reddy et al. 2005).

Furthermore, the inadequacy of care for mental disorders in primary centers has also been highlighted in the literature. As described earlier, the training of general practitioners in mental health is far from ideal in India and not enough personnel is expected to detect and manage mental disorders in primary centers (Khandelwal et al. 2004). As a result of low financing and poor governance, primary care services throughout the country are not tuned to offer adequate care for mental disorders (Khandelwal et al. 2004).

Hence, the poor in India will have difficulties benefitting from care received in their usual source of care. Currently in India, the providers they usually see are generally not capable of detecting and managing chronic diseases.

3.3. Governmental Policies Addressing Chronic Diseases

The rising prevalence of chronic disease means that changes must be brought to the way health services are financed and provided. Chronic disease affects both the way health services must be delivered and the ability of poor individuals to use these services. There is a variety of physical and mental chronic diseases, each with its own specific care requirements. But they also have common overarching characteristics related to risk factors and the chronicity status (Larsen 2006) :

> "Chronic illness is the irreversible presence, accumulation, or latency of a disease state or impairment that involves the human environment for supportive care and self-care, maintenance of function and prevention of further disabilities (p.5)."

Furthermore, as argued by Theme-Filha et al. (2005) because of their chronicity status and the need for lifelong treatments and self-care, it also means that the health system must be redesigned.

> "…effective treatment for chronic diseases also requires a change in the type of service offered, from the episodic care to a more active approach, emphasizing long term follow-ups. The barriers to health care access must be carefully analyzed and new service models investigated, besides reviewing methods of remuneration that are not only based on the number of consultations but on educational and advisory activities. (p.s51)".

Ideally, managing chronic diseases involves key steps of which early diagnosis from a general practitioner is the beginning. Early diagnosis in a regular setting of care is necessary to start treatment before major incapacitating complications or death can occur (Coleman et al. 1998; Mamo et al. 2007; Pandian et al. 2007; Ramachandran et al. 2008a; Ramachandran et al. 2008c). Opportunistic case finding and early diagnosis are based on the assessment of risk factors and identification of high risk status by a primary care provider (Beaglehole et al. 2008). To maintain optimal control, the management of chronic diseases is also based on a combination of pharmaco and psychosocial interventions with regular follow-ups and monitoring for the promotion of adherence and healthy behaviors (Beaglehole et al. 2008; Reddy 2002). The same authors outline how health services at the same time must also be equipped for prompt interventions in acute events related to complications. Overall, if full access is realized and careful diagnoses, complete treatments and appropriate follow-ups are achieved, the consequences that chronic diseases can have on the well-being of individuals and households can be reduced (Beran et al. 2005;Bjork et al. 2003; Mamo et al. 2007; Mody et al. 2008; Ramachandran et al. 2008a). The community and the health system have to be involved in this optimal scenario (Beaglehole et al. 2008). As outlined in organizational models of care, such as the chronic care model.

Health policies and other socio-economic policies can ultimately influence access by changing the way health systems are financed and the way services are provided and regulated, or by gradually modifying the socio-economic status of the population. The linkages existing between health policies and access are presented in the methodology section.

For the World Health Organization (2005), governments have to simultaneously take actions for: (1) the surveillance and assessment of risk factors in the population; (2) estimating the burden of diseases and related health needs; (3) improving the health of the population by a combination of health education on common risk factors, legislation on products and behaviors, changes on the build environment and advocacy and community mobilization; (4) healthcare must also to be re-

organized; with (5) shifting budget allocations; (6) and improving healthcare professionals competencies. Additionally they must accomplish this without compromising the individual's financial security.

Policies on health education, knowledge and legislation on risk factors are generally more cost-effective and accessible to developing countries that are already overwhelmed by a serious lack of resources and other health problems (Jha et al. 2007;Miranda et al. 2008;Reddy 2004;WHO 2005). At the same time, governments also have to transform healthcare for better management of chronic disease and this can represent an expensive challenge because of the massive investments and restructuring required (Miranda et al. 2008;Ramaraj et al. 2008;Reddy et al. 2005;WHO 2005). Especially in a context where infectious diseases are still highly prevalent:

> "The complexities are compounded when policy has to prioritize on the basis of disease burdens, cost-effectiveness, and equity while the delivery systems have to simultaneously cope with the transformative pressures of economic restructuring and health care reforms. The challenges of providing acute and chronic care for NCDs in such settings are immense, yet the imperatives of proper planning and performance for delivering such care become increasingly urgent as health transition rapidly rewrites a new agenda for health care in the India." (p1). (Reddy 2003).

Chronic diseases in India have only recently started to receive sustained attention from the central government (Reddy 2007a). The major increase in prevalence and the spread of risk factors across all sub-groups in the population have contributed to put them on the health policy agenda (Reddy 2007a). The first programs formulated by the government of India were the National Mental Health Program in the eighties and the National Cancer Control Program (Reddy et al. 2005). Newer initiatives include the Tobacco Control Act and a pilot version of the National Program on the Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (Reddy 2007a). At the same time, other initiatives such as the National Rural Health Mission are focusing on the upscale of services which has the potential to serve as a solid basis for future chronic disease programs in these regions (Reddy et al. 2005). Furthermore, authors have also underlined that the central government will increase the mental health budget on its next development plan, along with a budget for other programs on physical chronic diseases (National Human Right Commission 2008;Reddy et al. 2005;Siegel et al. 2008).

However, the last national health policy of 2002 was almost completely silent on physical non-communicable diseases (Mishra 2005). Hence, a thorough and coordinated government response to chronic non-communicable disease in India has been late in coming and initiatives are only beginning (Reddy 2007a). Moreover, the response so far has been more centered on technologies (versus increasing capacities at all levels of care) (Reddy et al. 2005). It is only with the pilot program on diabetes, cardiovascular diseases and stroke that the need for the education of the

entire population is thoroughly acknowledged by the government with the need to provide care for high risk individuals (Beaglehole et al. 2007a; Ramachandran et al. 2008a; Reddy et al. 2005).

It is clear from this literature review how barriers to access health services for the poor living with chronic disease is an important health problem in India. So far, important barriers to access have been described in the literature and many authors have been advocating for a better government response to the challenge of chronic diseases. Many are calling for a transformation of the healthcare system. However, there is a gap in knowledge on the extent to which health policies currently address the barriers to access health services for the poor living with chronic disease. Furthermore, which policy levers are selected by health policies to address barriers to access remains to be studied. Finally, there is a necessity to investigate what is the actual scope of national health policies on poverty and chronic diseases.

4. Research Question and Objectives

Research Question

What has emerged from the literature review is that access to health services is already problematic for the poor in India and the rise in illnesses requiring chronic treatment and more complex interventions represents an additional challenge for this health system. Governments can play a role and have to respond to these new challenges and pressures. The literature review has exposed a gap in knowledge regarding health policies in India and the extent to which access to chronic disease care for the poor is addressed. Accordingly, this gap in knowledge has prompted the following research question: To what extent current Indian national health policies address the main barriers to access health services for the poor living with chronic diseases?

Objectives

Given the nature of this research question, the analysis was guided with a set of three specific sub-questions. These sub-questions are directly linked to three specific research objectives. The sub-questions are guiding each of their objective and the analyses were structured accordingly.

The first objective of this research was to assess whether the goals, objectives, instruments and targeted populations, as formulated in current national health policies in India, address the main barriers to access health services for the poor living with chronic diseases. Specific research question 1: Which barriers to access are addressed by each national health policy?

The second objective was to assess the types of policy levers and instruments identified in current national health policies to address the barriers to access in each dimension of access. Specific research question 2: What are the main levers proposed by national health policies to tackle these barriers to access?

The third objective was to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor. Specific research question 3: Are more recent policies associated with a better focus on chronic diseases care and especially for the poor?

The methodology is detailed in the next section. Using the framework approach, a qualitative content analysis of selected Indian national health policies was conducted deductively using a pre-established framework on the barriers to access health services for the poor living with chronic disease. The framework was structured with a specific conceptualization of access and health system functions presented in the next section and filled with the scientific literature reviewed in the previous section.

5. Methodology

In this section, the methods used to answer the research question are presented. The *framework approach* of Ritchie and Spencer's (1993) is the qualitative content analysis method that was selected for this research. This deductive approach is based on a prior conceptualization of access, health system functions and the role of policy on access that are detailed first. Finally, reliability and validity precautions are presented, as well as the limits and strengths of the research design.

5.1. Conceptualizing Access to Healthcare

The main concepts on which this research is based are presented in the methodology section instead of the literature review. This is the case because the concepts of poverty and access, health system functions and the role of policy on access were used to structure the analyses. A thematic framework of the study problem was derived from these concepts and filled with elements from the literature review. Following this, all the analysis tools were also generated based on these concepts.

Poverty can be examined using an absolute or a relative perspective (Kawachi et al. 2002). Absolute poverty is the "inability to fulfill basic human needs and is measured with a "poverty line" (p.648)" (Coudouel et al. 2002;). Relative poverty on the other hand is defined in "relation with the standards that currently exist in society" (p.649) and is generally measured with a distributive approach (Coudouel et al. 2002). Hence, for these authors, relative poverty refers to the inequalities existing in a society, in the distribution of wealth and other indicators in the population. Furthermore, poverty is one of the many determinants of vulnerability which can be understood as the insecurity towards possible declines in well-being. Thus, vulnerability is the probability of falling into poverty or deeper into it, given a particular situation or economic shock (such as consuming health services) (Coudouel et al. 2002). The poor are vulnerable to the costs of basic needs and services, for example, including health services.

Poverty and ill-health are linked and this relationship runs in both directions. In general, the poor have worse health outcomes because of lack of opportunities and various constraints (such as access-related problems); while ill-health contributes to maintaining individuals and households in a state of poverty (Wagstaff 2002). In India, there are important disparities and significant portions of the population live in poverty. Hence, many individuals and households in India are extremely vulnerable to health problems and shocks.

The concept of access used in this research is derived from Lévesque (2006) and Peters et al. (2008a) and a review of the literature. Access is defined as the possibility for individuals in need to

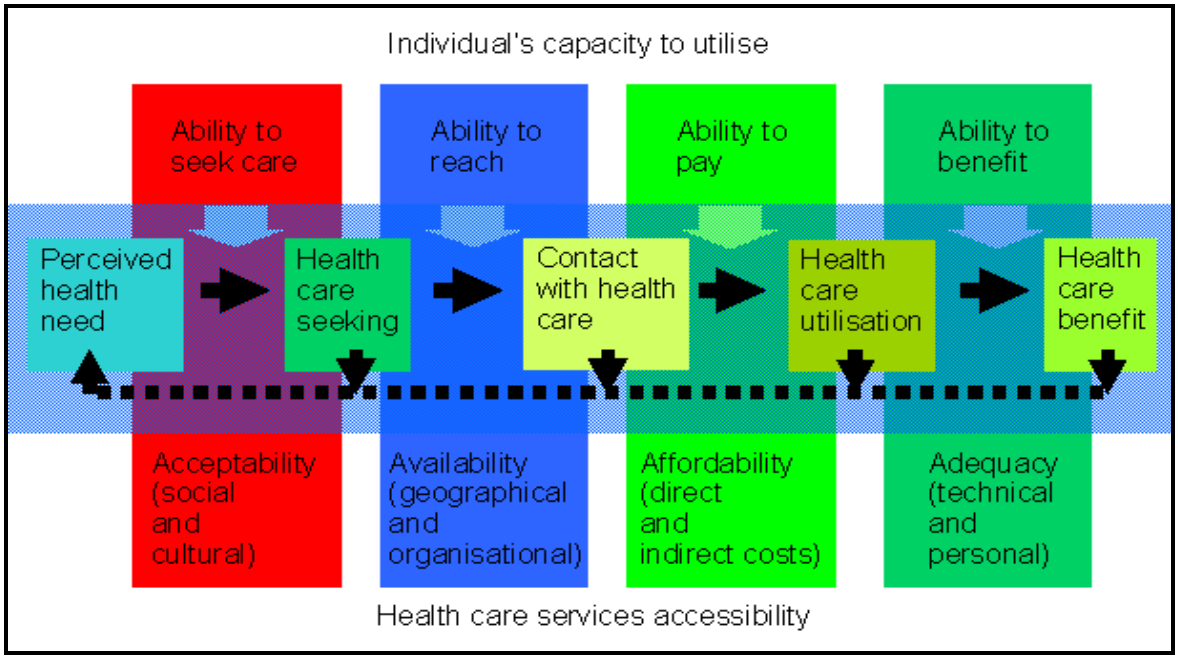
use health services (Frenk 1992; Waters 2000). As defined by Peters et al. “access is related to the timely use of services according to needs (p.162)” (Peters et al. 2008a). Furthermore, receiving equal services for equal needs incorporates equity into this definition of access (Waters 2000).

Historically, access was either analyzed from the perspective of the demand for or the supply of health services (Frenk 1992;Gilson et al. 2008b;Lévesque 2006;Russell 1996;Shengelia et al. 2003;Waters 2000). However, authors have started to understand access as the degree of adjustment existing between the health services and the population using them (Frenk 1992; Lévesque 2006; Peters et al. 2008a; Russell 1996; Shengelia et al. 2003; Waters 2000). Thus, realized access is based on the optimal interaction of population characteristics (demand-side factors) and health system characteristics (supply-side factors) (Lévesque 2006). On one side there is the presence of services and the capacity to produce them and on the other the ability of the population to use existing services and the real utilization made (Frenk 1992; Lévesque 2006). Multiple barriers can hinder the abilities of the population or the accessibility of health services (Frenk 1992).

In addition, resources and users' characteristics are categorized in specific dimensions. Four dimensions characterize healthcare resources and their accessibility and they are related to four specific individual abilities (Frenk 1992; Lévesque 2006; Peters et al. 2008a; Russell 1996; Shengelia et al. 2003; Shengelia et al. 2005). Health resources must ensure: the social and cultural acceptability of services to the population covered; the geographical (physical accessibility) and organizational (human resources, equipments, treatments and medicines) availability; the affordability of services to the population; and adequacy in terms of the appropriateness of services provided and their overall quality. Related to these resource dimensions, individuals have different abilities to access care that are in part determined by their socio-economic and demographic status: the ability to seek care from available health services and for specific health needs; the ability to reach health services and travel in distance; the ability to pay for health services; and the ability to benefit from care received.

In this perspective, individual characteristics must be in accordance with existing healthcare resources. People ultimately access healthcare if they have the ability to seek on the basis of perceived needs and reach available facilities. Once they have arrived there, people must be able to pay for these services. Finally, people must be able to benefit from the care they have received and paid for. This conceptualization of access and the sequence existing between its dimensions is illustrated in figure 5.1.

Figure 5.1: The Conceptualization of Access to Health Services



Source: Lévesque 2006

More precisely, the social and cultural acceptability of services refers to the characteristics of providers that are related to religious and cultural beliefs present in the population (such as the gender of providers). As it was explored in the literature review, acceptability is related to the capacity of individuals to seek care on the basis of their cultural beliefs or religious restrictions. One example already cited is the acceptability for women to travel to reach care unaccompanied or to consult a male doctor. Moreover, ability to seek care on perceived needs is especially relevant for chronic diseases.

The geographic and organizational availability of health services refers to the density of resources and their specific distribution in a given region. Moreover, it relates to the ability of individuals to reach these available resources. Access is not just a question of small or long distance between providers and patients, but it is also based on the capacity of people to travel to reach these resources. And if they can reach facilities where doctors and supplies are available on site.

The affordability of health services is related to the direct costs of services and the indirect costs of utilization. The direct costs of consultations, the purchase of medicine and treatments, traveling or the opportunity cost of lost income from time spent away from work can all affect the affordability of services and people's capacity to pay for them. Costs are also influenced by contexts and pathologies (Dror et al. 2008). Hence, even though individuals can act on perceived

need to seek and reach adequate health services, if they cannot afford and pay for this care, access cannot be realized. In addition, ability to pay can be influenced not only by income but also by insurance mechanisms or social protection scheme.

Finally, the adequacy of health services is related to their relevance and their overall quality. Existing and available services might not be those that can address the health problems of the person seeking care. Moreover, adequacy is also related to the quality of services. Access is not realized if people cannot seek and reach health services that will be effective for their needs. The possibility of using health services of poor or bad quality will not benefit the patient and it means that access is not realized.

There are many determinants to access that will shape the abilities of individual users or the characteristics of health services (Lévesque 2006). The determinants at the population level include, for example, living in a rural and urban community, gender, income and socio-economic status, culture and religion or employment. Regulation, jurisdiction, financing and remuneration mechanisms or geography and climate on the other hand, are all examples of determinants influencing the system's dimensions of access.

Individual socio-economic and socio-demographic characteristics influence their abilities to access health services. As a socio-economic status, poverty is a major factor that affects the individual's abilities to access (Peters et al. 2008a). Poverty is one major factor influencing abilities in India and other developing countries. But gender, education, ethnicity or communities are other important factors not specifically addressed by the current research.

As it was stated earlier in the literature review, poverty and access are closely intertwined. Poverty affects people's power to access existing health services. Without the possibility to access health services in times of need, poverty becomes a determinant of worst health outcomes. Peters *et al.* argue that "absolute levels of income and material deprivation influence people's risk of disease and ability to purchase health services" (Peters et al. 2008a). Quoting Sen, they also wrote that "relative income is important because it translates into capabilities or what you are able to do with what you have, which is an important factor in accessing health services" (Peters et al. 2008a; Sen 1992). The poor start at a disadvantage point on all the dimensions of access and are constrained in their access by more opportunity costs (Peters et al. 2008a). A good access to health services without barriers or consequences on one's own living standards is essential (Gilson et al. 2008b; Lévesque 2006).

The concept of access is complex and comprises different dimensions and thus it cannot be measured directly (Frenk 1992; Lévesque 2006; Shengelia et al. 2005; Waters 2000). There are various proxies that can be used to make inference about access to care for specific groups in the population. For example, utilization is one proxy of access which can confirm the entry in specific

health services given a set of individual characteristics (Aday et al. 1974; Frenk 1992; Lévesque 2006; Shengelia et al. 2003; Waters 2000). Similarly, utilization of services for specific health needs or the presence of untreated morbidities are other possible measures of access. The variation observed on utilization for equal health needs on the other hand is a proxy of disparities in access (Waters 2000). Furthermore, untreated morbidities and self-report of avoiding utilization can be the results of problems of access (Shengelia et al. 2003; Waters 2000). As stated by Lévesque, "utilization or not according to given needs is the expression of realized or failed access (p.45)" (Lévesque 2006).

Finally, it is important to bear in mind that the different dimensions of access are not sealed from one another. In fact, the dimensions composing access cumulate until access is realized and in some cases they even interact with one another. As it is illustrated in figure 1, it is evident that there is a sequence to access, going from perceiving needs and seeking care to actual utilization and benefiting from this consumption. Hence, the dimensions of access cumulate successively from seeking care in an acceptable source, reaching this available facility, paying affordable fees and benefiting from adequate care received. When this sequence is achieved only then is access realized. In addition, these dimensions of access can also interact with one another. For example, the costs associated with traveling to a city to reach specialized care. Here the geographic availability of a source of care can render access unaffordable for those who cannot afford to travel or be kept away from economically productive activities for too long.

5.2. Conceptualizing Healthcare Systems and Policies

Murray and Frenk (2000) have defined health systems as "including the resources, actors and institutions related to the financing, regulation and provisions of health actions (p.78)". And they have defined health actions as "any set of activities whose primary intent is to improve and maintain health". As stated by these two authors, differences in design, content and management of health systems are related to the differential weighting of valued social outcomes. Notwithstanding this differential weighting, Murray and Frenk (2000) have listed the standard social goals of health systems to be: improving the health of the population, be responsive to the population's expectations and provide financial protection against the cost of ill-health. Instrumental goals are different from social goals as they are necessary steps to achieve the latter. For example, access is one possible instrumental goal of health systems which will ultimately contribute to the health of populations.

Furthermore, Murray and Frenk have also presented a framework to understand the different functions of health systems (Murray et al. 2000). These functions include financing, resources generation, service provision and stewardship. Murray and Frenk define financing as the process

of collecting financial resources from different sources (donors, users or government), pooling these resources to untie them from specific contributors and share them within the system and allocate funds for providers' activities. Resources generation refers to the necessary supply such as human resources, medicines and facilities and even education and research organizations. Service provision is the combination of the necessary resources that leads to the delivery of interventions (health services). They are divided into personal services directly consumed by individual users (either preventive, diagnostic, therapeutic or rehabilitative services) or non-personal services aimed at whole communities (such as mass education) or the environment (such as basic sanitary interventions). Finally, stewardship is over the whole system and goes beyond regulation to monitor performance and enforce rules and includes defining the strategic direction for the whole system. They also divide stewardship even further into the components of overall system design, performance assessment, priority setting, intersectoral advocacy, regulation over rules and consumers protection.

How governments design and mix these functions ultimately shapes the system characteristics and impacts the population's experience of care. For example: the collection of resources through taxes or directly from user fees, the existence of separate fund pools for different groups in the population, the location of education institutions and the availability of human resources.

Aday and Anderson have outlined that ultimately health and other socio-economic policies can influence access (Aday et al. 1974). Health policies contribute to shape both the characteristics of resources and the socio-economic status of individuals (Aday et al. 1974; Purola 1992). For Peters et al. (2008a) health policies are even integrated in the conceptualization of access itself as a determinant of the characteristics of health systems and the socio-economic characteristics of households and individuals. For Purola (1992) policies can have an impact on either the curative system or the public. Furthermore, Frenk (1992) underlines that obstacles arising from healthcare resources are factors that can be modified on the short term by health policies. Wagstaff also presents a conceptual framework where health policies (macro and micro health system policies) and other government policies influence the determinants of health outcomes (Wagstaff 2002).

Therefore, health policies can be understood as a tool to transform the barriers influencing access. By planning to modify the functions of health systems, health policies can change the characteristics of health resources or, ultimately, the characteristics of the population and their abilities to access (Exworthy 2008; Kruk et al. 2008).

There is no consensus in the literature on one all encompassing definition of health policy (Exworthy 2008). However, in their textbook on health policy analysis, Buse et al. (2005) offer an interesting set of definitions going logically from policy to health policy. To begin with, a policy is

defined as “a broad statement of goals, objectives and means that creates the framework for activity. It often takes the form of explicit written document, but can also be implicit or unwritten (p.4)”. Using this definition, policies can originate from various levels of governments, but can also occur in private or intergovernmental agencies.

It is through public policies that governments can intervene on a variety of social problems. Hence, a broad definition puts forward the notion that public policies are the results of decisions made by governments (Howlett et al. 1995). Therefore, for these authors, not to intervene on specific social problems can also be considered as “public policy” in a certain sense, as it can be understood as a course of action chosen by a government. On the other hand, it is important to acknowledge that this “decision” not to intervene can also be the result of a lack of knowledge or priority for a specific problem not addressed by public policies. Still, public policies are also defined more precisely as “decisions taken by governments which define a goal and set out the means to achieve it (p.6)” (Howlett et al. 1995). Or they can also be defined as “a statement or a formal position of a government or a government department (p.6)” (Buse et al. 2005).

Getting closer to the field of health, definitions are getting more precise. Health policies are defined as “a course of action (and inaction) that affects the set of institutions, organization, services and funding arrangements of the health system. This is the case both in the public and the private sector (p.6)” (Buse et al. 2005). For Buse et al. (2005), two kinds of government interventions can occur under the title of health policies: interventions with public health goals and a population approach and interventions to change the curative system. Therefore, health policies can be understood as a course of action set by governments to generate changes in the functions of health systems, which can ultimately impact access (among other issues making the health policy agenda).

Health policies in this research are placed above health systems and access, and they have their own set of determinants, process and dimensions. It is important to layout these realities in order to set the boundaries for this research.

Buse et al. (2005) define the policy process as “the way in which policies are initiated, developed or formulated, negotiated, communicated, implemented and then evaluated (p.4)”. Public policies can thus be divided into different steps related to problem solving: recognition of the problem (political agenda), putting forward a solution (policy planning), choosing solutions (political decisions), applying the solution (legislation) and evaluating the results (policy evaluation) (Howlett et al. 1995).

There is no linearity in the dynamic policy process and it is difficult to assess when a particular decision was made by a government (Exworthy 2008; Walt et al. 2008). The process can go back and forth until implementation. Different determinants can influence the process at every stage

and their relative importance can change with time or depending on the problem. These determinants include a variety of actors: executive, legislative, bureaucratic, civil society, media, etc. (Howlett et al. 1995). In the end, policies are the result of a political and a social process at the same time (Gilson et al. 2008a). Some authors have come to understand policy as a triangle of actors, process and content, with each part influencing the others (Walt et al. 1994).

Because resources are limited, only some problems will be selected to build the content of a health policy. These problems and their solutions are evaluated by decisions makers according to many determinants such as costs, benefits, feasibility, acceptability, popularity, etc. (Blank et al. 2006; Howlett et al. 1995).

