



## Synopsis of the Research Project

Title: **NCCDs in India – A study of the gaps , quality and cost of care”**

Commissioning Organization: Chronic Care Foundation  
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New Delhi – 110049.

Research Organization: IMRB International  
Duration of Research: Release in November 2008

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Background: Chronic diseases (non-communicable diseases or NCDs) are major cause of mortality and disability in India. In a study report published by PWC-ASSOCHAM in 2007, in 2005, deaths due to chronic diseases in India accounted for 53% of all deaths and 44% of disability adjusted life years (DALYs). Though there is thorough improvement in technology in terms of treatment and the medicines, the system of financing and delivering care, particularly to these NCDs has been sluggish especially due to the changing nature of diseases. The crisis is both, in terms of the cost of treatment and, the quality and access to quality care.

In recent times the Government of India, NGOs and other stakeholders have laid stress on health care, particularly in infectious diseases and periodic epidemics segments - HIV / AIDS, Malaria, Dengue, Meningitis, Avian Influenza, etc. Nevertheless, in the process, chronic diseases and their care desire greater attention.

Chronic Care Foundation (CCF) founded, to promote good health by proactively minimizing the incidence and effects of chronic disease in society. It is committed to empowering the community with an accessible, efficient health care system that improves the safety and quality of care of patients with chronic, cardiovascular disease, diabetes and kidney disease in India; through prevention, advocacy, education and collaboration amongst stakeholders within the community.

Few of the objectives of CCF are:

- Generate, collect and serve as a one point source of information on population health statistics related to Cardio Vascular Diseases, Diabetes and Kidney Diseases
- Provide a platform for medical practitioners and other stakeholders to learn best practices in patient care

- Provide a platform and develop guidance packages for patients, their families and the community in general about awareness of disease, therapies and consequences.
- Advocate health promotion and chronic disease prevention and control, especially for poor and disadvantaged populations.
- Provide accessible long-term supportive welfare services for continuous care, and facilitate with any other services that maybe required in connection with the above.

To achieve the above, for CCF, it is important to have reliable data on the care practices and cost of care for chronic diseases, particularly from the primary and secondary level. Many studies have been conducted across India on the prevalence of chronic diseases condition and their burden at various levels of healthcare, but they do not have information on vital areas.

It is therefore need of the hour to identify:

- Types of services available in different regions of India – with respect to prevention, diagnostic, treatment & rehabilitation of Diabetes, Cardio Vascular Diseases (including Hypertension and Stroke) & Chronic Kidney Diseases
- Quality of care and standards being followed at different levels and compare to International good practices in chronic diseases prevention, detection and treatment.
- Gap between current level of Quality of Care received versus expected
- Cost of Care – both direct and indirect for the beneficiaries

CCF has commissioned a research study across four regions of India to collect information with a special focus on three chronic diseases. The research will be conducted at all levels of service delivery (Primary, secondary & tertiary) and would cover Government as well as private facilities.

The Research Study has been commissioned to a professional Market Research Organization, experienced in social and health related research and has nationwide presence. This would facilitate the fieldwork in different states and would take care of the language barrier.

**Objective:** The objectives of the proposed research study are:

- Identify international good practices in prevention, detection, care and rehabilitation of Non –communicable chronic diseases - Cardio Vascular Diseases (including Hypertension & stroke), Diabetes & Chronic Kidney Diseases and weigh against the standards being followed in India
- Identify and analyse the types of Services available in different regions of India, with respect to prevention, diagnostic, treatment, care and rehabilitation of these three diseases
- Identify and analyse the Quality of Care & standards being followed at different levels of service delivery points in India with respect to prevention, detection & treatment & its comparison to ideal/ standard/ desirable levels of practices for Non –communicable chronic disease

- Identify the gaps between the current level of service provided by the service providers and level of service expected by the patients/ community at large
- Assess the Cost of Care in terms of direct and indirect costs to the patient and the impact of the same on the treatment seeking behaviour.

## **Methodology:**

*Research Design:* The research is proposed to be conducted in two stages:

*Stage-1: Exploratory Stage:* is proposed to understand the critical service parameters and the standards of care for each non-communicable disease. This would be through Secondary - research and in-depth interviews with experts in India.

Secondary research on available literature is proposed to enable benchmark for chronic diseases - both internationally and nationally. Exhaustive interviews with experts are proposed to formulate the benchmarks for the services available in India. It is proposed to freeze these benchmarks in consultation with an expert panel (Medical Advisory Board of CCF). The services available in each of the selected Primary sampling units would then be compared with the identified benchmarks.

*Stage-2: Survey Stage:* is proposed to assess the extent of service availability, the depth and the quality of care available across the four regions in India. This stage is proposed to be conducted through a survey of the facilities and collection of information from the beneficiaries. Facility Survey would cover Government as well as private centers and the beneficiary survey would assess the levels of availing the services and key triggers and barriers for the service usage.