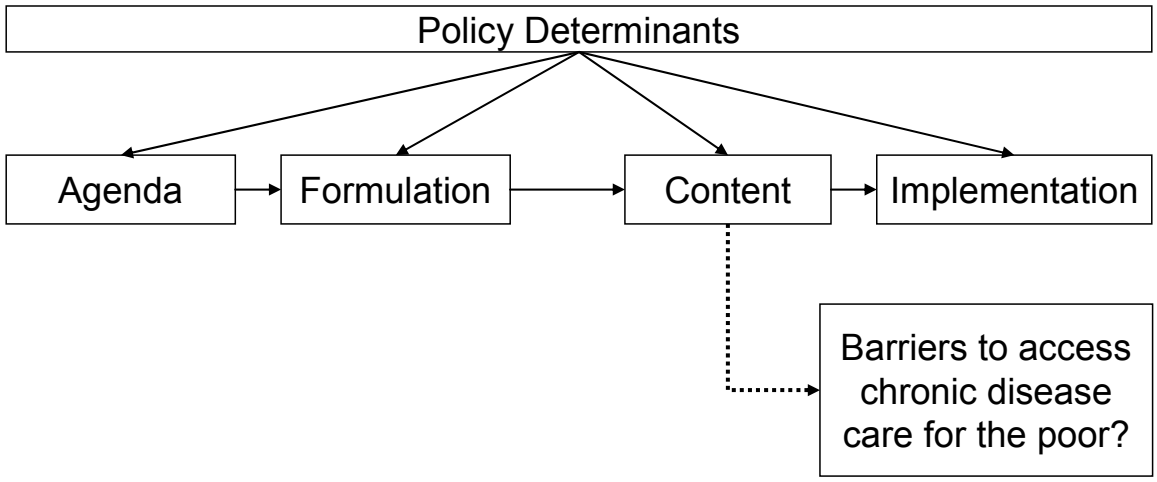
The content is the "substance of a policy which details its constituent parts (p.4)" (Buse et al. 2005). These constituents parts can be divided in problem definition, goals, objectives and instruments planned (Ham 1991; Pal 1987; Weimer 1992). A policy targets specific problems to meet certain objectives and goals with a given set of instruments. More precisely: "policy instruments are the range of options at the disposal of policy makers in order to give effect to a policy goal (p.121)" (Buse et al. 2005).

Consequently, the budget and the instruments of policies are seen as indicators of priority given to a specific problem by a government. Absolute and relative proportions of budgets are objective indicators of governments prioritizing a problem (Howlett et al. 1995). Furthermore, various levels of government involvement can be assessed through instruments. These levels go from low involvement where instruments are voluntary (private market or charity, for example); to medium involvement with mixed instruments (taxes, subsidies, providing information to the population, etc.); and high involvement with compulsory instruments for the government (direct regulation, provision of public services or state industries) (Howlett et al. 1995).

Finally, it is important to remember that the policy process doesn't stop at the formulation of policies. The content of a health policy and actual changes implemented in the system are two different elements. Between a policy and its goals, there is the actual implementation of instruments, activities and changes (Shiffman et al. 2007). Another set of determinants can influence the implementation process in itself. Furthermore, policies often have unplanned and unintended consequences as well (Hammer et al. 2007). Other authors have also underlined the lag in time existing between policy development and any measurable changes in a system or a population (Dugbatey 1999;Exworthy 2008). Hence, it is very difficult to establish direct causal relationships in policy analysis and caution must be applied when setting the boundaries of research (Exworthy 2008). Many determinants are influencing access and health policies are one distal factor among the others. Implementation stands between the content of a policy and reality,

and lag in time can occur before any measurable change can arise. The boundaries of analysis are illustrated below in figure 5.2.

Figure 5.2: The Boundaries of Policy Analysis



This study, looks at the content of specific policies and will thus not analyze the agenda and formulation process that led to the policies development, neither will it look at its actual implementation.

Policy analysis can be oriented towards determinants, content or impact (Ham 1991; Pal 1987; Weimer 1992). Thus, it is necessary to differentiate between analysis **for** policy and analysis **of** policy (Buse et al. 2005; Gilson et al. 2008a; Walt et al. 2008). Or, as formulated by Walt: "analysis of what happened versus what explains what happened" (Walt et al. 2008). As stated earlier, the present research project is focused on the content of Indian national health policies.

5.3. Qualitative Content Analysis

Content analysis as a method can be approached either quantitatively or qualitatively. Content analysis is "a method to make conclusions in an objective and systematic way in order to identify a specific character in a message" (here in a policy document) (Taylor et al. 2000). In their book on qualitative research in healthcare, Pope and May (2006a) state that "qualitative analysis seeks to develop analytic categories to describe and explain social phenomena" (p.67). To develop these analytical categories, a deductive or inductive strategy can be adopted. Thematic analysis, grounded theory and the framework approach are among some of the major approaches used for qualitative content analysis.

The method selected for the qualitative content analysis in this research is deductive and adapted from Ritchie and Spencer's framework approach (Elo et al. 2008; Ritchie et al. 1993). This approach was selected to conduct the content analyses and assess whether national health policies address the barriers to access chronic disease care for the poor. The framework approach was developed by an independent social research institute (the *Social and Community Planning Research* (SCPR)) and has been amended over the years (Ritchie et al. 1993). This approach is flexible and can be adapted to different study objectives.

The approach elaborated by Ritchie and Spencer includes the following stages: (1) sampling (2) familiarization (3) development of an index scheme, (4) indexing (5) charting, mapping and analysis. Then, (6) reliability and validity measures are also provided.

The approach is deductive and the thematic framework and index scheme were directly derived from a prior conceptualization of access and health system functions. This study is contextual as the content analysis served to shed light on the form and the nature of what exists. Ultimately, the analysis process was made iterative (Krippendoff 2004; Morgan 1993; Ritchie et al. 1993; White et al. 2006). The familiarization phase allowed for necessary adjustments to be made to the index scheme. And themes that were not directly derived from the literature review were recorded during the analysis.

Two main reasons have motivated the selection of the framework approach for this qualitative content analysis. One, this method was selected because of its deductive approach based on a clear framework for codification. This research is based on existing knowledge and clear concepts. Therefore, an inductive or more exploratory approach could not have been selected. This approach was also selected because the most structured deductive approach to qualitative content analysis. Two, this approach was also selected because of its clear validity and reliability features. The method has a clear and transparent process for codification that makes it replicable by others. This has also enabled a validity and reliability verification of the findings with a second analyst. Furthermore, the appraisal questions originating from this method are supportive of a thorough reflection on validity and reliability.

Sampling

The first stage of the research design consisted in sampling the necessary Indian national health policy documents. Given the research question and its objectives, the universe of possible textual data to sample was limited to Indian national health policies. Thus, taking into account this reality, a relevance sampling strategy (also called purposive sampling) was adopted (Krippendoff 2004). Relevance sampling is not probabilistic and the aim is not the representativeness of a population, but this small universe of documents is the population itself (Krippendoff 2004).

Exclusion and inclusion criteria purpose is to reduce this whole population into a more manageable size within the aims of the study (Krippendoff 2004).

The sampling phase was carried directly in New Delhi, India. A research internship at the Public Health Foundation of India (PHFI) and the Center for Chronic Diseases Control (CCDC) was realized during the months of January to April 2009. This internship served two main purposes: (1) to enrich the literature review and understand issues currently affecting the Indian healthcare system; and (2) to collect the necessary policy documents to submit through a qualitative content analysis. These two research organizations are independently funded and seek to increase institutional capacities for training, research and policy development for public health and chronic disease in India. These two institutions are located in New Delhi and cooperate on different research projects.

In order to set the sampling boundaries, the relevance sampling strategy was combined with triangulation. The following inclusion criteria were applied: the documents to be included had to be written health policy documents aiming at the curative health system, originating from the central government of India and effective between 1999 and 2009.

Then taking into account these inclusion criteria, three different sources of information were triangulated to identify the national health policies to sample: (1) the Annual Reports of the Ministry of Health and Family Welfare from 1998 to 2008, (2) the Economic Survey of the Ministry of Finance for the same years, and (3) the health sections of the 10^{th} and 11^{th} five-year plans of the Central Planning Commission. These government reports were obtained from different sources. The Economic Surveys and Five year development reports were obtained directly from the websites of the Ministry of Finance and of the Central Planning Commission. The Annual Reports of the Ministry of Health and Family Welfare were obtained from three different sources. Recent reports were available directly on the health ministry's website, while earlier reports had to be consulted in hard copy. These hard copies were obtained from the libraries of the National Institute of Finance Policy and the National Institute of Health and Family Welfare, two public research organizations located in New Delhi. From this triangulation of information, a list of policies meeting the inclusion criteria was generated.

Following this, a series of informal discussions were held in New Delhi and Mumbai with various key informants. One of the main objectives of these discussions was to validate the list of policies to sample that was generated from the review of government reports. Each informant had to validate the choice of policies for the relevance sampling and confirm that saturation was attained. Key informants from the following organizations were identified and contacted with the assistance of the CCDC: the World Health Organization offices in India, the Indian council of Medical Research, the All India Institute of Medical Sciences, the Ministry of Health and Family Welfare and the National Institute for Finance Policy in New Delhi, as well as the Indira Gandhi

Institute of Development Research in Mumbai. A phone discussion was also held with one informant at the National Institute of Mental Health and Neuroscience located in the city of Bangalore. The discussions with these key informants were not recorded because they were informal and took place in different settings.

Once every key informant was met and the list of policies to sample was finalized, the next step consisted in collecting the policy documents. On the six policies making the final list, only two were available directly from the Ministry of Health and Family Welfare website. The others were obtained with the assistance of the key informants who also confirmed their origin. Furthermore, once the documents were all sampled for the analysis, validation of their origin and authenticity was also obtained from the CCDC. The policy documents themselves are not presented in this document nor in the appendix given the length of certain documents. However, the source by which each document was obtained is stated in the sampling description in section 5.

Finally, two points regarding sampling have to be discussed here. First, the objectives of this research were deliberately set on national versus states health policies for two reasons. Given the level of involvement of the central government on health, to assess whether national health policies address the barriers to access to care for the poor with chronic disease is necessary. On the other hand, in the constitution, health is officially under state jurisdiction and each state has the responsibility to legislate and organize services on its territory. However, as stated in the literature, in reality, health is the object of cooperation between states and the center. For feasibility reasons and given the fact that this research project is the object of a master's degree, the scope was deliberately set on national level health policies. To focus on state level policies would have not been feasible. Second, this research is part of a greater project on vulnerability and inequalities in health in South Asia. This project focuses on the following chronic diseases: arthritis, angina, asthma, depression, schizophrenia and other psychoses and diabetes. Hence, taking this into account and in an effort of harmonization, the National Cancer Control Program of India program was excluded from the sample and this decision was submitted to the key informants.

Familiarization

Familiarization is the first thorough immersion into the data. Notwithstanding the familiarity with the documents that was gained during the sampling phase, this process is necessary to become familiar with the documents before sorting the data. Given its limited amount, all of the textual data was processed in the familiarization phase. These successive readings of the documents before the analysis allows for an understanding of all the material's scope. Furthermore, in this stage of the method, key ideas and recurring themes can be identified prior to analysis. All of which has contributed to improve the thematic framework and index scheme used

to codify the content of each policy document. This process is iterative as adjustments are made to the analysis tools with the familiarity gained with the documents.

Index Scheme

The following stages of the framework approach consisted in identifying a thematic framework and build an index scheme to codify the content of the documents. The thematic framework was directly derived from the conceptual framework on the barriers to access for the poor living with chronic diseases in India. Hence, as stated above, the deductive process of analysis started from a review of the literature and a specific conceptualization of access and health system functions.

With the construction of the thematic framework, a process of abstraction took place to reduce the concepts to a more manageable size in order to analyze the data. Once the thematic framework was completed, the index scheme was generated. The index categories and subcategories were structured logically and numbered accordingly. Each category was named using exhaustive theme and concept words that are mutually exclusive. The final result was a numbered index (categories and subcategories) that served to codify the content of the national health policies sampled. The final index is presented in appendix 1.

Indexing

The next step consisted in indexing all of the documents. Indexing is the systematic application of the index scheme to codify content. At this stage, all of the textual data was systematically read and annotated on the margin with a number corresponding to a concept in the index. This process of attributing a numbered code to specific content is a subjective judgment done by the main analyst. Annotating textual data in the margin with a number that refers to a structured index of concepts renders this process more transparent, clear and replicable by others. Other analysts can see what concepts were applied and how the content was abstracted.

To pursue the iterative process and test its appropriateness, the index was applied to all the policies a first time. This iteration has enabled the refinement of the index scheme and minor changes were brought to the structure of the index scheme. All these changes from this iterative procedure were recorded in a journal. Once the index scheme was finalized, all documents were indexed one final time. These raw outputs of indexing are not presented in this document.

Charting and Mapping

After the indexing process, all of the coded content was put into charts and map. First, one chart was generated for each policy where all the coded content was regrouped under higher order headings through an abstraction process. These charts served to build a picture of the textual data and enable associations between concepts to emerge.

Second, based on the coded content and the charts, a map of each policy was generated taking the conceptual framework on the barriers to access as a template. Each policy map was filled with the appropriate content. More precisely, the aim was to structure how each policy addressed barriers within each dimension of access. Furthermore, an empty space was reserved in each policy map to record unexpected content pertaining to the research problem. Once again given the sheer number of pages in each outputs of charting and mapping for each policy, these documents are not provided here. The policy maps template is presented in appendix 2. With the content of all policy document coded, structured and abstracted, the actual analysis process was conducted.

Analysis: Question Grid and Case Studies

In the last stage, the qualitative content analysis was conducted to assess if each policy addressed the barriers to access identified in our conceptualization and with what policy levers. To make this assessment, one question grid was filled for each policy. The question grid was built to contrast the conceptual framework of the problem with each policy map. The question grid template is presented in appendix 3. The question grid's role was to highlight the differences existing between the barriers identified with each dimension of access from the literature review to each policy's content. Furthermore, even if this approach is deductive, a space was also reserved in the question grid to record the unpredicted themes that have emerged from the content of policies

The second step of the analysis process was to write case studies for each policy using each question grid and policy maps. The aim of these case studies was to structure a short description on how the policies address the barriers to access and integrate a general description of the policies' timeline, goals, targets, objectives and instruments. The case study objective was also to present the findings in a clear and structured fashion. All the case studies are presented in appendix 4.

Validity and Reliability

Finally, three safeguards were adopted to ensure the validity and reliability of findings. The use of a second analyst, the use of illustrative quotations, the open process of the framework approach and the appraisal questions all contributed to increase the validity and reliability of findings

First, once all the content was analyzed and the case studies generated, a second analyst (JFL) took all the policy documents and re-submitted them through the indexing (codification) process using the same index scheme. The first analyst (DG) then compared the first indexing with the iteration of the second analyst. Following this, both analysts sat down to compare agreements and resolve disagreements. Furthermore, the second analyst (JFL) also applied an external look on all the analysis outputs (framework of the problem, index, charts, policy maps, question grids and case studies) after the second codification process to judge the quality of the findings. This exercise of codification and thorough reading by a second analyst has served to test the validity of findings. The results of this exercise were conclusive and the validity and reliability of the findings from the first analyst were corroborated by the second analyst. Codification by the two analysts did not differ significantly. The main difference in judgments between the two have arisen because of the exhaustive index scheme. This index is throughout and details every concepts in sub-concepts as well. Finally, no measure of inter-rater agreements, like the Kappa measure, was derived from this exercise due to the nature of the approach.

Second, illustrative quotations were used in the policy maps, question grids and case studies. The use of quotations to illustrate some statements has also served to increase the trustworthiness of the findings (Elo et al. 2008). These quotations can be found in appendix 4 in the case studies.

Third, as mentioned earlier, the framework approach itself is a clear and open process. The utilization of a numbered index to assign codes to textual content is increasing the transparency of the exercise. Ritchie and Spencer also proposed with their framework approach a set of appraisal questions serving as guidelines to quality (Pope et al. 2006b). These appraisal questions are linked to the processes of research and combined with a set of indicators. These appraisal questions were reviewed after the analysis as a measure of safeguard to the quality of the research's design, analysis and findings. The appraisal questions are presented in a table in appendix 5 with related indicators and a short explanation. These indicators are flexible and must be adapted to each research aim and purpose.

Finally, approval for this research was obtained from the ethics committee of the faculty of medicine of Université de Montréal.

Research Design Limitations and Strengths

There are three main limits imposed by the design of this research which must be acknowledged when reviewing the findings. First, the relevance sampling has limited data to a precise set of policy documents at the national level. Second, the content analysis is deductively based on the literature and on a prior conceptualization of access and health system functions. Consequently, the evidence generated by this research is limited to these specific conceptualizations. Third, possible generalization of findings is thus limited by the research design. Generalization of findings specifically on access, poverty and chronic diseases are possible at the country level when analyzing state level policies. They could also be applied to other countries undergoing a rapid epidemiological transition.

On the other hand, some limitations imposed by the research design also constitute some of its strengths. Perhaps the framework approach clear and specific design reduces the possible emergence of new ideas, but at the same time, it also constitutes a validity and reliability foundation. This clear and precise process is not only replicable by others, but it also prevents analyses from going in all directions. Hence, the analysis process is more structured and reliable. The strength and limits of the study and the findings are presented in the result section.

5.4. Summary: Research Question, Objectives and Methods

In table 6, the methodology is summarized. The research question is presented, followed by the three objectives that have guided the analyses. For each objective, the conceptualization on which the analysis was based is presented. Finally, the methods are summarized in the last column.

Table 5.1: Summary of Research Question, Objectives and Methods

<table>
<tr><th colspan="4">To what extent current Indian national health policies address the main barriers to access for the poor living with chronic diseases?</th></tr>
<tr><th>Objectives</th><th>Sub-questions</th><th>Conceptualization</th><th>Methods</th></tr>
<tr><td>(1) To assess whether the goals, objectives, instruments and targeted populations, as formulated in current national health policies in India, address the main barriers to access health services for the poor living with chronic diseases</td><td>Which barriers to access are addressed by each national health policies?</td><td>• Concept of access</td><td rowspan="3">1. Review of the literature
2. Research problem framework based on the conceptualization of access
3. Qualitative content analysis (The framework approach by Ritchie & Spencer, 1993): Sampling, Familiarization, Index Scheme, Indexing, Charting, Mapping, Analysis (question grid and case studies)
4. Results
a. Barriers addressed
b. Policy levers
c. Chronic diseases and poverty as policy targets</td></tr>
<tr><td>(2) To assess the types of policy levers and instruments identified in current national health policies to address these barriers to access</td><td>What are the levers proposed by the national health policies to tackle these same barriers?</td><td>• Health system functions
• The role of policy on access
• Instruments and the level implication of the government (Howlett, 1995)</td></tr>
<tr><td>(3) And the third objective was to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor</td><td>Are recent policies more focused on chronic diseases and the barriers of access?</td><td>• Concept of access
• The role of policy on access</td></tr>
</table>

6. Sampling Characteristics

The sampling results are presented in this section. Each Indian National Health policy that was sampled and analyzed is summarized here in table 6.1: name, date, source where the document was obtained, main goal and short summary of its content. The complete results are presented in the article in the next section (section 7).

Table 6.1: Sampling Description

National Health Policy 2002	Date	2002
	Source	Website Ministry of Health and Family welfare.
	Goals and summary	The NHP-2002 is the second national health policy in India, setting the vision and priorities for the whole health system. Its main goal is to achieve an acceptable standard of good health among the general population. *"To achieve an acceptable standard of good health among the general population of the country"* and "*maximize the broad-based availability*" of health services, especially at the primary level for a more equitable access. The policy's twelve objectives include the reduction or eradication of selected communicable and parasitic diseases, maternal and child health, public services utilization, public financing from the center and the states, and research and surveillance. The NHP-2002 addresses a variety of problems. The NHP 2002 only acknowledge physical non-communicable for research, surveillance and health promotion; but one section devoted to mental health.
Health Minister's Discretionary Grant	Date	Prior to 1990
	Source	Key informant - CCDC
	Goals and summary	*"Financial assistance up to a maximum of Rs 20 000 is available to the poor indigent patients from the Health Minister's Discretionary Grant to defray a part of the expenditure on hospitalization/treatment in Govt. Hospitals in cases where free medical facilities are not available."* The assistance is periodic, but the scheme allows for exemptions to be studied the financing of NGOs to provide care to the poor, and assistance for the poor disabled or chronically illed with T.B or leprosy (etc). But mental disorders are not specifically acknowledged by the scheme The Health Minister's Grant has been effective for more than two decades. Grants to the medical institutions where care is received.
Rashtriya Arogya Nidhi	Date	2003 (1996)
	Source	Key informant - CCDC
	Goals and summary	*"Provide for financial assistance to patients, living below poverty line, who are suffering from major life threatening diseases, to receive medical treatment at any super specialty hospitals / institutions or other government hospitals."* The grant covers the direct costs of treatments and is released directly to the institutions where care is received. The scheme was previously known as the National Illness Assistance Fund (1996) and renamed and transformed to the current policy in 2003. A provisional list of interventions covered is presented in the policy which includes acute interventions and health investigations for chronic disease. Mental disorders are not specifically acknowledged by the scheme. The funds are managed directly by medical institutions.

Table 6.1 (continued)

National Rural Health Mission	Date	2005
	Source	Website Ministry of Health and Family welfare.
	Goals and summary	The mission aims at modifying the "*basic architecture of healthcare delivery*" in rural areas and decentralizes management, to be more flexible and adapted to local settings. The NRHM was established in 2005 with the goal of modifying and improving the basic architecture of health service delivery in rural areas across the country. The mission is composed of seven goals on maternal and infant mortality, access, primary health services, population stabilization, the mainstreaming of traditional medicine and health promotion. Related to this, the mission also states seven national (maternal and infant mortality, communicable diseases, CHC service delivery, referral, and female voluntary workers) and community objectives (human resources, quality, immunization, referral for the poor, community insurance schemes and households sanitation). The NRHM includes non-communicable diseases prevention and control in its goals but they are mostly absent in the document's content. Mental disorders are not specifically targeted by the NRHM.
Mental Health Program	Date	2002-2007 (1982)
	Source	Key informant – Ministry of Health and Family Welfare
	Goals and summary	The program's main goal is to improve mental healthcare delivery. The main objectives are : to increase the availability of care within communities; to improve access to services; to reduce stigma and improve the rights of mentally illed patients; and to increase the coverage of the district level plan. The first National Mental Health Program was enacted in 1982 and is renewed with each five-year development plan. The program analyzed is for the 10th development (2002-2007). A district level program was introduced with the 9th development plan and is planned for expansion in the current program.
National Program for the Control and Prevention of Diabetes, Cardiovascular Diseases and Stroke **(Pilot program)**	Date	January 2008
	Source	Key informant - CCDC
	Goals and summary	*"The pilot program for prevention and control of cardiovascular diseases, diabetes and stroke, has, therefore, been planned with the objectives of providing effective promotion, prevention and control strategies to provide for an integrated action plan for these chronic diseases."* The program was launched by the central government of India in 2007. The initiative follows the recognition of the growing burden that represents physical non-communicable diseases and the current problems in the provision of curative and prevention services in the public sector for these diseases. The program is divided between primary and secondary prevention components, as well as research and surveillance. The pilot phase of the program is run only in the selected states of Assam, Punjab, Rajasthan, Karnataka, Tamilnadu, Kerala, Andra Pradesh, Madhya Pradesh, Sikkim and Gujarat.

7. Results: Access to Care for the Poor Living with Chronic Disease in India: Are Current National Health Policies Addressing Barriers to Access?

The results are presented in this section in the form of a scientific article to be published entitled: “Access to care for the poor living with chronic disease in India: Are current national health policies addressing barriers to access?. The authors are: Dominique Grimard, Jean-Frédéric Levesque and Mira Johri. Therefore, the background and methods and data sections are summarized and repeated here. The results of the qualitative content analysis are presented after and are followed by a short discussion of the results.

7.1. Background

Chronic disease prevalence has been increasing in India. Diseases such as diabetes, cardiovascular diseases and various mental disorders now comprise 53% of all deaths and 44% of Disability Adjusted Life Years (Reddy et al. 2005). This is happening in a country where poverty was affecting 27.5% of the population in 2005 (World Bank 2009a) and where infectious diseases still represent an important burden.

The poor are more susceptible to have untreated morbidities because of existing barriers to access (Ramaraj et al. 2008; WHO 2005). They will usually wait for complications before seeking care, increasing the amount of services they need and the costs of treatments (also called the “medical poverty trap”) (Withehead et al. 2001, Ramaraj et al. 2008). Furthermore, due to limited knowledge and capacities for choice, the poor living in deprived communities have less freedom of choice and present more unhealthy behaviors (Wagstaff 2002, WHO 2005). Even if risk factors are highly prevalent among affluent people (Boddula et al. 2008; Mathavan et al. 2009), an inverse social gradient of risk factors is also observed among the poor and rural inhabitants of India (Ajay et al. 2008; Anand et al. 2007; Reddy et al. 2007b).

The Indian healthcare system is characterized by underfinancing, weak public services and a large unregulated private sector. Major barriers to access for the poor arise because of low public expenditure on health, low coverage of social protection and health insurance and the fact that out-of-pocket expenditures account for 72% of financing (Duggal 2007; Peters et al. 2002). Moreover, the public sector only accounts for 20% of all health services offered (Peters et al. 2002). Private services are widely used, even by the poorest, as they are perceived to be of better quality and often represent the only care accessible (Kurian 2007; Da Costa et al. 2007; Roy et al. 2007, Ergler et al. 2010). The regulatory structure in India is inadequate and skimping on quality,

quantity and prices are reported in the public and private sectors (Peters et al. 2008b). On top of this, only a few private providers and public tertiary centers in major cities are able to deliver chronic disease care and prevention initiatives have only just begun (Joshi et al. 2006;Ramaraj et al. 2008; Reddy et al. 2005). Similarly, mental healthcare is in dire need of modernization and general providers usually don't manage mental disorders (Khandelwal et al. 2004).

Cultural beliefs on gender roles and traditional medicine are shaping health-seeking behaviors in India, especially for the poor and less educated (Khandelwal et al. 2004; Peters et al. 2002; Vissandjee et al. 1997). For example, it is often considered unacceptable for poor women to travel to seek care (Vissandjee et al. 1997) and the use of unqualified traditional healers is undermining the poor's access (Khandelwal et al. 2004). Moreover, the criticality of health literacy, as newer chronic diseases emerge, was also reported in the literature (Bjork et al. 2003; Mohan et al. 2005; Pandian et al. 2006b; Ramachandran et al. 2008a, 2008b; Reddy 2007b). Authors have underlined the extent of which the lack of knowledge and awareness of diseases like diabetes currently affects health-seeking behaviors and patient's ability to adhere to treatments. Similarly, the stigma associated with mental disorders and people's understanding of these diseases also affect utilization (Khandelwal et al. 2004). Moreover, literacy and knowledge affect the choice of providers and the ability to distinguish qualified from unqualified providers (De Zoysa et al. 1998; Vissandjee et al. 1997).

The availability of services is also problematic, in particular in urban slums, and rural and remote regions (Ager et al. 2005; Banerjee et al. 2008; Peters et al. 2002). In addition, infrastructures of care for chronic diseases and emergency transport are even scarcer (Joshi et al. 2006; Reddy et al. 2005). Hence, the majority of the population, especially the poor, has difficulties reaching health services' for chronic disease care, especially for regular follow-ups (Bjork et al. 2003; Pandian et al 2006a; Ramaraj et al. 2008; Yesudian 1999). Furthermore, the scarcity of medical human resources in the public sector is critical everywhere and for most professions (Peters et al. 2002). The concentration of mental health services, beds and specialists is also particularly low compared to the size of the population (Ganju 2000, Kermode et al. 2009). Overall, most care in rural areas are provided by unqualified private providers (Banerjee et al. 2008; Kumar et al. 2007).

In India, direct, indirect and opportunity costs of treatments are important barriers to access for the poor (Ager et al. 2005; Gupta 2003; NSSO 2006; Yesudian 1999). Health services are mainly financed through out-of-pocket payments (Duggal 2007; Roy et al. 2007). In addition, the coverage of any type of health insurance is very low at only 5% (Indiastat 2009). Hence, catastrophic expenditure and distress financing are often cited in the literature as affecting utilization (and inversely as motivating the non-utilization of health services) (Devadasan 2004; Peters et al. 2002; Roy et al. 2007; Van Doorslaer and al. 2005). In addition, authors have

highlighted the extent to which chronic diseases are associated with higher costs of care (Dror et al. 2008; Reddy 2003). The scarcity of services, the higher costs associated with multiple-regimen of drugs and treatments, regular monitoring and follow-ups, and the costs of hospitalization for complications are all factors that increase the usual financial burden of care (Dror et al. 2008; Grover et al. 2005a, b; Kapur 2007; Kotwani et al. 2009; Levesque et al. 2007;Ramachandran et al. 2007; Tharkar et al. 2009).

Quality problems affect the public sector, as facilities are not staffed and supplied adequately. Across the country, public health centers and hospitals lack necessary personnel, medicines and equipments (Peters et al. 2002, Ager et al. 2005; Banerjee et al. 2008; Kotwani et al. 2007, 2009). Furthermore, the poor rely more on unqualified providers when seeking care in the private sector, this also undermines their ability to benefit because they often receive care of poorer quality (De Costa et al. 2007; Kurian 2007; Das, J. et al. 2007). The opportunity to use services of poor quality is also a restriction of access (Lévesque 2006). Finally, the absence of capacities for the detection and management of chronic disease and the need for modernizing mental health services results in a situation of sub-optimal diagnosis and control (Bjork et al. 2003; Jindal 2007; Joshi et al. 2006; Khandelwal et al. 2004; Ramachandran et al. 2008a; Reddy et al. 2005). This is also a restriction of access.

For Reddy (2007a), India's response to physical non-communicable diseases has been limited so far and there has been a lack of correspondence between the pace of transitions and resources allocated. Chronic diseases challenge the way health services must be provided (Beaglehole et al. 2008, WHO 2005). This study has thus three objectives. The first objective was to assess whether the goals, objectives, instruments and targeted populations, as formulated in current national health policies in India, address the main barriers to access health services for the poor living with chronic diseases. The second objective was to assess the types of policy levers and instruments identified in current national health policies to address the barriers to access in each dimension of access. And the third objective was to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor.

7.2. Methods and Data

The Framework Approach

To meet these objectives, a qualitative content analysis was conducted on selected Indian national health policies using Ritchie and Spencer's framework approach (Ritchie et al. 1993).

This deductive approach uses thematic frameworks and index schemes derived from established conceptualizations to codify the content of documents (Pope et al. 2000; Ritchie et al. 1993). Hence, content analysis, in order to be optimally conducted, used a strong conceptual approach. Consequently a framework of the problem and the analyses tool were based on establish conceptualization of access, health systems function and the role of policies on access.

There are eight steps for the framework approach. The method starts with the (1) sampling of documents, and is followed by (2) a familiarization phase with these documents, (3) the production of a numbered index based on a thematic framework of the problem which serves to (4) index the content for each policy document. Once all the content is indexed, (5) charts are generated to highlight associations and produce a (6) policy map to structure the findings. In the end, a (7) question grid was used to conduct the analysis by comparing the original framework of the study problem with each policy map. All findings were then summarized in (8) case studies. The framework of the problem is illustrated in table 7.1 and was derived from a previous review of the scientific literature.

Given the limited population of possible data, a relevance sampling strategy was adopted and conducted using key informants and government reports. The following inclusion criteria were applied: the documents to be included had to be written health policy documents aiming at the curative health system, originating from the central government of India and effective between 1999 and 2009. A systematic research was done using annual reports of the Ministry of Health and Family Welfare, the economic survey of the Ministry of Finance and the health sections of the 10^{th} and 11^{th} development plan of the Central Planning Commission of India. From this research a list of policies meeting the inclusion criteria was generated and validated through informal discussions with key informants in public and private research organizations in New Delhi, Mumbai and Bangalore. The policy documents were collected from different sources: some were available directly on the website of the Ministry of Health and Family Welfare and others were obtained through key informants.

Reliability and validity considerations have been taken. By codifying the content with a numbered index, the process is rendered more transparent and replicable by others. Furthermore, illustrative quotations were used in the analysis tools to increase the reliability of findings. Moreover, a second analyst used the same index scheme to codify a second time all the documents. A comparison with the original codification was made and both analysts discussed disagreements. The second analyst also applied an external look to all the analysis outputs and results. Finally, a series of appraisal questions from the framework approach were used to assess the reliability and validity of the research design and findings.

Conceptualizing Access

As defined by Peters et al. “access is related to the timely use of services according to needs (p.162)” (Peters et al. 2008a). Furthermore, receiving equal services for equal needs incorporates equity into this definition of access (Waters 2000). Realized access is based on the optimal interaction of population characteristics (demand-side) and health system characteristics (supply-side) (Lévesque 2006). On one hand, there is the presence of services and the capacity to produce them and on the other, the ability of the population to use existing services and the real utilization made (Frenk 1992; Lévesque 2006). Multiple barriers can hinder the abilities of the population or the accessibility of health services (Frenk 1992).

In addition, resources and users characteristics are categorized in specific dimensions. Four dimensions characterize healthcare resources and they are related to four specific individual abilities (Frenk 1992; Lévesque 2006; Peters et al. 2008a; Russell 1996; Shengelia et al. 2003; 2005). Health resources must ensure: the social and cultural acceptability of services to the population; the geographical (physical accessibility) and organizational (human resources, equipments, treatments and medicines) availability; the affordability of services to the population; and the adequacy in terms of the appropriateness of services provided and their overall quality. Related to these supply-side dimensions, individuals have different abilities to access care that are in part determined by their socio-economic and demographic status: ability to seek care from available health services and for specific perceived health needs; ability to reach health services and travel in distance; ability to pay for health services and; ability to benefit from care received. As such, poverty, as a socio-economic characteristic affects individuals’ abilities to access and the opportunity costs they will have to face. This conceptualization of access and its sequence is illustrated in figure 7.1.

Conceptualizing Healthcare Systems and Policies

Health policies and even other related macro-socio-economic policies can have an impact on access by implanting actions on the different functions of health systems or the socio-economic characteristics of a population (Aday 1976; Murray et al. 2000; Peters et al. 2008a; Purola 1992; Wagstaff 2002).

The functions of health systems include financing, resources generation, service provision and stewardship (Murray et al. 2000). Financing is the process of collecting financial resources from different sources (donors, users or governments), pooling these resources to untie them from specific contributors, share them within the system and allocate funds for providers activities.

Resources generation refers to the necessary supply such as human resources, medicines and facilities, and even education and research organizations. Service provision is the combination of the necessary resources that leads to the delivery of interventions (health services). They are divided into personal services directly consumed by individual users (either preventive, diagnostic, therapeutic or rehabilitative services) or non-personal services aimed at whole communities (such as mass education) or the environment (such as socio-sanitary interventions). Finally, stewardship is over the whole system and goes beyond regulation to monitor performance and enforce rules. It also includes defining the strategic direction of the whole system. Murray et al. (2000) also divide stewardship even further into the components of overall system design, performance assessment, priority setting, intersectoral advocacy, regulation over rules and consumer protections. It is these functions that were used to characterized policy levers that are illustrated in figure 7.2.

Sample Description

The final sample was constituted with the following policies: the National Health Policy 2002 (NHP-2002), the Rashtriya Arogya Nidhi (RAN), the Health Minister's Discretionary Grant (HMDG), the National Rural Health Mission (NRHM), the Mental Health Program for the 10th development plan (MHP), and the Pilot Program for the Prevention and Control of Diabetes, Cardiovascular diseases and Stroke (PPCCDSC). These policies are briefly summarized here.

First, the NHP-2002 sets the visions and goals for the entire health system. Its main goals are *"To achieve an acceptable standard of good health among the general population of the country"* and "*maximize the broad-based availability*" of health services (especially targeting primary care). If mental health is integrated to the NHP-2002, content on physical non-communicable diseases is limited to health promotion, research and surveillance activities. The NHP-2002 states that its focus is more on communicable and mental diseases because of their relative priority and the level of available resources. A broad range of issues are covered by the NHP-2002, going from communicable disease control, the state of the public system, equity of access, women's health, medical education and human resources, to genetic research and medical tourism.

Second, the RAN and the HMDG are two financial assistance schemes addressing the affordability of interventions in government hospital targeting the poor specifically. For the Minister's grant: *"financial assistance up to a maximum of Rs 20 000 is available to the poor indigent patients from the Health Minister's Discretionary Grant to defray* ***a part*** *of the expenditure on hospitalization/treatment in Govt. Hospitals in cases where free medical facilities are not available."* Similarly, the RAN's objective is to: *"Provide for financial assistance to patients, living below poverty line, who are suffering from major life threatening diseases, to receive medical treatment at any super specialty hospitals / institutions or other government hospitals."* The

HMDG has been implemented more than two decades ago, while the RAN was originally formulated in 1996 and renewed in 2003.

Third, the NRHM goal is to improve the rural health system and its main objective is to modify the "*basic architecture of healthcare delivery*" and decentralize management to be more responsive to local realities. Improving access for vulnerable groups is among its main priorities. However, even if physical non-communicable diseases are acknowledged and placed in control and prevention goals, actual content is limited to health promotion and surveillance activities. In addition, prevention and control is planned only in case of available financing. Furthermore, they are not included in the planned outcomes of the mission which are focused on communicable disease control and public service delivery.

Fourth, the mental health program's main goal is to improve the state of mental healthcare and its main objectives are: to increase the availability of care within communities, to improve access to services, to reduce stigma, to improve the rights of mentally ill patients and to increase the coverage of the district level plan. The mental health program has also yet to be implemented in all states.

Finally, the program on diabetes, CVD and stroke is a pilot program only and the newest policy in this sample. It is the first attempt by the government to tackle the challenge brought by physical non-communicable diseases. Its main goal: *"The pilot program for prevention and control of cardiovascular diseases, diabetes and stroke, has therefore been planned with the objectives of providing effective promotion, prevention and control strategies to provide for an integrated action plan for these chronic diseases."*

7.3. Results

In this section, the barriers to access that are addressed (objective 1) and the gaps identified are presented for each dimension of access. These results are summarized in table 7.2. In addition, policy levers and instruments used to address these barriers (objective 2) are presented in table 7.3.

Acceptability and Ability to Seek

The NHP-2002 and the NRHM promote gender-sensitive services and the acceptability of traditional medicine. They aim to establish staffing norms for female doctors in PHC and more health programs on women's health. The NHP-2002 also underlines the popularity (and modest costs) of traditional medicine in remote, underserved and tribal regions. Similarly, the NRHM promotes the use of quality traditional medicines and the integration of traditional providers in

public services. Finally, the NHP contains one statement about the adverse effects of using faith-based care for mental disorders.

The NHP-2002 and NRHM acknowledge the increasing prevalence of non-communicable diseases and the need to educate the population. In addition, the mental health program and the NHP-2002 also address the need to raise knowledge and awareness of mental disorders, to decrease stigma and to improve the utilization of mental health services. Finally, the PPCCDSC is divided into primary and secondary prevention. It aims to improve health education, as well as transform communities, schools and work places. Its ultimate goal is to reduce the future burden of chronic disease.

On the other hand, the ability of the poor and less educated to differentiate qualified from unqualified providers is not addressed. Moreover, the focus of these policies on health education is placed on more general knowledge and the importance of healthy behaviors for chronic disease, rather than specifically addressing timely use of care, follow-ups, control and self-management. Finally, no proposals are made on the utilization of faith-based healers.

Geographic and Organizational Availability and Ability to Reach

The NHP-2002 and the NRHM plan to increase the number of PHC and CHC in rural and remote regions, while the NHP-2002 also targets urban slums and trauma services. The NRHM includes mobile outreach for remote regions and a network of female health activists (*ASHA*) providing services directly to their communities and households. Both policies intend to build public-private partnerships (PPP) to increase availability in certain regions.

The MHP, NHP-2002 and PPCCDSC plan for the geographic availability of chronic disease care. They aim to increase the number of facilities available with special clinics for CVD and diabetes in district hospitals, and mental health community care, mental hospitals and psychiatric wards in general hospitals. Moreover, the program on diabetes, CVD and stroke plans to capitalize on the NRHM to improve the delivery of chronic disease care in rural areas.

The NHP-2002 and the NRHM address the shortage of qualified human resources in the public sector. Various professions are targeted at all levels of care, but the NHP-2002 also focuses on underrepresented specialties (including family medicine, nursing and geriatrics). These policies also address the shortage of health professionals specifically in rural areas and aim to increase the availability of medical education, integrate rural concerns in the general curriculum and impose mandatory rural postings. The NRHM also plans to implement the *ASHA* voluntary female workers network and use male multipurpose workers in public centers. Finally, the NHP-2002 and the NHRM also plan to establish PPP to integrate private traditional and allopathic private providers in public centers to palliate to the shortage of human resources.

The MHP, the NHP-2002 and the pilot program also address the need for more specialized health professionals. An increase is planned in the number of mental health specialists available and the establishment of special clinics for diabetes and CVD in district hospitals with the appropriate staff.

At the same time, these analyses show that barriers associated with people's ability to travel are not specifically addressed by any of these policies. The focus is set on improving availability. Also, transportation modes and emergency transport are not instruments found in these policies. Moreover, the cost of traveling and the mixed barrier it represents for the poor was not addressed. Traveling to reach specialized care for chronic disease and regular travel for follow-ups are also barriers that remains to be addressed.

Affordability and Ability to Pay

Two financial schemes address the barrier that the affordability of interventions in public hospitals can represent for the poor, by covering the direct costs of interventions in these institutions. In the RAN, a list of possible interventions to be covered is presented and includes a variety of physical chronic diseases. However, this is not the case in the minister's grant. Even if the rules section allows for exceptions to grant assistance to the poor chronically ill patients with TB, leprosy, etc, and the disabled. The notion of chronically ill is addressed here but not in relation to non-communicable diseases. Moreover, both policies constitute periodic financial assistance and do not cover indirect or recurring costs of treatments.

The NHP-2002 and the NRHM acknowledge affordability and ability to pay to some degree. Proposals made include: encouraging the use of private secondary and tertiary care for those with the ability to pay; studying different schemes of public protection for private care utilization; promoting private and community health insurance; and examining other possible risk pooling mechanisms. The NRHM also contains a statement on financial assistance to be provided to the poor for premiums. The NHP-2002 and NRHM also acknowledge the adverse effects of out-of-pocket payments and catastrophic expenditure with private care utilization and the difficulties for the poor to bear the costs for these services. The affordability of drugs is addressed by the NHP-2002 with the TRIPS agreements and the need to advocate to control the adverse effects of globalization on the price of medicines. The NHP-2002 and NRHM also promote the use of affordable and popular traditional medicines in underserved, remote and tribal regions. Finally, the NHP-2002 also states the impossibility of full public protection for public service delivery given the sheer number of poor in the country.

The mental health program only emphasizes the cost-effectiveness of the community approach, while the pilot program underlines how the use of expensive and low-yield technologies

in the private sector affects costs. In addition, the mental health program also states that district teams are expected to provide services to needy mentally ill and their family along with daily outpatient care, limited inpatient care, referral and follow-ups services, community survey and the removal stigma in communities. On the other hand, no instruments related to this statement are detailed further, resources are not mentioned and 'needy' is not clearly defined.

Indirect and opportunity costs associated with utilization are not acknowledged by any policy. Costs associated with traveling, with time spent away from economically productive activities or the costs of drugs, tests and treatments are not targeted by any policy. Nor are distress financing strategies and their impact on ability to pay. Moreover, even though two financial assistance schemes address the direct costs of services in public hospitals and their affordability to the poor, the direct costs of other lines of services are not addressed. This is the case most notably for primary care for which availability is promoted by different policies. Furthermore, out-of-pocket payments and catastrophic expenditure are not linked to public services.

Given the current concentration of adequate chronic disease care in specialized private and public tertiary centers in major cities, the costs of care are consequently higher. Moreover, chronic diseases are expensive to treat, especially in the long term or in the event of acute events requiring hospitalization. Technology intensive treatments and multi-regimen of drugs increase the usual burden of treatment. And so are recurring costs associated with follow-ups and lifelong treatments. These important barriers of affordability and ability to pay for chronic diseases care that are not addressed by these six policies.

Adequacy and Ability to Benefit

The NHP-2002, NRHM and MHP recognize the consequences of decades of low financing on the quality of health services in the public sector. They all put great emphasis on quality improvements and modernization.

The NHP-2002 and the NRHM acknowledge the adverse effects of quality problems on utilization and the predominance of the private sector. Moreover, these two policies recognize the need to better regulate the private sector to improve quality. Therefore, in these two policies, statements and instruments are found related to the need for modernizing and upgrading public services, as well as improve regulation. And to improve the quality of curative and interpersonal services, these policies plan to increase public expenditure, to upgrade infrastructures and increase medical supplies availability. The NHP-2002 and the NRHM aim to improve the availability of essential and generic allopathic medicines. They also plan to improve availability of quality traditional medicines in rural, remote and tribal regions. Both aim to establish training and

continuing education programs to impact the quality of interpersonal services. Furthermore, the NRHM also aim to decentralize management for better responsiveness to local realities.

Some policies also aim to improve the adequacy of care for chronic disease. The pilot program aims to increase capacities for physical chronic disease care as the health system is not yet tuned for this type of care. It also aims to improve the knowledge of the population with mass education but also the capacity of providers to deliver knowledge and prevention activities. This is the case for every line of care in the system, as well as "harvest" these capacities in the private sector. Furthermore, the mental health program and the NHP-2002 address the need to improve capacities for mental disease management at all levels of the system with continuing education programs and improved medical education.

In addition, the NHP-2002 aims at improving health education and communication strategies to reach more efficiently the less educated and illiterates. The difficulty to deliver knowledge to this group is identified as an important issue. Related to this, the NRHM also plans to develop the capacities of rural health providers to deliverer health education, especially the ASHA voluntary workers.

The programs on mental and physical chronic disease also aim to upgrade existing and new services to ensure availability of necessary drugs and equipments for health investigations. In the mental health program, upgrading service infrastructures is also promoted as a way to respect human rights and move away from institutions that resemble more to prisons than curative facilities. Increased financing to modernize and upgrade all mental health services is one of the main instruments found in the program. The pilot program also makes plans for special clinics in district hospitals to be adequately equipped with all necessary supplies.

Plans are made to improve the quality of services in general and increase the system's capacity to deliver care and knowledge related to chronic diseases. On the other hand, no instruments in these policies are related to patients' ability to benefit.

The Time of Formulation and Addressing Poverty and Chronic Diseases

A timeline was established in this transversal sample of policies to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor (objective 3). These results are also illustrated in table 7.2.

What has emerged first is the difference of focus existing between earlier and newer policies on physical chronic diseases. While mental health on the other hand appears to have been on the health policy agenda for a longer period of time and it is also an integrated part of the NHP-2002.

Earlier policies have mainly acknowledged the existence and growing importance of physical non-communicable diseases. The NHP-2002 and the NRHM's focus is on health education, surveillance and research activities, while the minister's grant does not specifically address chronic non-communicable diseases. This suggest that a more far-reaching involvement on physical non-communicable diseases is recent. Full content on both health education and the provision of curative services for diseases such as diabetes and CVD is only found in the pilot program. On the other hand, even though mental health has been on the agenda for a longer period of time, these analyses suggests that important barriers to access are not addressed.

It also appears that the poor are often not specifically targeted with regards to chronic disease care. Overall, as a group, the poor are targeted for primary care, improving health education for the illiterate, and the barriers that the direct costs of public hospital services and out-of-pocket payments in the private sector represents. Only in one segment of the mental health program, where the district team is expected to provide for 'needy' mentally ill and their family, are the poor associated to access specifically in a context of chronic disease.

7.4. Discussion

This paper had three initial objectives on: the barriers to access for the poor with chronic disease that are addressed by Indian national health policies (objective 1); the policy levers and instruments proposed to address these barriers (objective 2); and whether these policies have improved over time for the delivery of chronic disease care to the population and more specifically to the poor (objective 3). Bearing in mind these objectives, specific themes emerging from the analyses are discussed below as they relate to primary care and chronic disease management, financial barriers, regulation of the private sector, abilities to access and reaching the poor with chronic disease interventions.

Primary Care and Chronic Disease Management

The role primary care can play in chronic disease management is recognized in the literature for developed (Bodenheimer 2002, Starfield 2005) and developing countries (Beaglehole 2008). New organizational models of care, like the chronic care model (Wagner 1999), have been proposed where medical teams provide information, education and treatments following guidelines in a supportive community environment. Patients have to manage their disease on a day-to-day basis and must have self-efficacy to undertake this effectively and positively. A pro-active patient-provider team is critical for empowerment, delivering information and teaching self-management skills (Bondenheimer 2002).

Obviously, India cannot make the same investments as countries such as the UK or Canada are currently undertaking. Nonetheless, some elements like multidisciplinary team, treatment guidelines and self-management education are realistic objectives for resource-poor countries (Beaglehole et al. 2008).

Primary care is the main tool proposed by Indian national health policies to ensure more equity in access for the poor. They also plan to strengthen primary care by increasing financing and generate resources for better quality of care. In addition, plans are made to improve capacities for the detection and management of chronic non-communicable diseases.

On the other hand, national health policies have also been criticized for their lack of clarity on how they plan to transform primary care (Nundy 2005). Furthermore, the central role of primary care is not thoroughly recognized for risk assessment, health promotion, early diagnosis, better self-management and regular follow-ups of chronic non-communicable diseases. Promoting utilization by bringing a system of community closer to home is only acknowledged by the mental health program.

National health policies must be commended for their pledge to increase healthcare financing. However, it must be accompanied by the system's capacity to channel new funds properly. Public expenditure on health is already biased towards the rich in India and the question still remains on how to reach the poor (Peters et al. 2002). Furthermore, caution must be applied in transferring the responsibility for the delivery of health services. As underlined by Ganju (2002), to increase the network of community care for mental health can be interpreted as an abrogation of responsibility. Especially if resources that are already scarce do not follow appropriately.

Financial Barriers in National Health Policies

Hospitalization can represent an important burden for the poor (Dror et al. 2008) and two financial schemes rightfully target the poor for hospital's interventions. On the other hand, the issues of recurring costs of treatments and, more basically, the affordability of primary care for the poor are not addressed. No content was found on the costs of chronic disease care and the financial burden it can represent for the poor. Some studies (Dror et al. 2008, Ramachandran 2007, Ramaraj 2008, Kotwani 2009) have demonstrated that chronic diseases significantly increase the financial burden of care. In India, these costs are also predicted to increase with time (Grover et al. 2005a, 2005b, Tharkar et al. 2009).

Even though user fees' impact is acknowledged for the poor's utilization of private health services, no instruments are proposed to correct the problem. Moreover, the same impact is not acknowledged for public services where informal payments and associated costs can be catastrophic for the poor (Peters et al. 2002, Levesque et al. 2007).

Financial barriers play a role in preventing the poor from having regular contacts with a general provider. Outpatient care for chronic disease can be expensive in the long run. The costs of ambulatory care for diabetes has been increasing in India (Kapur 2007) and complete compliance and adherence to treatments is expensive even for the wealthiest (Venkataraman 2007). Hence, it is also important to understand the financial burden of sustaining access over time for the poor in a chronic disease context.

National health policies plans are to encourage community and private insurance and study possible schemes based on private care and ability to pay. In 2001, the WHO report on the performance of health systems stated the importance of separating financing from utilization for more equitable systems (WHO 2000). The same report also recognized the low institutional and organizational capacities of developing countries to manage large risk pool. Thus, the same report states the importance of encouraging private or community mechanisms to move away from systems based solely on user fees. Market failures however can undermine these competing pools, hence the importance of regulation, subsidies and incentives to "correct" failures that are based on income and morbidities. Peters et al. (2008) have drawn attention to the difficulties of transforming healthcare financing when the majority of the population is poor, rural-based and works in the informal sector like in India.

Even if risk pooling or other financing mechanisms are being studied or encouraged, the difficulties and challenges they represent are not acknowledged. In addition, authors have also underlined how designing insurance products for chronically ill patients is warranted (Bodenheimer 2002, Ali et al. 2009). Insurance schemes should not only enable poor patients to sustain access over time, but also support them in their self-management choices.

As stated earlier, the NHP-2002 even declares that providing complete social protection in a universal public system is impossible given the important percentage of poverty in India. Still, international organizations in recent years have urged government to reduce financial barriers to access and have identified these barriers as critical in chronic disease contexts (Sachs 2001, WHO 2005).

Regulation of the Health System

As stated by Peters et al (2008b), poor health system regulation is suggestive of problems in governance. Even though laws, acts and rules exist, the regulation environment in India is not set to make providers accountable. Regulation in national health policies appears to be stated as an end in itself and the structure to achieve better regulation is not clearly defined.

If we take into account the types of private providers that are affordable and available to the poor, regulation also becomes a prerequisite to ensure them quality care (Peters et al. 2008a). As

stated earlier, many reasons motivate the poor in choosing private (and unqualified) providers. Ergler et al. (2010) have talked about the "entitlement" of the poor that often perceive private care as more expensive but necessary for a speedy recovery. They often see it as the only possible choice. But Das and Hammer (2007) have also emphasized that given the type of private providers the poor see, it means low-value advice for expensive care and often the prescription of unnecessary treatments.

Abilities to Access

Ability to seek is the only individual dimension of access for which actions (related to knowledge and health promotion) are planned. This means that important barriers like ability to travel are not addressed. Neither are the interactions of barriers, such as costs and traveling. Dimensions of access are not sealed from one another and can interact. In a chronic disease context, where specialized facilities are few, treatments expensive and regular sources of care inadequate, acting on the poor's ability to access is critical.

Furthermore, the poor's abilities to access exemplify how the response to the challenges brought by chronic diseases must be coordinated between sectors. Inter-sectoral coordination is an essential element to better health outcomes (Murray et al. 2000, Wagstaff 2002). Nutrition, education and employment fall outside the jurisdiction of the health sector but are elements that can ultimately play a role on abilities to access and health outcomes. To their credit, the pilot program on diabetes, CVD and stroke, and the NHP-202 have recognized the need inter-sectoral coordination and its impact on health determinants and outcomes.

Chronic Diseases in National Health Policies

Physical non-communicable diseases in India have recently started to reach the political agenda (Reddy 2007a) but they were almost absent from the last National Health Policy of 2002 (Mishra 2005). The timeline in table 7.2 corroborates this statement. The pilot program represents the first concerted attempt to integrate primary and secondary prevention, and increase capacities for the detection and management of these diseases (Reddy 2007a). So far, the policy response in India had mainly been population-based as these are the types of actions more accessible and cost-effective for a developing country like India (Jha 2007, Miranda 2008, Reddy 2005, WHO 2005). On the other hand, mental health has been on the health policy agenda for a longer period of time, but many policy gaps identified also apply to mental chronic diseases as well.

The most striking element in table 7.2 is the fact that the poor are not specifically targeted in chronic disease interventions. Overall, the poor's needs and the barriers to access they face for chronic disease care are blended in those of the general population. The poor are more vulnerable to the many opportunity costs of access (Peters et al. 2008a) and the importance of the vicious circle of poverty, restricted access and chronic disease has already been emphasized (WHO 2005). Even in countries such as Sri Lanka or even within India in the state of Kerala, barriers to access arise for the poor and the general population in a chronic disease context (Perera 2007, Levesque 2007). Those are health systems often praised in the literature for their public health services.

Public policies, as distal factors, can ultimately influence the poor's access and their health outcomes. However, reforming policies in this direction depends on how much it is made a priority (Peters et al. 2008). Currently, the content of national health policies is fragmented between the need to strengthen the health system and to scale up interventions for better chronic disease management. Key barriers to access for the poor with chronic diseases are summarized in table 7.4.

Strengths and Limits

This study is one of the first attempts to provide a framework to understand access in a context of poverty and chronic disease in India. Through a rigorous and systematic methodology, this study has looked at the content of national health policies of a country in transition to understand the policy gaps regarding barriers to access chronic disease care for the poor.

The sampling was purposive and achieved by combining a systematic document search, triangulation and a consultative process with key informants. Even though clear inclusion criteria were set, it could still be asked if all relevant policies were sampled. For example, the Cancer Control Program has been excluded from the sample because of the context of this research. After discussion with key informants, it was confirmed that this exclusion would not impact findings. Looking at the broad lines of this program corroborates this (Government of India 2010). Nonetheless, the program was elaborated in the 1970s and some issues such as the follow-up of cancer patients are present. This is an important limit of this research.

In addition, the method was derived from a general approach to qualitative content analysis rather than a specific tool for policy content analysis. Furthermore, it was structured using specific conceptualization of access, health system functions and the role of policy on access. It could also

be debated whether all key policy levers for changes were identified. Finally, this analysis is transversal and some policies are scheduled to be renewed in the near future.

7.5. Conclusions

These six policies were legislated at different times and obviously, one policy cannot address all health problems. Because of limited resources and the different weights attributed to social goals, health problems compete to reach the policy agenda. Physical non-communicable diseases have only recently started to be recognized as a health problem affecting the whole country. The National Health Policy 2002 states that it doesn't have the resources necessary to provide universal access given the number of poor in the country. Thus, at this point in time, one could argue that it is understandable that chronic non-communicable diseases have only started to be addressed. Child mortality and communicable disease continue to be major burdens in India (Peters et al. 2002).

As it is the case in other developing countries in transition, the Indian health system is currently at a cross-road. The challenges of chronic diseases are slowly being tackled. The Indian health system has already a lot to undertake at the same time: to upgrade its whole health system, to scale up interventions for chronic diseases and to address other issues including child mortality and infectious diseases.

If nothing is done, the poor could be further marginalized as the prevalence of chronic non-communicable diseases continue to increase with the changes in lifestyles and the aging of the population. With new policies to be formulated or existing ones renewed in the near future, the various policy gaps identified here can contribute to inform policy. At the time of sampling, the mental health program for the 11th development plan was being formulated and should be, in theory, implemented by now. The pilot program will be transformed into a full policy as well. And the National Health Policy 2002 will be renewed again around 2015 when the time frame for its own objectives will come to an end.

This research has focused on national policies, while healthcare is officially under state jurisdiction. This was motivated by the active role that the center plays on health. Still, it would be valuable to make the same analyses with state policies and assess variability. Different states being at different stages of the epidemiologic transition, it would be interesting to record variations in the content of state policies.

Finally, it must be stressed that between what is formulated in the content of health policies and what is actually implemented, there is another dimension with various determinants. Links made between policies and the characteristics of resources or the population must be established with caution. What was done in this research is to assess whether the content of current national

health policies in India is oriented to address barriers to access chronic disease care for the poor, as described in the scientific literature. A more evaluative study of what instruments and changes are effectively implemented in India will be necessary as this health problem will grow in importance.

7.6. References

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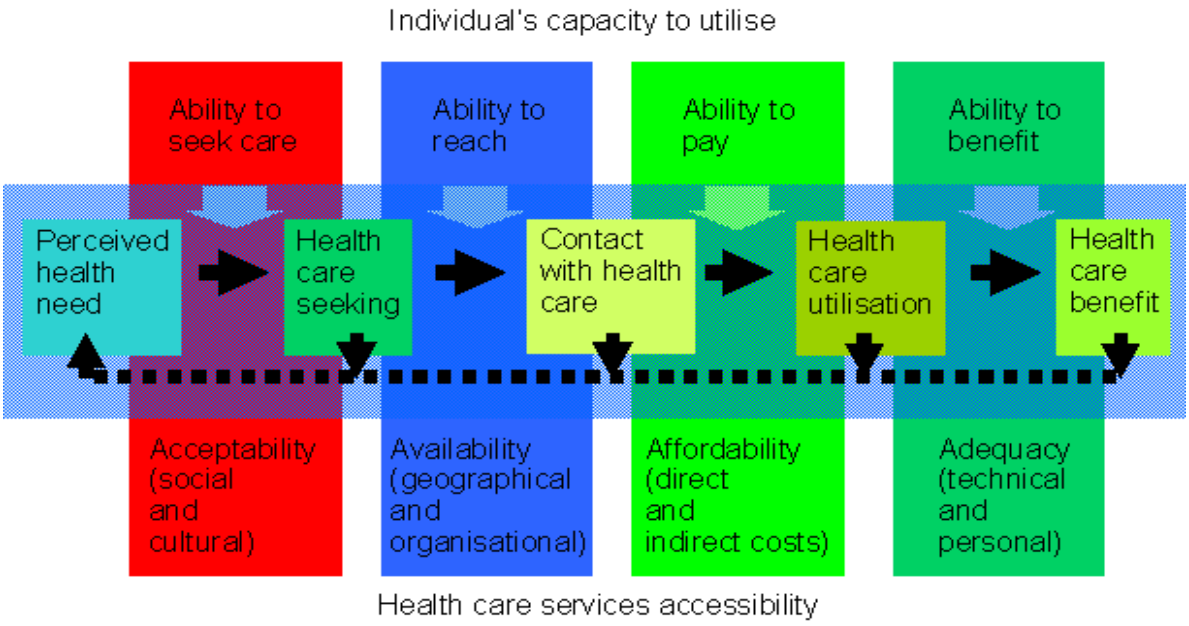
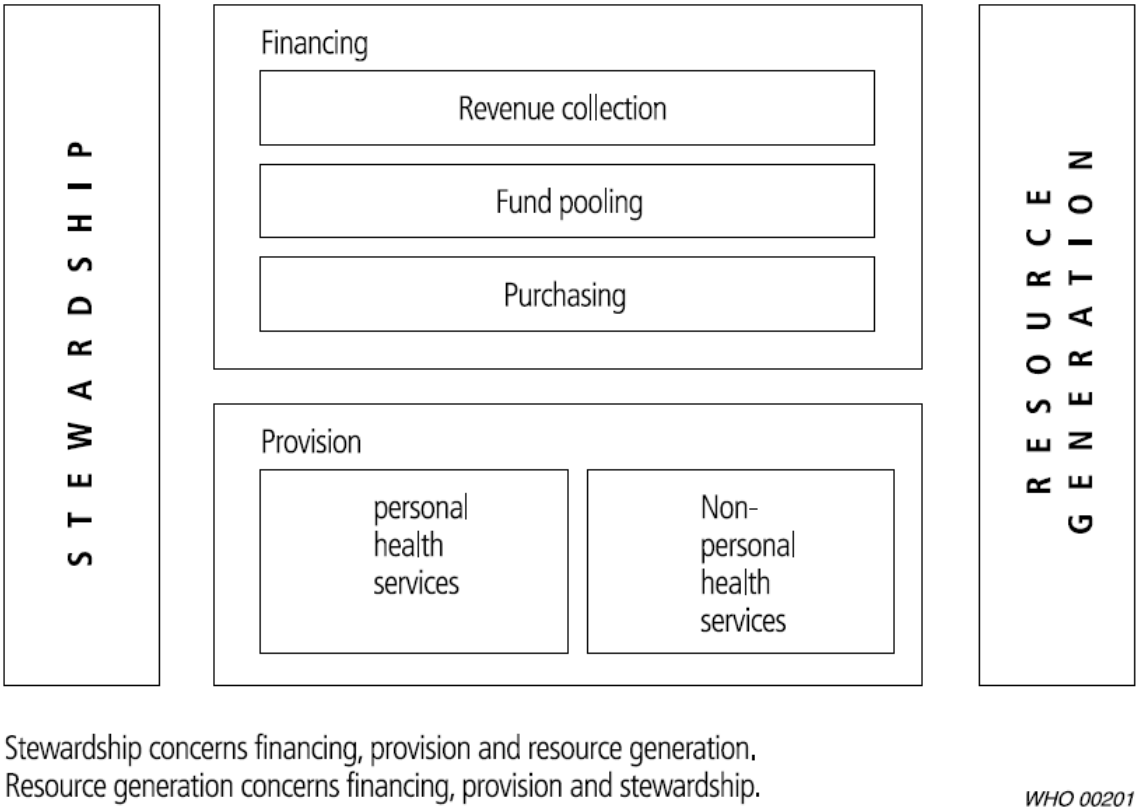
Figure 7.1: The Conceptualization of Access to Health Services



Source: Lévesque 2006

Figure 7.2: Functions of Health Systems



Source: Murray & Frenk 2000

Table 7.1: The Framework of the Study Problem

Acceptability	**Ability to seek**
o The poor face barriers to access related to the socio-cultural standards in their community. o Health services must be gender-sensitive. Poor women often face socio-cultural barriers to access, most often related to travel restrictions and provider's gender. o Traditional medicine is accepted and used in poor, rural and isolated communities.	o It is found unacceptable for poor women to travel outside their home to reach a healthcare facility. o It is also often considered unacceptable for poor women to consult male doctors and other male health professionals. o The poor often cannot differentiate qualified doctors from quacks, village doctors, faith-based healers and other unqualified providers. o Because of low health literacy, the poor often fail to acknowledge chronic diseases and the need to consult a professional in a timely manner. They often don't know this disease exists and fail to consult when symptoms arrive. o Health literacy/ also affects beliefs on the origins of mental disease for the poor and many will consult faith-based or traditional providers.
Geographic and Organizational Availability	**Ability to reach**
o The physical availability of health services is low, especially in underserved rural, isolated regions and urban slums. In particular, the availability of public PHC and CHC facilities is restricting access in these regions. o On top of this, organizational availability is problematic and most public health centers are understaffed. Shortages of doctors, nurses and allied health professionals are critical. In addition, absenteeism is also affects the organizational availability of services. o The problem of shortages and absenteeism is particularly worse in rural and isolated regions. o The physical availability of specialized services for physical and mental chronic non-communicable disease care is even lower. The availability of specialists is also a problem in public services.	o The poor have difficulties traveling in distance in order to reach health facilities. Difficulties caused by roads and infrastructures, modes of transportations and the geography of rural and isolated regions. Poor individuals in urban slums also report difficulties to reach health facilities located too far away from their homes. o Similarly, these difficulties mean that the poor have trouble reaching health services on a regular basis. o The poor with chronic diseases have even more difficulties to reach specialized services. o The poor with chronic diseases will also have difficulties reaching a primary care provider or specialist on a regular basis for follow-ups and control of their disease.

Table 7.1 (Continued)

Affordability	Ability to pay
o Health services in India are mainly financed by users and out-of-pocket payments. In addition, informal payments in the public sector are frequent. o The coverage of social protection and health insurance schemes is particularly low. Not more than 5-10% of the population is covered by health insurance of any kind. o Therefore, the cost of healthcare is a burden in India and an important cause of impoverishment and indebtedness. o The costs of hospitalization are high for the majority of the population. o The costs of care for chronic disease are higher and represent an even more important financial burden. Recurring costs for lifelong treatments, the costs of follow-ups and tests for control, expensive multi-regimen of medicines and interventions for acute events requiring hospitalization all increase the usual costs of care.	o The poor have a very low capacity to pay for health services by out-of-pocket payments. Most will have to sell assets, reduce other essential spending or acquire debts to pay for healthcare bills. Many will just opt to forgo the care they need. Therefore, catastrophic expenditure and distress financing strategies affects the poor's well-being. It will even reduce further their capacity to pay for any health services. o Opportunity costs and indirect costs (medicine or costs of traveling) also affect the poor's capacity to pay for care. o The poor cannot sustain access over time and the costs of regular and long-life care for chronic disease represent a major barrier to access. o The majority of the poor is not covered by health insurance. Many have difficulties paying for premiums and market failures based on income and morbidities are present.
Adequacy	**Ability to benefit**
o Healthcare in India is poorly regulated and skimping on quality, price and quantities are reported in the private and public sectors. o In particular, the availability of supplies and medicine in the public sector affects the quality of care. o Most providers in the public and the private sectors, especially primary care providers, cannot detect, refer and manage most chronic diseases. Few are adequately equipped to run basic tests and investigations. Most providers cannot apply recognized guidelines of care and few understand the necessity for close follow-ups and control. o Most providers also fail to deliver knowledge, education and health promotion activities for chronic diseases. o Many mental health facilities resemble more a prison than a curative facility and fail to respect basic human rights.	o Because the quality of services is abysmal in the public sector, the poor seeking care in these facilities will mostly not benefit from the care they have received. o Similarly, because the poor seeking care in the private sector often use the services of unqualified providers, they will also not benefit from the care received, which can also be harmful in some cases. o Because the providers they see cannot detect and manage most chronic diseases, the poor seeking care for these diseases in the public and the private sector often cannot benefit from the care received. The poor cannot benefit from early detection, appropriate controls and self-management education.

Notes: taken from the literature review.

Table 7.2: Barriers to Access addressed by Indian National Health Policies listed by Date

	HMDG	NHP 2002	MHP	RAN	NRHM	PPCC DSC
Date	Pre-1990s	2002	2002 - 2007	2003	2005	2008
Acceptability & Ability to Seek						
The unacceptability for some women to consult male doctors		√			√	
The unacceptability for women to leave home and travel to reach health centers						
The use of faith-based or unqualified private providers		√·**P**				
The use and acceptance of traditional medicine in certain communities		√·**P**			√ **P**	
Health literacy and ability to seek timely and appropriate care for chronic diseases		√·**P**·**C**	√·**C**		√·**P**·**C**	√·**C**
The capacity to use health services given one's own socio-cultural beliefs						
Availability & Ability to Reach						
The low physical availability of health services in certain regions		√·**P**	√·**C**		√·**P**	
The low availability of specialized health services for chronic diseases		√	√·**C**		√	√·**C**
Critical shortages of human resources and absenteeism in public facilities		√	√·**C**		√	√·**C**
The difficulty to travel in distance to reach health facilities and reliance on inefficient modes of transport						
The challenge and difficulties to reach specialized care or primary care for regular follow-ups and control						
Affordability & Ability to Pay						
The financial burden of user fees and out-of-pocket payments for health services	√·**P**					
The impact of catastrophic expenditure and distress financing strategies on people's capacity to pay						
The financial burden of the direct costs of inpatient care	√·**P**			√·**P**·**C**		
The financial burden of the direct costs of outpatient care						
The financial burden of the indirect and opportunity costs of using health services						
The low coverage of any type of health insurance scheme	√				√·**P**	
The low coverage of social protection schemes for the poor	√·**P**					

Table 7.2 continued						
The financial burden of chronic disease care: higher and lifelong recurring costs						
The capacity to pay for an insurance scheme					√·**P**	
Market failures for insurance products associated with income and morbidities						
Adequacy & Ability to Benefit						
The problems in the quality of care in public health centers and hospitals		√·**C**	√·**C**		√	√·**C**
Mental health institutions that do not respect human rights		√·**C**	√·**C**			
Skimping on price, quality and quantity in the private and the public sector		√	√·**C**		√	√·**C**
The capacity of providers for education, deliver knowledge and health promotion activities			√·**C**			√·**C**
The capacity of providers to detect and manage diseases		√	√·**C**		√	√·**C**
The capacity to benefit from care received in the public sector when quality of care is poor						
The capacity to benefit from care received from unqualified providers						

Legend: √ = Policy addressing barrier, **P** = targeting the poor, **C** = barrier to access addressed for chronic diseases

Table 7.3: Policy Levers by Barriers to Access Addressed

	Stewardship	Financing	Resource generation	Service Provision
Acceptability & Ability to Seek			• Staffing norms in PHC • Using traditional medicines and providers in public health centers	• Health education on chronic disease • NGOs for health promotion
Availability & Ability to Reach		• Increase public expenditure to improve availability	• Increase the availability of: o Health professionals o Support personnel o Chronic disease specialists o Mental health professionals o Medical supplies • PPP to improve the availability of HR • Integrating traditional providers and medicine in the public sector	• Providing primary, community, sector and tertiary public health services • Providing mental health services • Providing services for CVD and diabetes and the district level • NGOs for prevention and disease control

Table 7.3 (Continued)

Affordability & Ability to Pay	• Advocacy against the TRIPS / Affordability of drugs	• Covering the direct costs of interventions in public hospitals • Financial assistance for premiums • Examination / study of public protection schemes • Promotion of private and community health insurance • Examination of possible risk pooling mechanisms • Encourage the use of private services with ability to pay		
Adequacy & Ability to Benefit	• Quality Regulation in both the public and private sector • Harvest capacities for NCD in the private sector	• Increase expenditure to improve the quality of care in the public sector	• Improve capacities for the detection and management of physical and mental NCD at all levels of the health system	• Providing care for mental disorders, diabetes and CVD in the public sector

Table 7.4: Key Barriers to Access and the Policy Response

Barrier to access?	Addressed?
Perceived health needs …	
The poor have difficulties recognizing and seeking care for mental and physical chronic non-communicable diseases.	To some extent, the NHP-2002, NRHM, the MHP and the pilot program aim to educate the population, to increase knowledge, change behaviors and reduce stigma.
Healthcare seeking …	
The poor's utilization of private outpatient care and their capacity to differentiate qualified from unqualified providers.	Unaddressed. On the other hand, the NHP-2002 and NHRM state that the regulation of the private sector is a necessity.
The poor have difficulties traveling to reach specialized care because of infrastructures, distance and costs.	Unaddressed.
They rely on inefficient modes of transport.	Unaddressed.
The poor have difficulties traveling and reaching a primary care provider for follow-ups and controls.	Unaddressed.
Contact with healthcare …	
Inpatient care is expensive and the poor have a lower capacity to pay for interventions and investigations in hospital and specialized tertiary centers.	Two financial schemes directly target the poor for inpatient care costs in the public sector.
The poor on a more regular basis have difficulties paying for primary care and will often wait for a health problem to become incapacitating before using the services of their local providers.	Unaddressed.
The poor have difficulties paying to sustain access over time. Paying for recurring treatments, controls and follow-up is a burden. The costs of chronic disease care are higher.	Unaddressed.
The poor with chronic disease have difficulties adhering to an insurance program because of income and morbidity.	The NHP-2002 and NRMG aim to encourage and promote insurance. The NRMH aims to support the poor for premiums. On the other hand, market failures and the difficulties to reach the poor with insurance product are not addressed and neither are insurance products for people suffering from chronic diseases.

Table 7.4 (continued)	
Healthcare utilization …	
Currently there are few providers, especially in primary and community care centers who are capable and equipped for the detection and management of physical and mental chronic non-communicable diseases.	The NHP-2002, MHP and the pilot program aim to increase these capacities at all levels of care with training and education programs. The pilot program also aims to harvest these capacities in the private sector and in rural areas.
Few chronic diseases specialists are available other than in major cities.	The NHP-2002, MHP and the pilot program aim to increase the number of specialists available.
Healthcare benefit …	
The poor's utilization of unqualified providers for their chronic diseases often means low value advice, the prescription of unnecessary treatments and poor quality of care.	Unaddressed. Many open questions remain regarding the regulation of the private health sector as stated in the NHP-2002 and the NRHM only.
The poor have difficulties managing their own diseases and few are supported by a primary care provider.	Unaddressed.

8. Additional Results

In addition to the results presented in the previous section, policy levers and instruments found in national policies were also categorized to assess the level of priority and commitment they translate on specific health problems. Instruments are conceptually divided into: low involvement with voluntary instruments including the private sector or charity; medium involvement with mixed instruments including taxes, subsidies and the delivery of information; and high involvement with compulsory instruments like direct regulation and the provision of services (Howlett et al. 1995). These additional results are presented in Table 8.1.

Some instruments illustrate a high involvement of national health policies on certain barriers to access. First, the proposal to increase public financing to improve geographic and organizational availability of general and specialized services, as well as the quality of these services with education, supplies, upgrades and modernization all illustrate a high level commitment. Second, these policies also plan to be involved in the direct provision of personal public services. Either in general or for specialized chronic disease care, health services are planned to be delivered publicly. Third, these policies also plan to directly regulate health services to ensure quality in the private and public sectors. Proposals are made to ensure the quality of traditional providers and medicines, to harvest capacities for the prevention and control of non-communicable diseases in the private sector and to improve the regulatory structure in general. Hence, related to adequacy, a stewardship role is planned alongside financing. On stewardship, the national health policies also plan to take an advocacy role on the international scene against the TRIPS and the effect of globalization on the affordability and availability of medicines. Finally, the two financial schemes cover the direct costs of interventions for the poor in public hospitals.

At a lower level of commitment, there are a series of mixed instruments. This category includes health education and information to the population; most notably here on mental and physical chronic diseases. Overall, plans made to tackle the emerging problem of chronic disease have been mostly located here. Plans by the NHRM to provide subsidies to the poor for premiums payments can also be included in this medium level of involvement.

Finally, some proposed instruments demonstrate a low level of commitment. First, the majority of instruments proposed to tackle barriers of affordability and ability to pay are associated with examining possible schemes, encouraging private and community health insurance, and promoting private health services for those that have the ability to pay. Furthermore, PPP by cooperating with private allopathic and traditional providers are major instruments featured to overcome problems of organizational and geographic availability, alongside instruments that translate a higher involvement such as public expenditure and direct provision. So far, what is known in the literature is that true collaboration on health (and regulation for that matter) with the private sector has remained limited in India (Peters 2002, 2008b). Along the same lines, the pilot program also plans to incorporate

private resources in public institutions to improve capacities for chronic disease care. Finally, the involvement of NGOs in health education and service delivery is also promoted by some policies.

Table 8.1: Levels of Commitment of National Health Policies

	Instruments
High	▪ Increase public expenditure to improve quality of care ▪ Increase public expenditure to improve availability ▪ Cover the direct cost of interventions in public hospitals ▪ Assist financially for premiums ▪ Directly provide health services (general) ▪ Directly provide mental health services ▪ Directly provide services for diabetes and CVD ▪ Regulate quality over the private sector ▪ Regulate quality over the public sector ▪ Harvest capacities for NCD in the private sector ▪ Advocate against the TRIPS / Make drugs affordable ▪ Increase the availability of human resources ▪ Increase the availability of mental health specialists ▪ Improve capacities for mental health ▪ Increase the availability of chronic disease specialists ▪ Improve capacity for chronic disease management ▪ Increase the availability of medical supplies
Medium	▪ Provide health education on chronic disease and healthy behaviors ▪ Be knowledgeable and aware of mental disorders
Low	▪ Examination / study of public protection schemes ▪ Promote private health insurance ▪ Promote community health insurance ▪ Examine possible risk pooling mechanisms ▪ Encourage the use of private services with ability to pay ▪ Use NGOs for prevention and disease control ▪ Collaborate with NGOs for health promotion ▪ Establish PPP to increase the availability of human resources ▪ Use traditional providers and medicine in public health facilities

9. Discussion

9.1. Summary

Large proportions of individuals live in poverty in India and many people live in a precarious state not too far from it. This means that a considerable number of people in India are vulnerable and face various barriers to access health services. Furthermore, it was demonstrated that India's health system is underfunded, the public sector is weak and the heterogeneous private sector is largely unregulated. In the midst of all this, the prevalence of various chronic non-communicable diseases is rising and at a faster rate than what was observed in most industrialized countries. Diseases such as CVD, diabetes and major depression affect more and more people in India. As lifestyles continue to change and the population is aging, their burden will continue to increase. The health system in India is currently not geared and equipped to provide efficient chronic disease care. Authors have declared that the government response has been late in coming. Mental health on the other hand has been present on the policy agenda for a longer period time. Therefore, this research has investigated the extent to which current Indian national health policies address the main barriers to access for the poor living with chronic disease.

This study had three objectives. The first objective was to assess whether the goals, objectives, instruments and targeted populations, as formulated in current national health policies in India, address the main barriers to access health services for the poor living with chronic diseases. The second objective was to assess the types of policy levers and instruments identified in current national health policies to address the barriers to access in each dimension of access. And the third objective was to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor. Bearing in mind these objectives, the results are discussed further in this section around specific and cross-cutting themes.

Six Indian national health policies were analyzed: the National Health Policy 2002, the Rashtriya Arogya Nidhi, the Health Minister's Discretionary Grant, the National Rural Health Mission, the Mental Health Program for the 10th development plan and the Pilot Program for the Prevention and Control of Diabetes, Cardiovascular diseases and Stroke. This sample was thus composed of two broad-based health policies, two financial schemes and two policies focusing on mental and physical chronic non-communicable diseases.

However, four synthesis points have to be made prior to the discussion of the results. First, it appears that most of these policies do not have a clear plan of action to meet some of their own objectives. In many cases, the plan of action is only a statement of objectives. For example, regulating the private sector is said to be necessary in two of them without actually laying a plan of action to achieve it.

Second, although this was not an approach used in this research it is also necessary to make a reflection on priorities. In countries such as India, health problems compete to reach the policy agenda and few resources are available. There are opportunity costs of allocating resources to specific issues, as it means that less is available for other problems. What does this imply? It means that when the necessity of ensuring a playing field for the country in genetic science is found alongside issues such as critically understaffed rural health centers in national health policies (i.e. the NHP-2002), one way or another, there will be fewer resources available for rural centers. This being said, further discussions would require a careful analysis of health budgets. Still, comparing what problems are included in the content of a policy is a start. Therefore, if genetic science and the role of medical tourism are included in a national policy while poverty and chronic diseases are not linked together, it can be argued that access for the poor to chronic disease care is not prioritized.

Third, when studying access of the poor in a chronic disease context, it is important to bear in mind that the health sector doesn't have complete jurisdiction over all determinants of access and health outcomes. Ultimately, when formulating health policies there is also a necessity to coordinate with other socio-economic sectors (such as employment or education, for example). In many instances, inter-sectoral actions are the only way to completely transform some dimensions of access and have a greater impact on health outcomes. Health policies have their limits.

And four, in a country like India where jurisdiction on health is shared among government levels, the same reflection on coordination must apply. If the center is responsible for laying out the vision and general guidelines for the whole system, the state governments have the responsibility to manage healthcare directly on their territory and are accountable to their populations. It is necessary to see these two levels of policy as complementing one another. In observing what national health policies address and do not address, it is important to bear in mind this complementarity.

The health policy environment will be changing in the near future as new policies will be formulated and existing ones will be renewed. The results of this research have implications for future policy.

9.2. Targeting the Primary Care System

As stated earlier, the role of primary care for the successful management of chronic diseases has been established by different authors. Various models of care and calls of actions, urge governments to take actions and strengthen primary care for better chronic disease management. This has not only been the case for low and middle income countries such as India, but also for most developed countries. Because some barriers to access are absent from the content of

policies and that some open questions remain regarding instruments to strengthen primary care, these results suggest a number of policy implications for India.

Developing primary healthcare in India to improve chronic disease care for the poor

The central role of primary care is recognized in the literature and evidence exists on its role in the health system for equity (Starfield 2005). Primary care is associated with a more equitable distribution of health across a population. Primary care can play a central role in health systems and evidence exists of its fundamental role in chronic disease management. Primary care can be defined using an Institute of Medicine definition consistent with the one provided by the WHO in 1978 (Starfield 2005):

> "The provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."

The call to reform primary care for better chronic disease management in developing (Beaglehole et al. 2007a, b) and industrialized countries (Starfield 2005, Wagner 2010) is seen as a tool to decrease the health and costs consequences of chronic diseases. Evidence exists, but transforming primary care for high-quality chronic disease management is a challenge everywhere, even for rich countries. A crisis of primary care is described for countries such as the US (Bodenheimer 2006, Wagner 2010) and Canada (Hutchison 2008). In these countries, dissatisfaction with the primary care system and the difficulties to gain timely access to a family physician are observed. Furthermore, not only is the ratio of family physicians to population low, admissions to residency in family medicine have been declining and actual rates are not encouraging. Physicians are challenged by the increasing burden and complexity of their practice, caused in a good part by chronic diseases, multiple morbidities and population aging. The prevention and health promotion role required from physicians versus remuneration for time spent on such activities represents another challenge. Those are only a few elements of the primary care crisis in developed countries. Recent OECD and Commonwealth Fund surveys have painted a picture of varying performance of primary care across industrialized countries. Calls for reforms are made but the investments required are enormous and the challenges for providers are not negligible. The time and financial resources required from providers to meet the requirements of performing new organizational models are major, especially for physicians in small practices

What does this entail for a developing country such as India? Beaglehole et al. (2007a) have argued that a functioning and effective primary care system is a basic prerequisite and that government in developing countries should invest and integrate prevention and control of chronic

diseases in this line of service. Bearing in mind that India is a developing country and that little resources are currently made available to the health sector, this reflection on primary care, chronic disease and new organizational models still provides an interesting perspective to look at these results. Many of the investments that are called for in developed countries to reform primary care, like investing in EMR for example, are not realistic for a resource-poor country like India. A lot must be undertaken at the same time to strengthen primary care. Nevertheless, some features of these new models such as self-care and self-management, multidisciplinary teams, training of medical personnel for chronic disease treatment guidelines or community empowerment represent a start. Perhaps India is a resource-poor country, but the fact that it is a signatory of the Alma-Ata convention on primary care can certainly support this perspective.

Beaglehole et al. (2008) have also laid out the evidence and advantages of primary care for the detection and management of chronic diseases in low and middle-income countries. As it was stated in the literature review, these authors have exposed the steps for the optimal management of chronic diseases. This management relies on opportunistic case finding and assessment of risk factors for early detection of diseases and identifying high risk status in individuals. It relies on a combination of psycho and pharmaco interventions, regular follow-ups, the monitoring of diseases and the promotion of adherence to treatments. To achieve this, they claim that primary care must be strengthened everywhere and evidence exists (by referring to Jamison et al. 2006) for cost-effective interventions for mental and physical chronic diseases control in a variety of settings.

For Beaglehole et al. (2008), primary care has a number of advantages. The proximity to the patient can reduce traveling costs and support health promotion. It also makes coverage of the population's needs, follow-ups and continuity of care easier to deliver.

The authors have also underlined that several organizational models of care, such as the chronic care model (Wagner 1999), exist to strengthen the role of primary care. They underline the importance of linking primary care with community resources to support patients. They also highlight the central role of primary care in supporting and promoting patient’s self-management. They touch the notion of decision support and how all primary care personnel must integrate chronic disease treatment guidelines in their practice. They address the notion of system redesign and how primary care must integrate planned visits and a multidisciplinary team approach. They also underline the role of the government for its stewardship role to provide quality care and the work it must undertake on the fragmented system of care, in financing to ensure supply, in the implementation of information system and the development of more equitable financing schemes.

But of course, they also acknowledge how the advantages of primary care for chronic disease management can be offset by certain characteristics of health systems in these countries, which can constitute barriers to access. Primary care has a fundamental role to play for high quality

chronic disease management and the poor's access to health services. Overall, challenges are immense and financial and resource investments required to reform primary care are major.

Addressing Financial Barriers to Chronic Disease Care for the Poor

As these results suggest, financial barriers for the poor to access outpatient care and the financial burden imposed by chronic diseases are not prioritized in national health policies. These results have demonstrated that some financial barriers are addressed by two financial schemes directly targeting the poor. But these two schemes are only covering the direct costs of hospital and super-facility interventions. At a level that goes beyond regular care, early detection and regular follow-ups of chronic diseases. Actions that should ideally be covered by a primary care provider.

In the two broad-based policies, financial barriers did not appear to be among the main problems prioritized. Both policies however did underline the need to encourage private or community insurance. Apart from the rural mission who states that it will provide subsidies for the poor's premiums, the involvement of the government in this area is limited to encouraging the market and the population's adherence. In the previous section, the challenges of changing the financing system and correcting market failures when the majority of the population is poor, rural and employed in the informal sector were described. The content of these policies suggests that these issues are not prioritized.

Finally, the two policies more directly focused on physical and mental chronic diseases did not address financial barriers to access at all. They also did not target the poor specifically either. Thus, what these result show is that financial barriers to access primary care for the poor who are suffering from chronic disease are not made a priority.

Financial barriers influence the decision of poor people to access primary care, the type of care they will seek and whether they can sustain this access over time. The "medical poverty trap" is a real problem for the optimal management and control of chronic diseases and it can ultimately have an economic impact. Medical poverty was termed by Whitehead et al. (2001) to describe this process of impoverishment caused by healthcare payments. As it was seen in the review and result sections, the poor in India are more at risk of having untreated morbidities and higher rates of complications requiring complex care because they do not have access to a source of care for regular check-ups (Ramaraj 2008, Whitehead 2001, WHO 2005). In general, the poor avoid using care, often declare financial restraints for untreated morbidities or go into indebtedness to pay for care (Peters et al. 2002, James et al. 2002, Gupta 2003, Duggal 2007). Furthermore, was it was previously described, mostly with studies of diabetes, the costs of chronic disease are high and represent a major barrier (Bjork 2003, Kapur 2007, Ramachandran 2008a, Tharkar 2009,

Venkataraman 2009). These studies, among many others, have demonstrated that keeping up with the optimal control of diabetes, with all the necessary treatments, control, and contacts with a health professional, represents an important financial burden that increases further with hospitalization. Compliance to the medicine prescribed and adherence to a whole treatment is expensive even for higher classes (Venkataraman 2009). Total ambulatory care costs are high for the total amount of recommended care for diabetes and the majority of families are paying for such care directly with their income (Kapur 2007).

Because of low expenditure on health and the low coverage of social protection and insurance, people in India are forced into making out-of-pocket expenditures to access health services (Peters et al 2002, Duggal 2007). These financial barriers also mean that the poor in India will often resort to consulting a physician only in cases of need, if they will simply not be forced to forgo treatments completely (Devadasan 2004b). Even more so, if care is free in theory in public centers, there are still costs associated with reaching facilities far from home, purchasing medicines and tests unavailable in the center and the occasional informal fees charged by some public providers (Peters et al. 2002, Ager 2005, Dror et al. 2008, Kotwani, 2007, 2009, Lévesque et al. 2007)

This is a challenge that must be taken into account by the government if primary care is to be strengthened in the future. To protect the poor, more equitable financing schemes should be established or costs must be better regulated (Devadasan 2004b). Furthermore, if risk pooling is to be increased and insurance to be promoted, two concerns must be highlighted. First, as discussed earlier, the governments must subsidize and better regulate the system in order to correct market failures and better protect the poor that could be otherwise left out of the market. Second, some authors believe that something needs to be done to better design insurance schemes for chronic disease care. Ali et al. 2009 have rightly pointed out in their review of diabetes care in India that disease specific insurance schemes to ensure that patients can sustain follow-ups and have better self-management are necessary. This is a call that is also made by Bodenheimer et al. (2002) for developed countries.

Affordability and ability to pay are the dimensions of access that are the least addressed. The need to increase financing and to upgrade public services can indeed impact the poor's financial access if care that should be subsidized in theory is subsidized in reality. However, the NHP-2002 has stated the impossibility of a completely universal healthcare system for the country and turns towards encouraging other financing mechanisms and insurance, without much details and leaving out chronic disease care.

Hence, the situation for the poor in India is one where financial barriers contribute to prevent them from accessing primary care on a regular and adequate basis. Their situation is also one where once they have a diagnosis of chronic disease, they either receive it at an early stage but

cannot financially sustain treatments, or at a later stage when complications result in even more complex and expensive care. All of this, of course, is without taking into account that the majority of outpatient care in India is consumed in the private sector.

Improving Availability and Adequacy of Services for Chronic Disease Care for the Poor

Overall, barriers related to the availability and adequacy of health services were the most addressed. As stated repeatedly, national health policies have acknowledged the impact of low financing on the overall adequacy of public health services. By increasing financial resources, the availability of human and medical resources and the number of infrastructures, policies aim to improve the state of the public system. With regards to chronic diseases, one of the central features of the mental health program is to provide an integrated system of care within communities and improve the capacities of primary care practitioners to detect and manage mental disorders. Along the same lines, plans are also made in the pilot program to not only establish special clinics for CVD and diabetes at the district level, but also increase capacities for the detection and management of CVD, diabetes and stroke throughout the system. Thus, national health policies must be accredited for acknowledging the need to invest more in the public system and scale-up services to be able to meet basic requirements in the detection and management of chronic diseases.

The primary care system described by Beaglehole et al. (2008) is idealistic. It paints a portrait of primary care services where the medical personnel is adequately trained to detect and manage chronic diseases, in a functioning system where patients have regular access and where risk assessment, opportunistic case finding and early diagnosis can be made to the benefit of the patient. They also paint a system where multidisciplinary teams work in structures to support patients with reminders for follow-ups and promotion of adherence to treatments. However, many studies have deplored that this is currently far from being the case in India. In particular, authors studying diabetes, CVD and mental disorders in primary care settings have outlined major availability and adequacy problems in India.

Primary care in rural areas and even secondary facilities in town and cities across the country are not equipped for this type of care. Authors have stated repeatedly that primary care centers and even secondary centers are ill-equipped for the detection and management of chronic diseases (Karthikeyan 2007, Ramachandran 2008a, Ramaraj 2008, Joshi et al. 2006, and Joshi et al. 2008). General practitioners do not have the experience and knowledge necessary, and standardized guidelines are not applied. High quality chronic disease care exists in India, but is mostly available in major urban centers and to affluent groups (Reddy 2005, Ramaraj 2008). Studies of diabetes

care have underlined the inadequacy of primary care for the initial screening of diabetes which they also impute on general practitioners' lack of knowledge of the disease and its symptomatology (Bjork 2003). Most family physicians do not run the basic tests for diabetes and thus rarely represent the first point of diagnosis like the ideal description made by Beaglehole et al. (2008). Similarly, Khandelwal (2004) has deplored the fact that few primary care providers are actually expected to provide care for mentally ill patients. Again, taking diabetes as an example, two authors have denounced that most healthcare spending on diabetes in India is spent on treating complications rather than controlling the disease (Joshi et al. 2008, Ramachandran 2008a). The result is a situation where poor patients with chronic disease are not supported to achieve optimal control of their illness.

However, these cases of sub-optimal detection and control happen when the poor can actually access public centers and see a health professional. For the most part, health services are mainly concentrated in urban centers (Peters et al. 2002). Few primary care centers are available in rural areas; most suffer from shortages of medical professionals. Many primary care and sub-centers in rural India are vacant of medical personnel (Bajpaj & Goyal 2004). In this perspective, perhaps the multidisciplinary team approach in primary care could not only be seen as a way to increase the quality of care, but also as a potential solution to the shortage of physicians. It was also seen that the population’s opinion of health services in the public sector is very low in India (Peters et al. 2002, Kurian 2007, Roy et al. 2007, Ergler et al. 2010).

A working paper for the National Commission on Macroeconomics and Health for India (Nundy 2005) has also denounced the lack of clarity of National health policy on how it plans to transform primary care in the country. The report recognizes the efforts of the NHP-2002 in planning to strengthen, decentralize, provide universal health services and regulate the private sector. But it also blames the policy for failing to indicate how it will achieve its goals. At the same time, Reddy (2007a) also praises the pilot program as the government's first attempt to provide a plan to scale-up primary and secondary prevention of chronic disease. The necessity is two-fold. Basic primary care services need to be strengthened and upgraded and, at the same time, there is a need to go one step further and increase general practitioners' capacities to manage chronic diseases.

To some extent this is acknowledged by national health policies. Most policies plan to increase financing and generate resources to palliate to shortages. Primary care is even stated as a goal to improve equity in access. The poor state of public services is recognized and the aim is to provide more adequately equipped facilities, especially in rural regions. With regards to chronic disease care, the need to improve adequacy of services is also acknowledged. An integrated system of community care for mental health services is planned and the increase of other providers’ knowledge and capacities. For physical non-communicable diseases, if services are planned at the

district level, the need to increase capacities for the detection and management is targeted to be expanded at all levels of care. Even more so, the pilot program sees the rural mission aim of strengthening rural healthcare as a basis on which to promote its own goals for chronic disease care.

However, some questions remain. It is unclear how this will be implemented and if necessary funding will be channeled to accomplish this. Also, which route should be prioritized first? As Mahal et al. (2010) have underlined, many issues regarding access to chronic disease care are not unique to these diseases. This research framework and these results also highlight how the health system as it currently exists in India suffers from major problems that already affect the poor's access. Many of these barriers are related to the adequacy and availability of primary care. Chronic diseases are one determinant that exacerbates existing deficiencies. Hence, as these authors state:

> "An efficient and equitable health care system becomes a key tool for NCD control as it is for control of other health conditions. However, with the NCDs becoming more common, improving efficiency, quality, and access to a sound health care system is good strategy for NCD control. Likewise, efforts to improve health care delivery and access for NCDs will improve the infrastructure for the broader health care system. The ultimate challenge is to strategically focus on policies that will yield the best returns (p. xxii)."

Regulating Private Outpatient Care for Better Chronic Disease Care for the Poor

National health policies recognize that financing and quality problems in the public sector have enabled the private sector to grow significantly. They also recognize that the poor are often forced to the private sector for their outpatient care and that means they will have to bear out-of-pocket payments. This represents a catastrophic expenditure for the poor. The varying quality of services provided in the private sector does represent a barrier to access that this also acknowledged.

For national health policies, the private sector has to be better regulated and the government should take a more far-reaching stewardship role. In addition, given the problems of availability of human resources and medical supplies, national health policies also see the private sector as a partner and plans are made to increase cooperation: public-private partnerships are planned for resource generation. Finally, if better chronic disease management must be nurtured in the public sector, the pilot program also understands that capacities must be "harvested" in the private sector as well. Hence, the government also wants to better regulate the private sector and influence its practices.

Private services are predominantly used for outpatient care in India, even by the poor. Even if public services are subsidized for the poor, barriers to access affect their health-seeking behaviors. However, when the poor consume private outpatient care, it is mainly from unqualified providers (Peters et al. 2002, Kurian 2007, Da Costa et al. 2007, Roy et al. 2007, Peters et al. 2008). The majority of traditional and modern medicine providers in rural areas are unqualified. Most of these providers prescribe and administer treatments for which they did not receive appropriate training. They also did not receive the training necessary to detect and treat most common diseases, let alone chronic diseases. Hence, the ability of the poor to benefit from this inadequate care is low and even more so, it can have drastic consequences on their health.

The majority of the poor use private services for primary care sometimes because of their proximity and sometimes because of costs. But private services are also often seen as the only possibility to get cured while public services are seen as a waste of time and money. This is what Ergler et al. (2010) have called the entitlement of poorer individuals that perceive they should receive better care. The private sector is often more expensive (Duggal 2007, Dror et al. 2008) and providers often prescribe unnecessary treatments to make more money (Das, J. et al. 2007, Peters et al. 2008). But using private services is seen by the poor as a necessary investment to get better faster (Ergler et al. 2010, Das, J. et al. 2007). Nonetheless, the poor are underserved according to some authors because of the lack of competence of the providers they get to see in the private sector and the limited efforts public providers actually do for them (Das, J. et al. 2007). For Das and Hammer (2007), it's money for nothing for the poor, as they often receive low value advice and/or are prescribed unnecessary treatments.

For some authors, the regulation structure falls short of protecting the poor (Peters et al. 2008). Existing problems in implementing regulation limit the effects of policy interventions to change the quality of care in India (Das, J. et al. 2007). Regulation is a function of government, using laws, order and rules on enterprises, citizens and even the government itself (Bloom et al. 2008). For these authors, problems arise when there is asymmetry of information between the public (in our case poor patients) and actors of the system (private primary care providers). They see four objectives for healthcare regulation: quality of care, value for money, social agreement and accountability. Overall, these authors say that India lacks an overarching strategy in healthcare regulation. They also identify professional medical associations as hindering complete regulation. The *Consumer Protection Act (1986)* and the *Right to Information Act (2005)* are the only formal protection for patients (Bloom et al. 2008, Peters et al. 2008).

There is no standard policy on the pricing of health services and this results in a situation where one provider may charge more than necessary for a simple procedure, especially if he is the only option available in a distance. Out-of-pocket expenditures represent an opportunity for certain

providers to increase their income by increasing the volume of care they deliver, often unnecessarily (Peters et al. 2008).

The policy response for many authors is to transform the regulation environment to effectively protect patients and strengthen the health system (Bhat 1999, Bloom et al. 2008, Peters et al. 2008). For these authors, this is essential given the size and importance of the private sector in primary care. For other authors, the impact of training to improve practices is limited and incentive mechanisms only partially explain the situation (Das, J. et al. 2007). For these authors, fundamental and important changes cannot be brought to the way doctors are paid, monitored and rewarded for their performance. The best policy option is then to help patients become better consumers of care through awareness and information campaigns.

There is a number of implications between these results and what various authors have stated about the use of private outpatient care by the poor and the state of the regulatory structure in India. It is clear that there is a dire need to strengthen the regulatory structure over the private market and the public sector as well. National health policies seem to acknowledge the need to regulate the private sector and harvest better practices for chronic disease care. On the other hand, the claim of regulation also appears to be an end in itself in the content of some national health policies. The details on how this regulation is to be achieved are not written. Nowhere are instruments laid out to specify a policy on pricing or how performance will be monitored and malpractice sanctioned.

These results also suggest that the poor's ability to seek care from qualified providers is not prioritized. It also described as the ability to differentiate qualified from unqualified providers. Informing the poor better is a role that national health policies could take to work indirectly on problems generated by information asymmetry. On the other hand, although this is a policy option in the absence of enforced regulation, this type of mass education and awareness campaigns translate a low level of priority to the problem. The need to improve and enforce regulation policies will need to be better prioritized in the future (Bhat 1999, Bloom et al. 2008, Peters et al. 2008).

Finally, these results have also demonstrated how national health policies plan to cooperate more with the private sector. More resources need to be generated for public primary care and involving the private sector through PPP is set as a policy instrument. On the other hand, even though this is a claim made by some policies, notably the NHP-2002, some authors have deplored that cooperation with the private sector has historically been nearly non-existent and both systems only function parallel to one another (Peters et al. 2002). Given the size and importance of the private sector, not only is regulation warranted, but indeed cooperation is a policy option. Moreover, in seeking cooperation with the private sector, national health policies should also pay more attention to informal providers. As a major source of care to the poor, they not only have to be

better regulated, but they also could be targeted for training and cooperation in a perspective of "harvesting" capacities.

9.3. Improving the Poor's Ability to Access Chronic Disease Care

The Poor's Ability to Reach Health Services for Chronic Disease Care

The concept of ability to travel and its interaction with costs is not a barrier that is addressed. This is the case even though availability is one dimension where most barriers to access are addressed by national health policies. Ability to travel, transportation modes, reaching appropriate or specialized care for chronic disease in a timely manner are all barriers reported by the literature that are not addressed by these policies. It appears that the focus is on the supply of services on a geographic basis.

We have seen that the poor in rural areas, and even the urban poor, face difficulties in traveling to reach primary care facilities and many report these barriers as a reason for untreated morbidities (Duggal 1992, Yesudian 1999, Peters et al. 2002, Ager 2005, Levesque 2006). This was exemplified in the study of Kermode et al. (2009) with the necessity for patients living in rural Maharashtra to travel to major cities in order to see a psychiatrist. Furthermore, modes of transportation are often inefficient, especially in emergency situations, and this was outlined by different studies of stroke care in India (Karthikeyan 2007, Pandian 2006a, 2007). Finally, traveling to reach care involves not only costs related to the action of traveling, but also opportunity costs for time spent away from work or the necessity for a second member of the household to accompany the ill-member.

Thus, in the sequence of access illustrated in figure 7.1 of the result section, we can see how there is a gap when linking all the dimensions of access for the poor living with chronic disease. Even if plans are made to scale up care for chronic disease through availability, acceptability and adequacy, access cannot be realized if they remain unaffordable or if people do not have the ability to reach and pay for them, let alone benefit from the care received. This is illustrated in the results section in table 7.2, where it can be seen that the bulk of barriers addressed are concentrated on supply side barriers.

In the literature review it was demonstrated how knowledge and awareness of physical and mental chronic diseases affects health-seeking behaviors and access. The impact that stigma and individuals' understanding of the origin of mental disorders have on utilization is recognized in the literature. The fact that many people in India have poor knowledge of what are chronic diseases such as diabetes and heart diseases is also detailed and the effect it has on utilization is also understood. Knowledge of chronic diseases does not only affect practitioners and the adequacy of care they provide, but also the population and their ability to seek care. Furthermore, going back to the organizational models for chronic disease management discussed earlier, it is clear that health literacy goes further than ability to seek appropriate care for chronic disease. Because of the nature of chronic diseases, it also means that poor patients must have self-efficacy in managing their own illness. Patients must have the capacity to participate in the management of their own disease and a strong support is necessary from primary care providers to help patients acquire skills (Beaglehole et al. 2008).

These results suggest that national health policies are targeting health literacy. Educating the population on lifestyles and non-communicable diseases is an instrument proposed in the content of national health policies. In addition, the NHP-2002 acknowledges the need to improve education and information strategies to reach more efficiently the illiterate masses. Finally, the pilot program on diabetes, CVD and stroke is based on the Rose theory and the WHO step-wise approach. It is divided into primary prevention and health promotion in schools, work places and community, and secondary prevention for high-risk groups. Increasing the capacity of the system to deliver knowledge is also a focus of this program.

Health literacy is critical to empowerment (Nutbeam 2000). As it was stated in the literature review, education and literacy influence health-seeking behaviors (Ensor et al. 2004). It influences the capacity of individuals to produce health, integrate health messages and is a basis for individuals to evaluate their needs and the best health-seeking strategies (Ensor et al. 2004). Moreover, functional health literacy is a skill that enables patients to apply health materials and prescriptions (Nutbeam 2000). Having a low functional literacy is a barrier for the system to educate patients with chronic disease.

Going back to the ideal primary care described by Beaglehole et al. (2008), it is clear that the lower health literacy of the poor can constitute an important barrier to access adequate care. In the chronic care model, prepared and pro-active teams interact with informed and activated patients (Bodenheimer et al. 2002). Self-management by patients is central. The fact that patients manage their own illness on a day-to-day basis is inescapable (Bodenheimer et al. 2002). By making

decisions every day on lifestyles, nutrition and their own medication, patients manage their own disease. For Bodenheimer et al. (2002), self-management can not only have a positive impact on the health of individuals but can also have positive economic impacts related to the population burden of chronic disease.

There are two ways in which self-management education is transmitted in primary care: in the traditional mode where information and technical skills are transmitted to the patient, and the self-management mode where problem-solving skills are also taught (Bodenheimer et al. 2002). These problem-solving skills touch the medical, social and emotional aspects of illness. Both modes complement each other and the result is typically an agreed action plan for the patient to take home. In addition, a major element for self-management is self-efficacy: the confidence of individuals to sustain the behaviors necessary to the achievement of their goals (Bodenheimer et al. 2002).

For the same authors, there are three main barriers to self-management education in primary care, which find echo in the current Indian scenario. The lack of adequately trained medical personnel in primary care centers, patients with chronic disease who have socialized in a more traditional setting of care and finally, insurance plans that don't support patients in their self-management activities at home.

The poor in India, having less education, face more challenges related to health literacy. As stated by Reddy et al. (2007), education is related to better health-seeking behaviors. The medical personnel in most settings of care are not readily equipped to deal with chronic diseases detection, let alone self-management education. Mental health literacy is also a challenge. A good proportion of the poor in rural areas will seek care from village doctors or faith-based providers who often end up prescribing inefficient treatments (Ganju 2000, Khandelwal et al. 2004). If mental disorders are acknowledged they are often not considered as real illnesses (Kermode et al. 2009). There is still a lot of stigma attached to mental disorders that affect individuals' utilization of health services (James et al. 2002).

Studies have also demonstrated that most patients with physical chronic diseases often fail to seek care to control their illnesses, even when care is free (Ajay et al. 2008). Most individuals suffering from chronic diseases such as asthma (Jindal 2007), diabetes (Bjork et al. 2003, Mohan et al. 2005) or stroke (Das, K. et al. 2007, Pandian et al. 2006b) lack knowledge about symptoms and do not understand the necessity of controlling their disease with regular monitoring, tests and follow-ups. At the same time, this research has also underlined that human resources, especially general providers, are not qualified to manage chronic diseases (Bjork et al. 2003, Karthikeyan et al. 2007, Ramachandran 2008b, Ramaraj et al. 2008). Studies, most notably on diabetes care (Bjork et al. 2003, Ramachandran 2008b, Joshi et al. 2008), have demonstrated that providers lacked comprehension on the necessity of monitoring and follow-ups. Therefore, the optimal team

of prepared medical providers and proactive and informed patients described by Bodenheimer et al. (2002) is far from reality in India.

The promotion and support of self-management in primary care, especially for poor patients, is not an issue that is prioritized so far by the government. Enormous investments must already be made and implemented. Nonetheless, it can be can argue that self-management should be better promoted in future policies addressing primary care.

9.4. Towards Integrated Policies to Improve Chronic Disease Care for the Poor in India

Linking Poverty and Chronic Disease

In 2005, the WHO has published a document entitled *Preventing chronic diseases: a vital investment* (WHO 2005) where one chapter was devoted to making the case for the existing links between poverty and chronic disease. The statements are clear. Poverty and chronic diseases are linked and these association run in many directions. Evidence of these associations has been established. The poor are affected by chronic diseases and the burden is highly concentrated within this group. In many industrialized countries, the prevalence of diseases such as diabetes and cardiovascular problems are concentrated in lower socioeconomic classes. Risk factors such as the use of tobacco and poor dietary habits have come to a reversed social gradient and are now more prevalent among the poor. For a long time, chronic diseases were seen as diseases of affluence, especially in developing countries where the choice of a westerner's lifestyle was the privilege of the better-off. However, numerous studies in India and other developing countries in recent years have corrected this misconception. They have demonstrated that the prevalence of risk factors of chronic diseases is high among the poor (Ramachandran et al. 2002, 2008c, Anand et al. 2007, Ajay et al. 2008) and that the poor do suffer from chronic diseases (Ramachandran 2002, Joshi et al. 2006, Reddy et al. 2007b). They also have increased exposure to undernutrition and unsanitary environments. These results suggest that this association is not firmly acknowledged by the national health policies.

Moreover, because of an increased exposition to risk factors and decreased access to health services, the poor are more vulnerable to chronic diseases. The poor have increased exposure on account of their limited means, living environment, psychosocial stresses and their limited ability to make healthy life choices. In addition, as a result of barriers to access, the poor also have a reduced exposure to medical advice and often wait for complications before resorting to care. This means that early diagnosis and its advantages are impossible. In these cases, the quantity of services needed is often bigger and the consequences on health and costs are greater. In many

instances, the poor will not be able to sustain access to health services for the lifelong treatments they might be requiring. This research has focused on barriers to access for the poor because decreased access is one of the factors making them more vulnerable to chronic diseases. This problem is even more serious in a health system like India, where access is already problematic for the poor. When access is realized, the care received is often inadequate as they often consume care from unqualified providers. But when they do seek care from qualified providers, the majority are not equipped nor do they have the appropriate knowledge to detect and manage diseases such as diabetes or mental disorders.

In addition, there is an interaction existing between poverty and chronic disease. The WHO states that not only does poverty make people more at risk for chronic disease, but these diseases themselves can draw people further into poverty. In general, the poor in India often have no other choice, but to forgo the care they need and this can cause tremendous consequences to their health. This often means that households might lose a productive income earner. In the majority of cases, when individuals do seek treatments, they will have to devote an important proportion of their income to out-of-pocket expenditures as the majority are not covered by insurance. This is catastrophic expenditure. What it implies is that some households will indebt themselves, some will have to sell productive assets and lose future income, while others will reduce the opportunities of younger members by reducing expenditure on schooling for example. Caring for the ill member for the rest of its life entails many costs and is especially dramatic if this member was the main income earner. In the long run, chronic disease care is a major financial burden and in the majority of cases, poor households will not be able to bear such costs over time. Hence, the poor are at risk of chronic diseases and when it strikes, it has the devastating potential to draw them further into poverty. For middle-income families, it can also mean to be easily impoverished as well.

Ultimately, for countries such as India, it can have a tremendous economic impact and even challenge the development of the country itself. A recent World Bank study (Mahal et al. 2010) makes the demonstration of the economic impact of non-communicable diseases in India. Bearing in mind that many chronic diseases like CVD strike at younger and productive ages in Asia and India (Jha et al. 2007, Reddy 2002) this means that the country will have to bear losses in productive life years (Reddy et al. 2007a). Non-communicable diseases can have an impact on the income of families and the productivity of the country, coupled by increased demands on the health system. For a country on the fast track to economic growth, chronic diseases have the potential to obstruct the future development of the country (Reddy et al. 2007a)

The Policy Response

Finally, the WHO calls for investments to prevent chronic disease in developing countries where a high proportion of the population lives in poverty. The WHO recognizes the vicious circle of poverty and chronic diseases and identifies the potential poverty alleviation impact of preventing chronic diseases

What is planned by national health policies in India? These results demonstrate that the poor are not linked to chronic diseases, except in one statement of the mental health program on "needy" patients. The poor are targeted, especially through the idea of strengthening primary care for more equity in access. But when tackling chronic diseases, national health policies seem to blend the poor's concerns in those of the general population. Policymakers are recently and slowly starting to react with initiatives such as the pilot program on diabetes, CVD and stroke or the national tobacco control program (Reddy 2007a).

National health policies must be credited for providing some planning for the dual task of strengthening the healthcare system, increasing public expenditures on health and scaling-up interventions for chronic diseases. This research showed that: (1) some gaps remain and that national health policies fail to address important barriers, such as the financial barriers to outpatient care; (2) that some of the proposals of national health policies either translate in a low involvement (encouraging private insurance without addressing market failures) or leaving many open questions (such as the regulation of the private sector); (3) national health policies do not significantly attempt to reach the poor with chronic disease interventions yet. (4) Notwithstanding these results, it was also seen that there are plans made in national health policies to increase expenditure, strengthen the whole health system, especially primary care, and the delivery of services in rural areas, as well as upgrading mental healthcare and scaling-up interventions for lifestyle diseases with more primary prevention and extending public services for diabetes and cardiovascular diseases. As entitled by Reddy et al. (2007a), India is "waking up" to the threat of chronic diseases and parallel to the pilot programs, initiatives such as tobacco control program are being implemented.

However, tackling the issues brought by the interaction of poverty and chronic diseases requires policy interventions that go beyond access to healthcare. Looking at the big picture, it can be observed that other policy actions are warranted, that investments and transformations required to tackle this complex problem are massive, and that ultimately this also falls outside the jurisdiction of the health ministry.

This perspective is clear when looking at Wagstaff's (2002) framework on the determinants of health outcomes (appendix 7). Health policies and actions made to reduce barriers to access are only one piece of the puzzle. Other sectors' macro-policies and regulations can affect the determinants of health outcome. Intersectoral actions on health are also raised by Murray & Frenk

(2000). Many health actions, as defined by these two authors, fall outside the realm of the health sector and increased intersectoral cooperation to influence other sectors are critical for better health outcomes. Going back to Wagstaff's (2002) framework and bearing in mind the risk factors of chronic diseases, it can understood how policies related to water and sanitation, nutrition or education for example, all represent distal determinants of health outcomes. Furthermore, the necessity for intersectoral actions becomes clearer when looking at abilities to access. For example, there is the education system's role on health promotion and ability to seek, the role of roads and infrastructures on ability to reach, or the role of employment benefits on ability to pay. Policies in other sectors can also aim at poverty reduction/ alleviation itself. Also, initiatives for health insurance for poor families such as the *Rashtriya Swasthya Bima Yojana* managed and designed by the ministry of labor and employment of India will complement policies coming from the health sector and can act on the economic impact of chronic diseases (Mahal et al. 2010). The fact that determinants of chronic diseases also lies in other sectors (pilot program on diabetes, CVD and stroke) and the role of inter-sectoral contributions on health (NHP-2002) is acknowledged to some extent by national health policies.

10. Conclusion

As it was seen throughout this research, poverty and chronic disease interact. The poor are more vulnerable to chronic disease and seeking care for these diseases has also the potential to push households further into poverty. Because of barriers related to the acceptability, availability, affordability or adequacy of services and their related individual abilities, decreased access is one factor explaining the poor's vulnerability to chronic diseases. In India, the prevalence of diseases such as diabetes, chronic respiratory problems or depression has been increasing rapidly in the last decade. An increasing number of studies has demonstrated the prevalence of major risk factor such as tobacco consumption or hypertension in the general as well as in the poor population. They have also demonstrated that morbidity and mortality are on the increase.

This happens at a time when the performance of the Indian health system is described as very poor. Modern and good quality care for chronic disease exists in India, but is limited to private facilities or specialized tertiary public hospitals in major cities. Hence, it is mainly available and affordable to the most affluent. The rest of the health system is mainly underfinanced, with a big unregulated private sector providing the majority of health services. The care that the poor usually have access to is not adequate. The role of primary care, in theory, is central to the optimal control of chronic diseases. However, throughout India and especially in rural areas, providers are not equipped to detect and manage these diseases.

The majority of the poor have untreated morbidities because they cannot access care on a regular basis for early detection or opportunistic case findings. Most will wait for major complications before resorting to care because of barriers to access. Authors have deplored the fact that the prevalence of complications among the poor was high for diseases such as diabetes, and that more money was spent on treating these complications rather than achieving optimal control. At this point, the risks of the further impoverishment of the poor are significant. This is especially significant in the perspective that they face lifelong treatments and medication, tests and follow-ups to control the disease or in the perspective of complications that require hospitalization. Poor households are mostly not covered by social protection or insurance, and have to pay for care directly from their income. This scenario only happens when health services are used.

For a long time, the problem has been neglected by health policies. Chronic diseases were seen as a problem of the urban rich. When looking at recent commitments of national health policies, it is clear that things are starting to change, at least on paper. The government has pledged to increase the healthcare budget and the proportion attributed to mental health. Furthermore, recent initiatives such as the pilot program for diabetes, cardiovascular diseases and stroke attests to these recent efforts.

The situation however can also be worsened by three important factors. First, as it was stated previously, this increasing burden of chronic non-communicable diseases has led to a situation of

double burden with infectious communicable diseases. As it was demonstrated in table 2 and 3 in the literature review, the top list of diseases causing the most mortality and morbidity is now composed of both types of disease. The composition of this burden has changed rapidly in the last decade and will continue to do so in the future. There is a challenge in transforming the health system to scale-up interventions for chronic disease without stopping to take actions to reduce the burden of infectious diseases as well as maternal and child mortality. This means a tremendous pressure on already scare resources. It also means careful planning at the center with the different states of the country as the epidemiological transition is not unfolding at the same rate across the country.

Second, as the population continues to age, the burden of chronic non-communicable diseases will continue to increase. The elderly are projected to outnumber the 0-14 group by 2019 (Chaterjji et al. 2008). The elderly in India represent a vulnerable economic group in the population, where as much as 40% of them live in poverty (Purohit 2003, Kapur Mehta et al. 2003). Hence, more actions to promote access and decrease barriers for the poor will be necessary as the burden of chronic disease can worsen the well-being of the poor elderly.

And third, as described in the literature review, the interaction of mental and physical health problems also has to be considered. There is “no health without mental health” as phrased by Prince et al. (2007). The increasing prevalence of physical non-communicable diseases has the potential to increase the prevalence of mental disorders, and vice versa. The mechanisms of these interactions are manifold and the danger for the well-being of patients is very real. Mental disorders must not be forgotten when talking about the need to improve access for chronic disease. To its credit, India has integrated mental health to its National Health Policy. Still, many of the gaps in barriers to access identified for physical non-communicable diseases are valid for mental ones. Even if mental health has been on the policy agenda for a longer period of time. Mental healthcare hasn’t been prioritized and it is not until recently with major legal battles that more attention has started to be paid and more resources promised to upgrade mental healthcare.

In light of this context, the purpose of this research was to investigate to what extent current Indian national health policies address the main barriers to access for the poor living with chronic diseases? More specifically, using qualitative content analysis, the goals, objectives, problems, targets and instruments of national health policies were examined to see whether they addressed this important question. This deductive method was based on a prior conceptualization of access, health system functions and the role of policy on access. From these conceptualizations, a literature review was completed to feed a framework of the problem (i.e. what are the barriers to access for the poor with chronic disease in India). This framework served as the basis for the content analysis using the framework approach of Ritchie and Spencer (1993).

This research also had three main objectives that have served to structure the analyses and results. For each objective, the main conclusions and policy implications are presented below.

Objective 1: Barriers Addressed

The first objective was to assess whether Indian national health policies, as they are formulated, are oriented in a way to address the barriers to access for the poor with chronic disease. These results suggest that a number of barriers to access are addressed.

The central government's efforts to upgrade the system, as planned in the content of its policies, must be acknowledged. Overall, the fact that the government recognizes the impact of years of low public expenditure and the fact that it pledges to increase financing must be recognized.

The main barriers that were identified as being addressed and which reflect a higher level of commitment from the central government were related to the need to strengthen the public system. More infrastructures of primary, community and specialized chronic disease care must be made available, existing ones must be upgraded and all must be staffed appropriately. The private sectors, both allopathic and traditional, must be regulated, but their participation must be sought also in upgrading the delivery of services to the population. Furthermore, the population must also be educated on emerging lifestyle diseases. On the financial side of access, the burden of hospital interventions for the poor is recognized and two financial schemes are devoted to this issue. But overall, barriers related to affordability and ability to pay are addressed by the variety of schemes to be studied and different forms of insurance that must be highly encouraged.

Hence, bearing in mind the framework of barriers to access for the poor with chronic disease, it is clear that the central government's focus is twofold. First, its focus is on the need to commit more public resources and increase investments on the health system, as well as strengthen and upgrade its core basis and broad availability. Second, the need to scale up interventions for chronic disease is addressed by improving the knowledge of the population and improving the management of chronic diseases by increasing the availability of specialized care and capacities for detection and management at all levels of the system.

On the other hand, these results also suggest two key policy gaps. To begin with, apart from instruments aiming to increase the knowledge of the population on chronic disease, most barriers addressed by policies are system-related. It means that (1) the poor’s capacity to seek care from qualified providers, (2) their capacity to pay for traveling and the modes of transport they select, (3) their ability to pay for health services, for outpatient care and for insurance and (4) their ability to benefit from care received for chronic disease are all barriers that are not addressed by national health policies.

Barriers that were not addressed so far should be given more attention in the future as new policies are formulated and current one renewed. This is the case especially in the perspective that primary care must be strengthened and can play a central role in chronic disease care and in ensuring a more equitable distribution of health outcomes in the population. It was demonstrated that the poor face barriers when they need to travel to reach care and often cost-related barriers are intertwined. When they need to access outpatient care, they often resort to private unqualified providers. A mix of reasons influence this choice, including the fact that traveling is required to reach public facilities that are judged to be of poor quality anyway and the fact that unqualified providers are available near their home, sometimes at a better price. In some cases, it is also understood as an investment to get better faster and go back to economically productive activities. Ability to seek and ability to benefit in a context of chronic disease will also be influenced by health literacy and self-management skills. Primary care providers can play a central role to support patients in acquiring those skills. Finally, there are numerous financial barriers that the poor can face when accessing outpatient care. Not only these barriers have to be given more careful attention, they must also be understood in terms of increasing costs for chronic diseases. For example, if risk pooling is pursued as a way to achieve more equitable financing, insurance products must be designed not only to overcome difficulties in reaching the poorest and those already sick, but also to support patients in the lifelong care they have to receive. The notions that treatments and medication for chronic disease are costly, that providers must be seen on a regular basis to achieve control of the disease and that patients must be supported to manage their own disease, all should be considered by the central government when formulating future policies or regulating the private sector.

Objective 2: Policy Levers

The second objective was to assess the types of policy levers and instruments identified in current national health policies to address the barriers to access in each dimension of access. A number of cautions and open questions were underlined in the result section. Even though increased financing is more than necessary for the entire healthcare system, it is not clear how this will accompany a capacity to channel new funds appropriately. Moreover, it is also stated in the literature (Peters et al. 2002) that healthcare financing is biased towards the rich and no particular stand was uncovered on how these policies plan to reach the poor with these new funds. Some policies also state that risk pooling must increase, that different schemes will be studied and that private and community insurance will be promoted and encouraged. How the usual market failures in reaching the poor will be addressed is an open question. Will the subsidies follow their way to address market failures is another question. The rural mission has planned subsidies for the poor

to pay for premiums. Nonetheless, for many authors, the regulation of the insurance market is inadequate and the coverage of any type of insurance is very low in India.

Furthermore, even though better regulation is planned, how this plan is to be achieved remains an open question. Many authors have described the regulatory structure and environment as completely disconnected from reality and inefficient in the current context. How will future health policy address this more thoroughly, especially in the perspective that the majority of poor go to the private sector for their primary care? If capacities for mental and physical chronic diseases will be harvested in the private sector and extended to all levels of care in the public sector, how this will be achieved is also an open question. Changing the way health services are provided, especially primary care services, is an important challenge that will require massive investments in resources. Primary care can play a central role in offering quality chronic disease management which can reduce the costs and health consequences of these diseases. However, as primary care is described in the literature, it is not currently equipped to do so. Furthermore, the poor face a variety of barriers in accessing primary care that will also have to be addressed for such investments to meet their objectives. Hence, the role of primary care regarding chronic disease will have to be planned in more details in future policies with instruments to alleviate barriers to access for the poor.

Overall many barriers addressed are formulated like objectives and few instruments are detailed to achieve these objectives. Thus, in the end, many open questions remain on how policies will regulate the private sector, increase capacities for the detection and management of chronic diseases, and strengthen primary care.

Objective 3: Timeline and Scope on Poverty and Chronic Diseases

And finally, the third objective was to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor. It was established with this transversal sample of policies that poverty and chronic disease care are not linked in the content of these policies and that the focus on chronic diseases is more recent. But even though this is correct for physical chronic disease, mental health has been on the policy agenda for a longer period of time. This is not to say that no policies in this sample target the poor with their various objectives and policy instruments. When the poor are targeted there is even a desire, most notably with the NHP-2002, the NRHM and the two financial schemes, to achieve more equity in access. For the most part, the poor are targeted when policies aim (1) to increase the availability of PHC, CHC and traditional medicine, (2) to cover the costs of hospital interventions, (3) to encourage community insurance and provide financial assistance for premiums, and (4) to improve mass education and communication strategies. But when national

health policies aim to scale up prevention of chronic disease, the poor's concerns are blended into those of the general population.

Future policies will have to acknowledge the fact that poverty and chronic disease are linked. They will have to recognize that the poor are more vulnerable to chronic diseases and they will have to acknowledge the potential of chronic diseases in causing impoverishment. National health policies' attention to chronic diseases is new. If future policies fail to acknowledge the interaction of poverty and chronic diseases, it could jeopardize the development of the country. Experts agree that the prevalence of various chronic diseases will continue to increase. As mortality declines, the population ages and as the prevalence of risk factors continues to increase, the burden of chronic diseases will increase as well and continue to add up to the burden of communicable diseases. The health and economic consequences of this are critical. Future health policies will have to see poverty as a determinant of chronic disease and chronic disease as a factor contributing to poverty.

In addition, addressing barriers to access for the poor must be a key component of a government strategy to prevent chronic diseases. However, barriers to access must also be understood as a whole. As it was laid out in this research, access involves many dimensions of health system and individual abilities that must be taken altogether. Barriers to access are found in all dimensions. Making sure that high quality chronic disease care is available in the country and that primary care providers are equipped to provide care for these diseases is insufficient to guarantee access if the poor face financial barriers in accessing this high quality care and that they end up consuming health services from an unqualified provider. There is a sequence to access and scaling-up interventions for chronic disease will be ineffective if access for the poor is not addressed in all its dimensions.

This research has looked at the content of Indian national health policies in order (1) to assess whether the goals, objectives, instruments and targeted populations, as formulated in current national health policies in India, address the main barriers to access health services for the poor living with chronic diseases, (2) to assess the types of policy levers and instruments identified in current national health policies to address these barriers to access and (3) to assess whether national health policies in India have improved over time with respect to ensuring chronic disease care to the population and more specifically to the poor. Without a doubt, more research at the policy level are warranted given the many levels, determinants, dimensions and dynamic process of policies. State level policy should be submitted through the same analyses. Policies formulation, agenda and ultimately the content are influenced by different determinants. Using existing theories in political sciences to understand which actors influence the content of policies is another important research that should be undertaken. Moreover, as it was asserted earlier, it will also be critical to have more evaluative research on the implementation phase and outcomes of these same policies.

Furthermore, the call has been made in this research, as well as in some of the policies that were analyzed, for inter-sectoral coordination and cooperation. It will also have to be the object of research as well. In the near future, some of the policies analyzed in this research will be renewed while new ones will also be formulated. This research represents an humble attempt to policy prescriptions for these future policies.

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12. Appendix

Appendix 1 – Analysis tools: Index Scheme

1. Health system division:

    1.1. Mental healthcare
    1.2. General/physical healthcare

2. Health policy element (to classify the structure of the document):

    2.1. Problem
    2.2. Social goal
    2.3. Instrumental goal
    2.4. Objectives
    2.5. Instruments

3. Governance (by whom)

    3.1. Central government
    3.2. State government
    3.3. District government
    3.4. Local government
    3.5. Pachayati Raj Institutions
    3.6. Medical institution
    3.7. States / district where the program / policies is presence
    3.8. States / district where the program / policies is absent

4. Actions planned

    4.1. …Modify
    4.2. …Ameliorate / Improve
    4.3. …Increase
    4.4. …Decrease
    4.5. …Correct imbalances / inequalities
    4.6. …Decentralization
    4.7. …Targeting a group
    4.8. …Coverage of…..
    4.9. ….Not covering / Not admissible / Excluding

5. Service provider

    5.1. Utilization of…
    5.2. Public
    5.3. Private
    5.4. Public-private partnership
    5.5. Traditional healers / Ayush / alternative system of medicine
    5.6. NGO

6. Health system functions

- 6.1. Financing
  - 6.1.1. Public expenditure
  - 6.1.2. Low level of …
  - 6.1.3. External financial assistance (donor).
  - 6.1.4. Financial assistance to programs
  - 6.1.5. Remuneration methods
  - 6.1.6. Costs
- 6.2. Resource generation
- 6.3. Stewardship
  - 6.3.1. Regulation
    - 6.3.1.1. Price of services
    - 6.3.1.2. Quantity of services
    - 6.3.1.3. Quality of services
  - 6.3.2. Regulation over the private sector
  - 6.3.3. Ethics in care delivery and public health
  - 6.3.4. Ethics in research
- 6.4. Service delivery
  - 6.4.1. Personal
    - 6.4.1.1. Interpersonal health service
    - 6.4.1.2. Referral system
    - 6.4.1.3. Local capacities to detect and treat chronic diseases / early diagnosis
    - 6.4.1.4. Local capacities to apply treatment protocol and guidelines for chronic diseases
    - 6.4.1.5. Ability to follow-up patients
  - 6.4.2. Non-personal
    - 6.4.2.1. Research
    - 6.4.2.2. Evaluation and monitoring
    - 6.4.2.3. Disease surveillance
    - 6.4.2.4. Prevention and control of diseases
    - 6.4.2.5. Health promotion
    - 6.4.2.6. Information and education communication (IEC)
    - 6.4.2.7. Public health interventions – hygiene and sanitation
  - 6.4.3. Inpatient care / hospitalizations / surgical interventions
  - 6.4.4. Administering treatments
  - 6.4.5. Administering drugs
  - 6.4.6. Health investigation
  - 6.4.7. Outpatient / ambulatory care
  - 6.4.8. Primary health care
  - 6.4.9. Community healthcare
  - 6.4.10. Secondary healthcare
  - 6.4.11. Tertiary healthcare / specialized care
  - 6.4.12. Community care / participation
  - 6.4.13. Responsiveness of the system

7. Access
   - 7.1. State of…
     - 7.1.1. Problems in …
     - 7.1.2. …As an instrumental goal
     - 7.1.3. Universal access

- 7.7.4. Drugs
- 7.7.5. Essential medicines
- 7.7.6. …According to different schedules (Time-availability)
- 7.7.7. …Specialized care and treatments for chronic diseases on care site
- 7.7.8. …Specialized medicines for chronic diseases on care site

7.8. Acceptability
- 7.8.1. Socio-cultural sensitive services

7.9. Ability to Seek
- 7.9.1. Perceptions on the availability of services and treatments
- 7.9.2. Knowledge and awareness
  - 7.9.2.1. …On chronic diseases origins and gravity
  - 7.9.2.2. …On the importance of seeking diagnosis and treatment for NCD
- 7.9.3. Ability to seek diagnosis and treatments for chronic diseases

7.10. Adequacy
- 7.10.1. Quality in interpersonal services
- 7.10.2. Quality in infrastructures and availability of medical supplies
- 7.10.3. Bad quality in health services

7.11. Ability to benefit
- 7.11.1. Perceptions on the quality of services
- 7.11.2. Benefit from utilization of public services
- 7.11.3. Benefit from utilization of private services
- 7.11.4. Benefit from care sought for chronic diseases

8. Diseases
- 8.1. Mortality
- 8.2. Morbidity
- 8.3. Major / serious illness
- 8.4. Disabilities
- 8.5. Chronic diseases /Non-communicable diseases / lifestyle diseases
- 8.6. Chronicity of disease / chronically illed
- 8.7. Arthritis
- 8.8. Angina / Cardiovascular diseases / heart diseases
- 8.9. Asthma / chronic lung diseases
- 8.10. Depression
- 8.11. Schizophrenia / psychosis
- 8.12. Diabetes
- 8.13. Communicable diseases
- 8.14. Risk factors / behaviors / health determinants
- 8.15. Epidemiological / demographic transition

9. Target populations
- 9.1. The poor
  - 9.1.1. Below the poverty line
  - 9.1.2. Relative poverty
  - 9.1.3. Absolute poverty
- 9.2. Vulnerability
- 9.3. Inequalities
- 9.4. Catastrophic costs and expenditure
- 9.5. Rural
- 9.6. Urban

Appendix 2 - Analysis tools: Policy Map Template

Table 12. 1: Policy Map Template

NAME OF POLICY DOCUMENT	
Name of coder and Date:	
Policy date: Policy content: Goals and objectives : Instrumental goals:	
Health system functions	
Financing and resource generation	
Stewardship .	
Service provision	
Access	
Acceptability	Ability to Seek
Geographic and organizational availability	Ability to reach
Affordability	Ability to pay
Adequacy	Ability to benefit
Unexpected themes:	

Appendix 3 – Analysis tools: Question Grid Template

Table 12.1: Question Grid Template

QUESTION GRID	
Name of the policy:	
Name of the coder and date:	
Question	**Answer & Instruments**
1. What are the main objectives and goals of the policy?	
2. Overall, does the policy target the poor and chronic disease?	
3. How public expenditure on health is approached?	
4. Are the higher costs associated with chronic disease and the ability of the poor to pay for chronic care addressed?	
5. Are out of pocket payments, catastrophic costs, distress financing and low coverage of social protection/insurance, and the related ability of the poor to pay for health services addressed?	
6. Is the geographic availability of services addressed?	
7. Is the physical availability of specialized care and services for chronic disease addressed?	
8. Is the organizational availability of drugs and treatments addressed? Specifically for chronic disease?	
9. Is the organizational availability of health human resources addressed?	
10. Are the local capacities in detection, treatments and management of chronic disease addressed? Its improvements at all levels of care?	
11. Are quality problems in the public and in the private sectors recognized? Is quality planned as an instrument?	
12. Is the regulation over price, quantity and quality addressed? Is the need for regulation over the private sector addressed?	
13. Is the system responsiveness to the socio-cultural sensitivity of services addressed?	
14. Is the knowledge and awareness about chronic disease and the important to seek care for chronic disease addressed?	
15. Are the patterns of utilization of health services by the poor addressed?	
Notes:	

Appendix 4 - Case studies

National Health Policy - 2002

Context, Objectives and Instruments

The National Health Policy 2002 (NHP-2002) is the second national health policy in India. This policy gives the vision and sets the priorities for the whole health system. The 1983 policy was reviewed in 2000, and new goals and objectives were set in place for 2015. The main goal of the NHP-2002 is *"to achieve an acceptable standard of good health among the general population of the country"*. Compared to the 1983 policy, the current policy announces that its vision is now more reasonable, with more achievable objectives given the level of available resources. The document is divided into on the current scenario of the health system, goals and objectives, instruments related to each problems raised in the scenario section and a final summary of the document.

The National Health Policy is also seeking to "*maximize the broad-based availability*" of health services, especially at the primary level for a more equitable access. The NHP recognizes equity problems in regards to access and acknowledges the disparities existing between rural and urban settings and between the different states. Furthermore, the policy also recognizes the need to redefine the roles of the center and the different states regarding the health system, to allow for more flexibility on local issues. In this perspective, the role of the *Panchayati Raj*[7] institutions is also planned to be more important in the future.

The thirteen instrumental goals of the NHP-2002 are: to eradicate polio and yaws; eliminate leprosy; eliminate kala azar; eliminate lymphatic filariasis; achieve zero level growth of HIV-AIDS; reduce by 50% mortality due TB, malaria and vector and water borne diseases; reduce the prevalence of blindness by 0.5%; reduce maternal and infant mortality by 30/1000 and 100/100000; increase the current level of utilization of public services to 75%; establish an integrated system of surveillance, national health accounts and health statistics; increase public expenditure on health to 2% of GDP; increase central government grants to take 25% of health spending and finally; increase the state expenditure on health to 7% of their budget. These instrumental goals are set for 2015.

The NHP-2002 addresses many problems and numerous instruments are. Overall, the policy addresses the issues of low financing and resource generation through user fees; equity in access; availability of health services infrastructures and quality of public services; utilization of private services and the need for regulation over that sector; availability of health professionals and the

quality of their services, especially in the family medicine, public health and nursing professions; availability of medicines, generic drugs and good quality traditional medicines; urban health problems; mental healthcare services; research, health statistics and surveillance gaps; NGO's for service delivery; ethics in service delivery and research; women's health; globalization impacts and TRIPS agreements; and environmental and occupational health problems. The policy also discusses population stabilization and the need for inter-sectoral cooperation on health, even though it admits that these two issues are beyond the scope.

Due to the broad spectrum of the NHP-2002, many dimensions of access are included in the policy. Improving access of vulnerable individuals is among the objectives set by the policy. However, chronic diseases are little present in the content of the NHP-2002.

The policy does not address fully physical chronic diseases, as they are mentioned only occasionally throughout the document. One instance is at the beginning of the document where an increase of life-style disease is acknowledged. The policy states that: *"…seen an increase in mortality through 'life-style' diseases diabetes, cancer and cardiovascular diseases. The increase in life expectancy has increased the requirement for geriatric care."* What is planned for non-communicable diseases is to improve research, surveillance and health statistics, as well as the promotion of healthy life-style. Hence, the focus on non-communicable diseases in the NHP revolves around the need for better health statistics and health education. On the other hand, mental health is integrated in the NHP-2002. The policy recognizes that communicable diseases are still predominant, and in this perspective, the relative priority of diseases is dictating the amount of resources given. In this light, it is important here to underline the absence of chronic disease among the thirteen goals of the NHP-2002.

The poor as a group are targeted in some elements of the policy. This is a broad policy and concerns all the citizens. Some elements, most notably the improvements and increase in availability of primary care, are planned to favor a more equitable access of vulnerable groups (including the poor). On the utilization of health services by the poor, there is recognition of the importance of public services for this group and of the need to improve PHC and CHC to improve equity in access. However, even if improvements and increase in public services are planned, many actions involving the private sector are present in the policy.

Health System Functions

Even though non-communicable diseases are not at the center of the NHP-2002, given its role of orienting the whole health system, many of the dimensions involved in the more general

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[7] Raj means government / rule. The *Panchayati Raj* is a local governing body in India with three units of administration: village, block and district levels.

conceptualization of access are addressed. All of the system functions are addressed by the policy: financing and resource generation, the provision of services and stewardship. And through these functions, the NHP-2002 intervenes on the different dimensions of access.

The low level of public expenditure and the consequences it has on quality of public services is one problem recognized by this policy. Increase in public expenditure, decentralization and better management of funds are all planned to improve the geographic and organizational availability of quality of public health services. As far as resource generation goes however, the component present is related to user fees in the private sector only.

The NHP-2002 aims at the improving the provision of health services: health promotion , inter-personal and curative services. One concern raised by the policy is the need to improve of health education and IEC to effectively reach the all groups in the population, composed of a good proportion of poor and illiterate.

Stewardship over the system is also a concern of the NHP-2002. The need for regulation over price, quantity and particularly quality, is raised by NHP-2002. The need to increase health statistics on private care utilization for a better regulation over the system is one element present in the content. Stewardship over the health system and current needs to improve ethics in research and medical practice are also a major component of this policy.

Geographic Availability and Ability to Reach

Regarding geographic availability of health services and the ability to reach, problems of inequality between urban and rural regions, as well as isolated and underserved areas are recognized. Increase in the number of infrastructures at the PHC and CHC levels in rural settings, as well as PHC is urban settings, are planned to improve access for vulnerable groups.

One section is focused on urban settings and the particular problems of availability for slums dwellers. The policy indicates that problems of geographic accessibility of services forces slums inhabitants to resort to private care though out-of-pocket expenditure: *"…such unplanned habitations, forcing people to avail of private health care through out-of-pocket expenditure."* Furthermore, the need to increase the geographic accessibility and availability of trauma services in view of the constant increase in urbanization and road injuries is also raised by the NHP-2002 urban health section.

Hence, the policy focus on the geographic availability of services is to improve the geographic accessibility of primary and secondary care for vulnerable groups and underserved regions.

Organizational Availability and Ability to Seek

The availability of drugs is addressed through the need for generic, cost-effective and locally adapted technologies. The policy underlines the importance of locally manufactured drugs and the need to sustain this industry in India. Research and actions are planned in this direction. Furthermore, the NHP-2002 recognizes the importance of the costs and acceptance alternative medicines for the poor, underserved and tribal regions. The policy acknowledges this as a venue to improve availability of medicines for these target populations. On the other hand, the availability of drugs specifically for chronic diseases is not present in the content.

The availability of human resources in the health sector is one of the main focuses of this policy, both for physical and mental health services. Problems of availability and the varying quality in inter-personal services in the public sector are addressed. What is planned for is to improve availability and simplify access to education, as well as focus on underrepresented and emerging disciplines (family medicine, geriatrics, public health, genomics, nursing, etc.). There is a special focus on the public health and family medicines disciplines, with one section of the document dedicated to this gap in availability. Mandatory posting in rural areas, traditional practitioners in allopathic medical centers and using private human resources in public infrastructures are other instruments planned to palliate to problems.

There is no content specifically on the availability of services for physical chronic disease. The need to increase availability of medical expertise in emerging fields, including geriatrics is addressed. The need to improve the referral linkage is addressed, and this component can be critical in cases of complications and acute interventions. But the availability of an integrated infrastructure of services for physical chronic diseases is not an issue raised by the NHP-2002. What is present in the NHP-2002 in this dimension concerns mental health services.

Thus, on the present capacities for detection and management of chronic disease at all level of care, all the content is on mental health. The need to improve capacities for mental health among physical health practioners at all levels of care is the main instrument present in the policy to improve availability. The policy states that: *"…The program outline for such a disease would involve the diagnosis of common disorders, and the prescription of common therapeutic drugs, by general duty medical staff".*

Acceptability and Ability to Seek

In the NHP-2002, emphasis is put in the need to increase knowledge about mental diseases to decrease stigma and favor access of the mentally ill. Furthermore, the NHP-2002 recognizes the need for health promotion of healthy behaviors and acting to reverse the trend on non-

communicable diseases. And as mentioned earlier, the NHP-2002 also recognizes the need to improve health promotion methods to effectively reach all subgroups of the population, including those with less education. Though these concerns, the NHP-2002 is planning to improve the knowledge and awareness of the population, hence their ability to seek effectively health services.

Concerning acceptability, the NHP-2002 contains one section specific to women's health. The NHP-2002 recognizes the vulnerability of women and their socio-cultural barriers to access The NHP-2002 plans to improve access of women to primary care, with more programs focused on women's health and review staffing norms to include both males and females doctors in primary health centers. In regards to mental health services, the policy does underline the important of faith-based access patterns, where individuals see mental disorders as spiritual diseases and seek care through unqualified providers, often worsening the health status of mentally ill individuals who are often in need of more serious medical attention.

Adequacy and Ability to Benefit

The NHP-2002 recognizes problems of quality in public services. As mentioned earlier, the NHP-2002 acknowledges that the low level of financing has caused a degradation of services in the public sector. Increased public expenditure is planned to improvement in the quality of infrastructures and the availability of services of both general and mental healthcare. Improvements and an increased availability of medical education are planned to improve the availability of human resources in various medical fields.

Upgrading psychiatric wards of general hospitals and mental hospitals is also a focus of the NHP-2002. The quality of mental health services is a central concern of the policy, with the respect of human right as a main motivator.

Affordability and Ability to Pay

The ability of the poor to pay for health services and the financial consequences of utilization are addressed by the policy in particular ways. What is recognized is the link between private care utilization, out-of-pocket and catastrophic expenditure: *"…This is despite the fact that most of these patients do not have the means to make out-of-pocket payments for private health services except at the cost of other essential expenditure"*. The same issues are not linked to public service utilization.

The policy acknowledges the fact that the poor need public services and those pressures on the system are important. To relieve these pressures, there is a plan to encourage the use of private secondary and tertiary care for those with the ability to pay. Also, social protection is to be

examined under a scheme where public social protection could be provided for private care utilization. All of this even if increase in utilization and improvement of public services is among the main goals of the NHP-2002. Increasing the availability of private assurance schemes is also an instrument planned. The policy underlines in this perspective, the sheer number of poor in the country and the difficulty of having an exclusive government mechanism to provide affordable services to all citizens.

On the other hand, the higher costs involved with chronic disease is not addressed. Higher costs involved with treatments and the financial consequences of these diseases are not raised. However, the NHP2002 brings attention to one issue that was not covered by the original conceptualization of the problem. TRIPS and globalization could have a devastating impact on the price of drugs and technologies. Thus, when the policy argues for more generic drugs, cost-effective and low yield technologies, this can be acting directly on the affordability of expensive treatments and medicines for chronic diseases. Still, the particularities of chronic diseases, its impact on the affordability of acute interventions or regular visits and monitoring with a health professional are not expressly addressed by the NHP-2002.

Summary

Overall, there is some correspondence between the NHP-2002 and the barriers to access chronic disease care for the poor. Physical chronic diseases are not one of the main focuses of this policy. Mostly, mental diseases are addressed through improvement in quality, availability of staff, capacities in general care and the need to increase knowledge and awareness among the population. However, by planning action to improve the public system's quality and availability; the content of the NHP thus addresses some of the barriers affecting the poor individuals' access to care. The twist that physical chronic disease bring on access, the costs of these diseases and the re-orientation needed to generate system of chronic care are not parameters raised in the NHP-2002.

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Rashtriya Arogya Nidhi

Context, Goals and Objectives

The Rashtriya Arogya Nidhi is a financial scheme addressing the poor's ability to pay for interventions in government super-facility hospitals. Because of the specific objective of the scheme, other parameters of access are not addressed. The main objective of the scheme is to *"provide for financial assistance to patients, living below poverty line, who are suffering from major life threatening diseases, to receive medical treatment at any super specialty hospitals / institutions or other government hospitals."* The scheme functions as a one-time grant to the medical institution where care is given. The financial scheme is divided in objective, target population, coverage and technical guidelines for the management of funds.

The Rashtriya Arogya Nidhi was modified and renamed in 2003. Previously, the scheme was named the "National Illness Assistance" fund and was originally enacted in 1996.

The Rashtriya Arogya Nidhi is a periodic financial assistance for specific interventions in government hospitals (including cardiac surgery and cardiology, orthopedic and various health investigations). In the policy, a list of interventions covered is provided; but as the funds are managed by the medical institutions the policy allows for other interventions to be included. However, being periodic, this means that the scheme but excludes long term treatments and recurring costs.

Health System Functions

The Rashtriya Arogya Nidhi is acting on financing to facilitate the poor's access to interventions for life-threatening diseases in government hospitals. Through financial assistance, the scheme acts on the affordability of government hospital services and the ability of the poor to pay for these services.

Geographic Availability and Ability to Reach

These dimensions are not addressed by the financial schemes. However, in terms of geographic availability it is important to point that the Rashtriya Arogya Nidhi is not yet available in all states. The states of Assam, Manipur, Himachal Pradesh, Meghalaya, Orissa, Punjab, Uttar Pradesh, and Nagaland have not set up the financial scheme to replace the old National Illness Assistance fund.

Affordability and Ability to Pay

The Rashtriya Arogya Nidhi targets the poor for treatment of major life threatening diseases in government super-facility hospital. By the nature of interventions covered, the scheme includes chronic disease care for the poor. However, the scheme excludes long-term and recurring costs associated with chronic disease care. Recurring costs of treatments, follow-ups and medicines can represents an important toll on poor households, especially given the higher costs of chronic disease treatments. The scheme does not address this issue. Furthermore, indirect costs involves with utilization are also not considered by the scheme.

Health Minister's Discretionary Grant

Context, Goals and Objectives

The Health Minister's Discretionary Grant is another financial assistance scheme, also focusing on the poor's ability to pay for interventions in government hospitals. The Health Minister's Discretionary Grant has for objective: *"Financial assistance up to a maximum of Rs 20 000 is available to the poor indigent patients from the Health Minister's Discretionary Grant to defray a part of the expenditure on hospitalization/treatment in Govt. Hospitals in cases where free medical facilities are not available."* This financial scheme is divided into objective, target population and technical guidelines for the management of funds.

The minister's grant has been active for more than two decades. Again, by the nature of the interventions covered, interventions for chronic disease are included. The minister's grant covers the fees for intervention in government hospitals, and thus indirectly chronic diseases are included. The document dates back to a time when non-communicable diseases were not prioritized, and especially not recognized as a major health problem among the poor.

Health System Functions

As it is the case for the Rashtriya Arogya Nidhi, the Health Minister's Discretionary Grant is acting through the financing of health services. With one time grants up to 20000 RS, the schemes acts on the parameters of affordability and ability to pay.

Affordability and Ability to Pay

The coverage of the Health Minister's Discretionary Grant is similar to the Rashtriya Arogya Nidhi. The Minister Grant is a periodical financial assistance for treatments received in government hospitals where free care does not already exist. Hence, this financial scheme acts on the affordability of public hospital services and the poor's ability to pay. In the same way, the minister's grant also covers part of the financial burden imposed to households y chronic disease. However, the scheme does not cover long term treatments and recurring costs, as well as other indirect costs of utilization.

The minister's grant is periodic and excludes recurring costs, where: *"Prolonged treatment involving recurring expenditure is also not admissible under rules…".* However, its does allow for exemption to be studied in providing assistance to poor chronically ill patients: *"…giving relief to poor and needy chronic patients, suffering from, T.B, Leprosy, **etc**., and to the blind and disabled…".*

This statement present in the policy is vague but could allow for the interpretation that poor chronically ill patients from other diseases, such as diabetes, could be eligible.

Summary: Two Financial Assistance Schemes

Altogether, these two schemes focus is on the affordability and ability to pay for the poor for interventions in government hospitals. Thus, they can assist the poor for acute interventions and health investigations related to chronic diseases in public hospitals. These two schemes have precise objectives and do not target the other dimensions of access. Overall, the schemes content are mostly about management structure and technical guidelines for the funds. Both schemes are silent on the financial assistance needs of mentally illed patients.

National Rural Health Mission

Context, Goals and Objectives

The main goal of the National Rural Health Mission (NRHM) is to improve the structure the health system and the management of programs in rural areas. The mission aims at modifying the "*basic architecture of healthcare delivery*" in rural areas and decentralizes management to be more flexible and adapted to local settings. The mission aim is thus set to improve primary and community health services in rural areas, with a special focus on vulnerable and north-eastern states.

The mission was enacted in 2005. The document is divided into a preamble, statement on problems, objectives and goals, ten policy components where instruments planned are elaborated, the various institutional roles, management structure of the mission and technical guidelines, a timeline for the mission and objectives at the national and the community level. The main problems identified by the mission are reduction and current low levels of public financing on health; lack of community ownership of services and participation; regional and inter-class inequalities in access; low coverage of insurance and risk pooling mechanisms; and catastrophic health expenditure.

The Rural Health Mission is composed of seven distinct goals: to reduce maternal and infant mortality; to achieve universal access to public health services; act on the prevention and control of communicable and non-communicable diseases; improve the architecture and access to an integrated system of primary health services; increase population stabilization with gender and demographic balance; revitalize local traditions and mainstream Ayush; and promote healthy life-styles. Hence, related to these goals, the mission document provides objectives at the national and community level. At the national level, the objectives are: to decrease child and maternal mortality; decrease mortality due to communicable diseases; improve service delivery at the CHC level; increase the utilization of the referral system; increase the presence of the ASHA female voluntary workers. At the community level, the mission' objectives are: to increase the availability of human resources; ameliorate the quality of health services at the PHC and CHC levels; improve access to immunization; improve service delivery and access of people below poverty line to referral services; increase the availability of community insurances schemes by voluntary organizations; increase availability of toilets at the household level; increase outreach of services.

The ten component of the mission, where instruments are planned for the above listed goals and objectives are: the accredited social health activists; strengthening sub-center; strengthening primary centers; strengthening community heath centers for first referral; a district level health plan; converge hygiene and sanitation into the rural health mission; strengthening disease control

program; public-private partnerships for health goals and regulation of the private sector; new health financing mechanisms; and re-orienting medical education.

For the most part and as it is the case for the NHP-2002, non-communicable diseases are planned though the need for health education on healthy behaviors and risk factors. As it is stated at the beginning: *"Developing capacities for preventive health care at all levels for promoting healthy life styles, reduction in consumption of tobacco and alcohol etc."* Notwithstanding the goal of prevention and control of both communicable and non-communicable diseases, content on non-communicable is limited to this throughout the document. Chronic diseases are not found among the outcomes planned by the rural health mission, even thought they are previously addressed as a goal. Furthermore, mental health in rural areas is not a focus of the NRHM. Increase in prevention and control of non-communicable diseases at the PHC and CHC levels is only planned for in one section in cases of available financing: *"In case of additional Outlays, intensification of ongoing communicable disease control programme,* ***new programmes for control of non-communicable diseases****, upgradation of 100% PHCs for 24 hours referral service, and provision of 2nd doctor at PHC level (I male, 1 female) would be undertaken on the basis of felt need."*

The poor as a group, as well as other vulnerable groups like women and children are often the main targeted group. Improvements of availability of quality health services for rural areas, the poor, women and children are central to the NRHM. The mission also has a focus on eighteen vulnerable states and the north-eastern states.

Health System Functions

As it was the case for the NHP-2002, the low level of public expenditure is one of the main problems addressed in the policy. Its consequences on availability and the quality in public services are raised. What is planned for is an increase in public expenditure from the center, to the states and the districts, as well as a decentralization of funds. The provision of curative, interpersonal and health promotion services are at the center of the Rural Mission and its goal of modifying the architecture of the health system in rural areas. Regulation over the quality and price of private and public services is addressed.

Geographic Availability and Ability to Reach

On the geographic availability of services, the focus is obviously on improving availability of infrastructures in rural areas, and especially in poor and remote regions. There are instruments planned for mobile outreach, mobile accredited female workers and public-private partnerships to increase the geographic availability of health services.

The improvement of the referral system and the assistance to the poor in cases of referral for maternal health are two instrument plans. *"Improved facilities for institutional delivery through provision of referral, transport, escort and improved hospital care subsidized under the Janani Suraksha Yojana (JSY)[8] for the Below Poverty Line families".*

The mission thus aims at improving the availability of service infrastructures in rural areas and indirectly, the ability of rural dwellers to reach these services. The focus being on the rural healthcare, instruments planned are for improvements of PHC and CHC. The availability of specialized care for chronic diseases however is not addressed by the NRHM.

Organizational Availability and Ability to Seek

Regarding organizational availability, the mission raises the issues of availability of medicines and of human resources.

The availability of a qualified medical workforce in rural areas is one of the main problems raised by the mission. The main component is on the training and the operationally of female accredited health workers that would provide basic services and education to local rural populations. The problems in availability of medical professionals are also addressed through medical education and the need to integrate rural issues. The provision of male multipurpose workers and including Ayush practioners in allopathic centers are also other instruments planned. However, there is no content in the mission's document on capacities to detect, treat and manage chronic diseases among the rural providers.

The availability of generic and traditional medicines is addressed by the policy. What is planned for is to ensure adequate supply of essential medicines in centers and to the accredited female health workers. Both the availability of generic allopathic medicines, as well as mainstreaming traditional medicines is planned. However, the need to increase availability of drugs and treatments in rural areas specifically for chronic disease is not addressed. Along the same lines as the NHP2002, the mission document also underlines the need for generic drugs as an instrument to improve the availability and affordability of medicines.

Acceptability and Ability to Seek

The current gap in the population's knowledge on chronic disease is addressed by the mission. Through improvements in health promotion for healthy life-styles and the development of capacities on prevention by the health workforce, the mission can affect the rural population's ability to seek.

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[8] Centrally sponsored scheme, replacing the National Maternal Benefit Plan. The objective is to assist pregnant women aged <19 and below poverty line, and increase the number of institutional deliveries.

Regarding the acceptability of health services, there is only one instance where the NRHM approaches this dimension. In one sentence, the mission confirms the importance of staffing norms and the need to have males and females physicians in primary centers: "…*and provision of 2nd doctor at PHC level (I male, 1 female) would be undertaken on the basis of felt need…".*

Adequacy and Ability to Benefit

The quality of rural health services is among the chief concerns of the Rural Health Mission. Improvements in the quality of infrastructures and inter-personal services are two instruments planned on the adequacy of health services and indirectly the ability of individuals to benefit. The regulation of public and private sectors to increase quality is also an argument in the NRHM. Finally, one major instrument planned by the NRHM is decentralization to increase the responsiveness of the system and adapt services to local issues. The mission vision is to give more flexibility to program management by local governing bodies, to insure the adequacy of health services to health problems and needs of local populations.

Affordability and Ability to Pay

What is addressed on ability to pay is on risk pooling mechanisms for the poor. The mission plans to examine different risk pooling mechanisms, improve community schemes and financial assistance to the poor to pay for their premiums. The focus is on risk pooling but there are little mentions of the current low coverage of insurance in India and the different problems associated. However, the need to assist poor individuals for premiums is raised: *"The Central government will provide subsidies to cover a* ***part*** *of the premiums for the poor, and monitor the schemes."* This statement is not further detailed in the mission's document. Furthermore, as detailed earlier, financial assistance in case of referral is for obstetric cases.

On the other hand, user fees, catastrophic payments and distress financing, the higher costs associated with chronic diseases, the impact of indirect costs are also absent.

Summary

Overall, the NRHM content is oriented towards some of the dimensions of access to care for poor individuals with chronic diseases. Through improvements of regular health services, their quality, affordability and availability, the NRHM content's has the potential to act on the improvement of access to care for the poor. However, as far as chronic disease goes and the additional complications it brings to the problem of access, this issue is not fully addressed. There is no

content in the NRHM on current capacities for the management of chronic diseases and the special vulnerability of the poor when facing these diseases. The NRHM recognizes the existence of these diseases and but the focus is on health education and surveillance.

National Mental Health Program

Context, Goals and Objectives

Mental health is integrated into general health planning as part of the NHP 2002. In this perspective, the mental health program is a more detailed planning on mental healthcare. It is adjusted for each five years planning. The first national mental program was elaborated in 1982, but the current policy, whose content was analyzed, was for the 10th development plan (2002-2007). The Mental Health Act for the rights of mentally ill patients was enacted in 1987 and has contributed to the advancement of the rights of mentally illed patients.

The mental health program's main goal is to improve mental healthcare delivery. The main objectives are to: increase in the availability of care within communities; improve access to services; reduce stigma and improve the rights of mentally illed patients; and increase in the coverage of the district level plan. The district level plan was elaborated in 1996 and integrated with the 9th development plan. It is extended into the present mental health program. The mental health program is currently being revised for the 11th development plan (2007-2012).

The document is divided into background information, goals, objectives and instruments, the district level program, and technical, monitoring and financial guidelines. The program also underlines the work of the National Human Right Commission in reviewing the state of mental health services in India and has formulated recommendations on that basis.

Instruments are planned in five divisions: expansion of the district mental health program; strengthening and modernizing mental health hospitals; upgrading psychiatric wards in general hospitals and medical college; information, education and communication strategies; and research and training in mental health.

The focus is this policy is mental health. On the other hand, the program is silent about patterns of utilization of the poor and the use of faith-based traditional care for mental disorders.

The poor as a group are not specifically targeted by the program, except for one segment on the needy mentally ill patients and their families at the: *"District Mental Health Team will be expected to provide service to the needy mentally ill patients and their families as follows :…Daily out patient service, ten bedded in-service facility, referral service, liaison with primary Health Centre, provide follow-up service & also community survey is feasible. Also remove stigma of mental illness by creating awareness in the community."* In this segment the policy refers to the needy patients and their family. However, this statement limited. The poor are not defined clearly and the instruments planned for the teams to provide services are not exposed. The statement only specifies that the district team is expected to provide services.

Health System Functions

Problems related to the low level of public expenditure are recognized. Increased public expenditure to improve quality and availability of mental health services is planned. The program also aims at modifying the structure of mental curative and inter-personal services, as well as information and education communication. And stewardship over the system, for both quality and respect of human rights is planned in the content of the program.

Geographic Availability and Ability to Reach

As mentioned earlier, an important component of the national mental health program is to increase the mental health services within communities. Along with an increase in the number of infrastructures at all levels of care, these instruments can favor of the geographic accessibility of mental health services and the ability of poor individuals to reach these services. Integrating services within communities is planned as a way to favor utilization and early diagnosis. Availability of mental health services and an integrated system of services at the community level are at the core of the mental health program. The focus is with community care on early detection, adequate treatments and reducing stigma. The programs adopt the new thinking in mental health to integrate mental health services within communities. Mental health services are to be available at the lowest level of care. This component is central to the program.

Increase in the number of psychiatric wards in general hospital and of community and mental hospitals, are instruments found in the document.

Organizational Availability and Ability to Seek

The need to improve the referral system for mental cases and the ability to follow-up patients is also addressed by the program.

Availability of medicines and mental health professionals are both addressed by the program. The availability of a mental health workforce is one major problem addressed by the policy. Instruments planned on availability are oriented towards education opportunities and training for general practitioners in metal health. The program puts emphasis on increasing capacities for mental health among physical practitioners, not only in tertiary, but also in primary and community centers. By increasing capacities to detect and manage mental diseases cases in general practice, the program could have an impact on access.

As for medicines and other medical equipment, the program recognizes the need to purchase equipments and the need for a minimum level of medicines available. Grants to institutions for upgradation and modernization purpose include these aspects of availability.

Acceptability and Ability to Seek

With increase of care within communities, the program also plans for an increase in health education and IEC on mental diseases, to increase knowledge of the population and decrease the associated stigma. The vision is for an increase in health education and care within communities for: *"Provision of mental health services and integration of the same with general health services will result in "acceptance of mentally ill within the community" and also result in early identification and treatment within the community almost at its "doorstep".* Knowledge to improve the population's ability to seek health services, near their communities.

Adequacy and Ability to Benefit

As mentioned earlier, increased financing is planned for quality improvements. Modernization of mental health hospitals and upgrade of psychiatric wings of general hospitals are two instruments planned to address the current quality problems. The mental health program recognizes that historically, mental health services were in poor adequacy with human rights.

Hence along availability of mental health professionals and of infrastructure of care within communities, quality is among the central concerns of the Mental Health Program.

Affordability and Ability to Pay

The cost-effectiveness of mental care within the community is addressed. The main logic behind care within communities is to improve access and reduce stigma associated with mental diseases: *"The new thinking on mental health at the national and international level is to make the services of mental health, community based rather than hospital based. Such community-based services are cost-effective, help to ensure respect for human rights, limit the stigma of receiving treatment, and lead to early treatment and recovery"*. Apart from this, the program is silent about issues of affordability of care, ability to pay and the higher costs involved with chronic care. The program is also silent on the financial consequences of utilization (like distress financing and catastrophic expenditure)

As detailed in the first section, the district program team is expected to provide services to needy mentally ill patients and their families. However, this is not detailed further.

Summary

Overall, the mental program acts on important dimensions of the problem of access to mental care: Increase public expenditure, availability of services in communities, increase and improvement in existing infrastructures of care, increase in availability of mental professionals and capacities for mental health among other health professionals, and increase the knowledge and awareness of the population on mental diseases. The dimensions of acceptability, affordability and ability to pay are not dimensions that received attention by the program. Furthermore, the poor, even thought targeted at one point in the program, are not a focus of this policy.

When looking at the outline of the program under the 11th development plan, we see that most instruments panned under the 10th planned are still present. Problems in financing, availability of infrastructures, quality and availability of mental health professionals are important problems that will still be addressed by the next program.

District Program for the Prevention and Control of Diabetes, Cardiovascular disease and Stroke (Pilot program)

Context, Goals and Objectives

Following the recognition that physical non-communicable diseases are now a major public health problem in India, the central government is planning a program for diabetes, cardiovascular diseases and stroke. The main goal of the program, still in its pilot phase, is to increase health promotion and the prevention and control of non-communicable diseases. The main objective is: *"The pilot program for prevention and control of cardiovascular diseases, diabetes and stroke, has, therefore, been planned with the objectives of providing effective promotion, prevention and control strategies to provide for an integrated action plan for these chronic diseases."* The program underlines that changes in the prevalence of risk factors, changes in life-styles, urbanization and industrialization have propelled the current increase of non-communicable diseases. And that these changes are not limited to urban areas. The pilot program was launched in January 2008 in selected states: Assam, Punjab, Rajasthan, Karnataka, Tamilnadu, Kerala, Andra Pradesh, Madhya Pradesh, Sikkim and Gujarat.

The pilot program is divided into instruments for primary and secondary prevention and embraces the WHO step-wise approach. In fact, the pilot program is divided into primary prevention for the healthy population in workplace, schools and communities; secondary prevention for the high risk groups and sick individuals; and research and disease surveillance gaps.

The focus of the program is specifically on physical chronic diseases: diabetes, cardiovascular diseases and stoke. A special focus on rheumatic heart fever is also integrated. On the other hand, the program does not target the poor as a group. The poor will benefit from changes brought in prevention and availability of curative care for chronic disease. Nonetheless, they are not a target of the pilot program.

Health System Functions

The pilot programs main concerns are the provision of inter-personal and curative services to the healthy and high risk populations and prevention.

Stewardships and regulation is another function planned for in the program. Regulation of costs is planned to encourage more cost-effective technologies for chronic diseases care, even in the private sector. As it is written in program's the document: *"The private sector is the main provider of management and care for elevated risk conditions. There is a need to correct the imbalance towards care using high cost, low yield technologies and use of more cost effective interventions."* At the same time, we can see that there is recognition of the important part taken by the private sector.

The program also plans for stewardship over the private sector, to coordinate efforts on care and prevention in that sector.

Geographic Availability and Ability to Reach

Physical accessibility and ability to reach are mainly addressed by the pilot program with special clinics in district hospitals for CVD and diabetes. Also by improving capacities among health professionals of all levels of care, the geographic availability of chronic care could partly be improved. Apart from this, the program has limited content on geographic availability and ability to reach.

Organizational Availability and Ability to Seek

The need to improve availability of care for chronic disease is addressed. In this perspective, the program plans for secondary prevention aims at early diagnosis and appropriate management. Improvement of the referral linkage and the setting up of specialized clinics at district hospitals for diabetes and CVD are two main components addressing the gaps in availability. Towards the high risk groups the program states that: *"…Interventions aimed at early diagnosis and appropriate management is suggested for reducing morbidity and mortality in this category."* The need to improve availability of drugs, treatments and equipments necessary for health investigations is also addressed by the program. The program also plans to capitalize on the existing national rural health mission to promote availability of chronic care in rural areas.

On the availability of medical professionals, the programs plans for the presence of the private workforce within the public services, increasing staff for the referral linkage and the involvement of medial college for continuing education. The need to increase local capacities to detect and manage chronic diseases is addressed by the program. Training must be provided to give medical professional the capacities to apply treatments guidelines at all level of care. For the program, these capacities must also be cultivated in the private sector. Once again the program pans to capitalize on the national rural health mission and train the ASHA for chronic disease care and health promotion.

The program also plans for a special focus on rheumatic heart fever, which can have dramatic consequences and make individuals chronically ill for the rest of their life if not treated adequately. The program thus underlines the importance of early diagnosis and adequate treatments for rheumatic hearth disease.

Acceptability and Ability to Seek

The other main focus of the program is on prevention. Using the Rose theory, the programs planned for primary prevention in the general population (community, schools and workplace), and secondary prevention for the high risk groups. The program plans for an increase in knowledge and awareness on chronic disease and risk factors. Increasing the knowledge and awareness of the general population can impact individual's ability to seek.

Adequacy and Ability to Benefit

The program does not addressed issues of quality of services. On the other hand, by aiming at improving capacities for chronic care, the pilot program is oriented to improve the adequacy of services for chronic diseases and the related ability of the population to benefit from this care.

Affordability and Ability to Pay

The parameters of affordability and ability to pay are not fully addressed by the program. What is found in the content of the pilot program is a call for the regulation over the costs of technologies and the financing of non-governmental organizations for health promotion.

Summary

Overall, the pilot program on diabetes, CVD and stroke, underlines the need to re-orient the system towards chronic care. The statement found in the policy document is clear: *"Chronic care has to be added to the pre-existing services which are geared towards delivering maternal and child health services and meet communicable disease control requirements".* Their main components for action are primary and secondary prevention. At all levels of care, the pilot programs plans to increase infrastructure, human resources, training and improve the referral linkage for chronic disease care, to decrease risk factors in the population and increase the capacities in the system for early detection, adequate treatments and complications.

Changes are required for the whole system of care to improve access to chronic disease care and the program is focused on this problem. However, the poor's problem in accessing care for chronic diseases is not targeted by the pilot program on diabetes, CVD and stroke.

Appendix 5 – Appraisal Questions / Framework Approach

Table 12.3: Appraisal Questions for the Framework Approach

Findings		
How credible are the finding?	Findings supported by study evidence	Use illustrative quotations and case studies to support evidences from the study.
	Findings make sense	Findings make sense and go in accordance with the hypothesis stated in the previous section and based on a prior conceptualization of access.
	Findings resonant with other knowledge	Findings are in accordance with the literature; on current problems affecting the Indian healthcare system, on barriers in access for the poor and the fact that reforms towards population prevention and chronic care are only starting.
How has knowledge or understanding been extended by the research?	Literature review summarizing previous knowledge and key issues raised by previous research	The first section presented a literature review to summarize knowledge on poverty and the barriers in access to care in a context of chronic diseases in India. Key issues related to the barriers in access already present and those additional barriers imposed by chronic diseases on the poor and the general population.
	Aims and design related to existing knowledge, but identify new areas for investigation	New areas of research were identified for the dynamic process of policy: the need to evaluate the correspondence with future policies following reforms and with state level policies.
	Credible, clear discussion of how findings have contributed to knowledge and might be applied to policy, practice or theory development	Findings on the level of correspondence and the gaps with the research problem are linked to a discussion on reforms.
	Findings presented in a way that offers new insights or alternative way of thinking	Access related problems for the poor living with chronic diseases are dissected using a conceptualization and linked to the content of different national health policies
How well does the study address its original aims and purpose?	Clear statement of aims and objectives, including reasons for changes	Aims and objectives of the study stated in section 3 and reiterated in the presentation of results in section 6.
	Findings clearly linked to the purpose of the study	Findings presented in section 6 are directly linked to the alignment of the policies with the conceptual framework.
	Summary/conclusions related to aims	Conclusions presented in section 8 related to the aims of the study to analyze the correspondence of current policies and links are made to reforms required from the system.
	Discussion of the limitation of the study	Limitations of the study are presented both in results and discussion section.
Design		
How defensible is the research design?	Discussion of how the overall research strategy was designed to meet the aims of the study	The deductive strategy based on the framework approach was adopted to uncover the correspondence between the content of policies with the barriers in access for the poor living with chronic diseases reported in the literature.

Table 12.3 (continued)		
	Discussion on the rational for the study design	Motivations for the framework approach and relevance sampling discussed in the methodology. Choice based on the clarity and flexibility of the approach and accounting for the limited universe of possible data.
	Convincing for specific features/components.	Relevance sampling strategy discussed along with validity precautions: triangulation and the use of informal key informants. Case study component adopted to summarize results contained in the question grid and provide descriptive information.
	Discussion of the limitation of design and their implications for evidence produced.	Limitations of the study design are discussed in the methodology section. Relevance sampling limiting data to a precise set of policy documents at the national level. Deductive analysis based on the conceptualization of access limiting the evidence to this perspective.
Sample		
How well defended is the sample design or target selection of cases/documents?	Description of study locations and how and why chosen	Sampling conducted in India at the PHFI and CCDC in New Delhi. This location chosen for an efficient data collection phase with triangulation of information sources, key informants and collection of policy documents.
	Description of the population of interest and how sample selection relates to it.	Population of interest is composed of Indian national health policies. Relevance strategy selected with inclusion criteria's given the limited universe of possible data. Strategy combined with triangulation of information and key informants to set the sampling boundaries.
	Rational for selection of target sample, settings or documents	Rational for the focus on Indian's national health policies discussed in terms of feasibility and relevancy for the study.
How well is the eventual sample composition/case inclusion described?	Detailed description of achieved sample/ cases covered.	Achieved sample presented in the sampling description; where dates, goals, objectives and instruments of each policy are listed. Achieved sampled also presented the results and the cases studies' findings in annex.

Table 12.3(continued)		
	Efforts made to maximize inclusion of all groups.	Inclusion criteria are enumerated in the sampling section of the methodology. Criteria are set to be reasonably broad to include the necessary documents.
	Discussion missing coverage in sample/cases and implication for study evidence	Rational for the exclusion of the cancer control program given in the sampling section. Limited impact on evidence stated.
	Discussion of access and methods, and how these might have affected coverage	Method of access varied for each document. Collection of documents directly on the field guaranteed the completion of the targeted sample. Methodology and sampling description sections
Data collection		
How well were the data collected?	Discussion of who collected the data; procedure and documents used; check on origin, status, authorship of documents	Check on origin and authorship of documents with informants and the CCDC. Procedure for collection stated in the sampling description and case studies by document; either obtain on official government websites or through key informants.
	Audio or video recording of discussions and if not justifications?	Discussions with key informants were informal and done in different settings. Rational given in sampling section.
	Demonstration through portrayal and use of data in depth, detail and richness were attained in collection.	Case studies to expose the depth and richness achieved.
How well are the contexts of data sources retained and portrayed?	Description of background, history and socioeconomic / organizational characteristics of study sites / settings.	Literature review providing information on health system and health policy in India. Context of each policy detailed in the results section and the case studies in annex.
	Explanation of the origin of written documents.	Documents analyzed all written Indian national health policies. Context and origin of documents are given with the sampling description and case studies in annex.
How well has diversity of perspective and content been explored?	Discussion of contribution of sample design/ case selection to generating diversity	Sampling section giving rational on the limited universe of possible data. Specific aim of the study but inclusion criteria's as broad as possible to obtain diversity of documents within the limited population.
	Description of diversity / multiple perspective / alternative positions in the evidence displayed	Case studies presenting context and findings for each policy.
	Evidence of attention to negative cases, outliers or exceptions.	Space reserved in the analysis tools for unplanned content to be recorded and integrated.
	Identification of patterns of association / linkages with divergent positions / groups.	In the results, position of each policy sampled presented on chronic diseases and the barriers in access for the poor.

Table 12.3 (continued)		
How well has detail, depth and complexity (i.e. richness) of the data been conveyed	Identification of patterns of association / conceptual linkages within the data.	Policy charts to highlight patterns of associations between concepts within the coded data.
	Presentation of illuminating textual extracts / observations	Key findings were presented with illustrative quotations from policy documents when necessary.
Reporting		
How clear are the links between the data, interpretation and conclusions?	Clear conceptual links between analytic commentary and presentation of original data (commentary related to data cited).	Cases studies presenting the findings for each policy's content in relation with the conceptual framework of the barriers in access. Commentary supported by illustrative quotation when necessary. Results section based on these case studies.
	Discussion of how/why a particular interpretation is assigned to specific aspects of the data, with illustrative extracts to support it.	Idem.
	Discussion of how explanations, theories and conclusions were derived: how they relate to interpretations and content of original data; and whether alternative explanations were explored.	Analytical approach detailed in the methodology. Conclusions derived by indexing content using the conceptualization of the problem and translating the coded content back into a policy map to be analyzed using a question grid.
How clear and coherent is the reporting?	Demonstrate links to aims / questions of study	Results structured to expose the correspondence and gaps of policies with the conceptual framework.
	Provides a narrative or clearly constructed thematic account	Case studies represent the narrative for each policy document on their correspondence with the conceptual framework for the barrier in access.
	Has structure and sign posting that usually guide the reader	Results and case studies structured systematically with the conceptualization of access and the correspondence / gaps within each of its dimensions.
	Provide accessible information to target audiences	Results presented in a scientific article.
	Key messages are highlighted or summarized	In the results section, a table summarizes the correspondence of all the policies with each dimension of access and their related barriers for the poor. Gaps in correspondence highlighted in the results directly extracted from this table.

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Table 12.3 (continued)		
Reflexivity, neutrality and auditability		
How clear are the assumptions, theoretical perspectives and values that have shaped the research and its reporting?	Discussion / evidence of main assumptions, hypotheses and theories on which the study was based and how these affected each stage of the study.	Hypothesis presented in section 3 and based on the literature on the current problems affecting the Indian healthcare system and the reforms required in a context of epidemiological transitions.
	Discussion / evidence of ideological perspectives, values, philosophy of the researchers and how these affected methods and substance of the study.	Research based on two conceptualizations (access and health system functions) that directly shaped the analysis and the findings. Discussion aligned on the perspective of reforms required from health systems facing an increase in the prevalence of various chronic diseases.
	Discussion of how error or bias may have arisen at each stage of the research and how these threats were assessed, if at all.	Reliability and validity safeguards listed in the methodology section.
How adequately has the research process been documented?	Documentation of changes made to design and reasons; implication for study coverage	Changes at each stages of the study recorded in a journal.

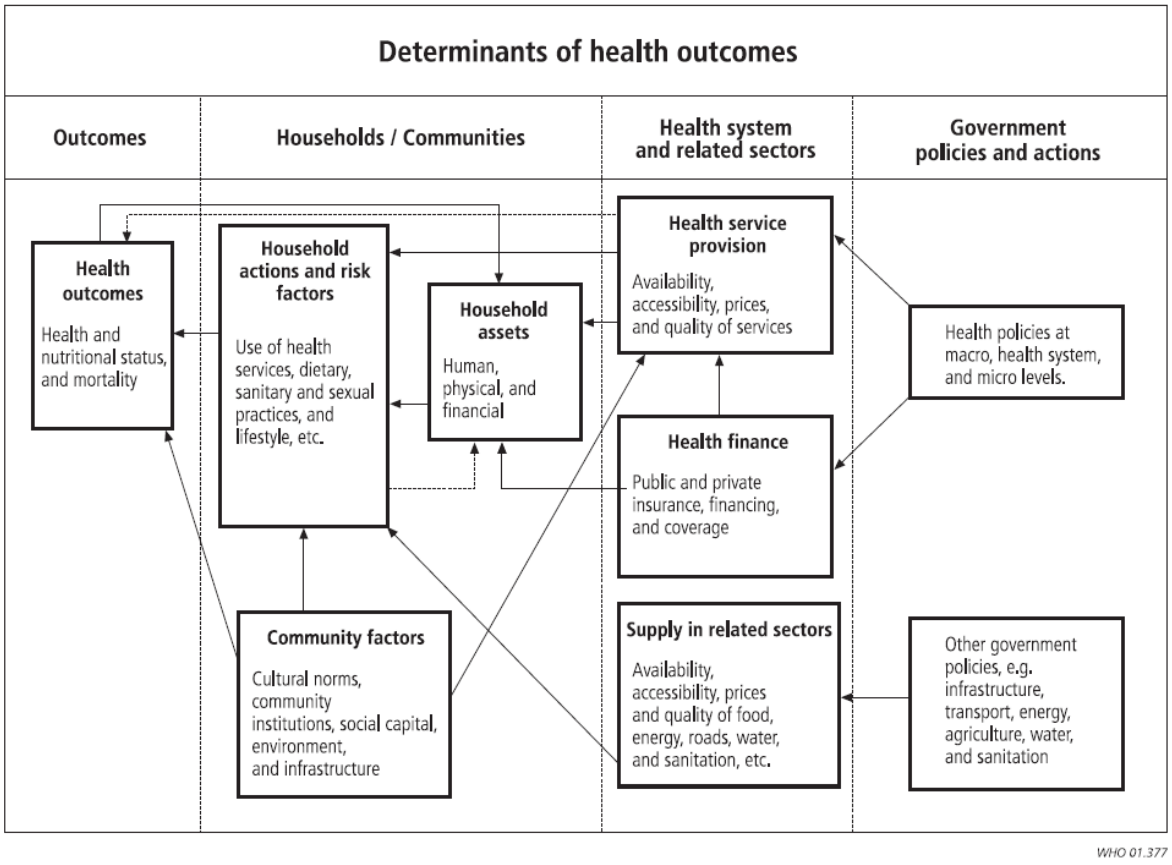
Appendix 6 – Map of India

Figure 12.1: Map of India

Source: Nations Online Project, Online at: http://www.nationsonline.org/

Appendix 7 – Determinants of health outcomes

Figure 12.2: The Determinants of Health Outcomes (Wagstaff 2002)



Source: Wagstaff 2002