*Target Groups:* for the study would be:

*Medical Service Providers* (from government and non-government health institutions): This would include doctors who attend specific non-communicable diseases (CKD, CVD & Diabetes) and also a small sample of those who attend to all kinds of medical complaints in the selected units of study (PSUs – Primary Sampling Units- either a village or a ward). The sample for the study would include service delivery points at primary, secondary & tertiary levels at each of the selected PSUs.

*Beneficiaries:* Patients affected with any of the three non-communicable diseases (Diabetes, CKD & CVD) would be interviewed in the selected PSUs.

*Geographical Coverage and the Sample Size:* The study is proposed to be conducted across all four regions of India (North, East, and West & South) and would cover three geographic levels – urban, semi-urban and rural. The sampling of the PSUs is proposed with the help of Census of India and as there is no legal definitions of 'semi-urban' in the Census, the differentiation between 'urban' and 'semi-urban' would be taken into consideration with the help of POPs data. This POPs data will facilitate the sampling in urban wards according to the population statistics and would help to cover areas with different levels of population. The analysis of the data can also be done with this stratification.

*Sample Size for Healthcare facilities:* For a holistic coverage across the regions, the study would cover 90 PSUs in each region. These 90 PSUs in each region would be a proportionate mix of villages and urban wards. In total 360 PSUs would be covered across India.

*Sample Size for Beneficiaries:* The beneficiaries would be afflicted households (with any of these three chronic diseases) and it is proposed to cover 5 afflicted households per PSU. In total 1800 beneficiaries would be covered across India.

*Proposed Stages for the survey:*

*Preparatory Stage:*

- Exploratory Research consisting collection of Secondary data, review of available literature and depth interviews with experts.
- Preparation and pretesting of Research tools, and their translation into regional languages after pretesting
- Sampling and selecting the PSU through Census (wards & villages selected with the size of population) within each region (North, East, West & South)
- a. For facilities: Census of all medical facilities in each PSU and  
b. For beneficiaries: Sampling of the beneficiaries in the PSU
- Training and briefing of the Field Team.

*Execution Stage:*

- Collection of data from:
  - a. Facilities: Availability and type of services offered for three chronic diseases at the medical facility within the selected PSUs, together with the assessment of cost of care.
  - b. Beneficiaries: Information on type of initial disease suffered, treatment sought, level of satisfaction from the medical facility for prevention, diagnosis, treatment, & rehabilitation and assessment of the cost of care –direct as well as indirect.
- Data entry and analysis

- Evaluation and assessment of services and quality of care provided in each facility vis-à-vis to those as benchmarked by expert panel.
- Report on critical indicators and explanatory variables, along with the measures on the critical indicators for each group. Indicators are expected for each region, rural-urban, service type, service level for all the Target Groups that are covered in that region.
- Detailed draft report on the basis of the above.
- Final report with both qualitative and quantitative findings together with all additional analysis required and as suggested by expert panel.

Expected Results:

The overall aims of the research are stated as objectives.

Specifically the research would provide information on:

i. *Secondary information on Service Quality:* Through secondary data collection and literature review, information is proposed to be collected quality parameters, some of which are:

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|-----------------------------|---------------------|
| a. Responsiveness           | h. Competence       |
| b. Reliability              | i. Courtesy         |
| c. Access                   | j. Patient's Demand |
| d. Security                 | k. Empathy          |
| e. Communication            | l. Assurance        |
| f. Understanding            | m. Reliability      |
| g. Credibility & reputation | n. Responsiveness   |

ii. *Information from Health Care providers:* Some of the proposed information to be collected are

a. Awareness & prevention efforts

- Service facilities offered for the non-communicable diseases (CVD, CKD & Diabetes) & level of awareness of symptoms, causes & preventative techniques of these
- Level of awareness of various types of treatments available of each NCD
- Type of IEC material on display & offered to patients
- Counseling for prevention of such diseases

b. Facilities available for diagnosis, treatment & rehabilitation

- Number of qualified personnel & Scope of services offered within the facility for each NCD (CKD, CVD & Diabetes)
- Diagnosis process followed and types of treatments offered

- Reasons for non-availability of certain services, if any
  - Number of patients in last 1 year for each NCD & average number of visits per patient
  - Administration of various types of tests & treatment of other health problems
  - Monitoring of medication & nutritional counseling offered for each NCD
  - Alternate therapies offered/ counseled like foot therapy, aerobics, strength training, weight management etc
  - Infrastructural capacity of the facility (number of rooms, patient capacity, machines etc)
- c. Cost of Care
- Cost of the treatment (all types)
  - Subsidized costs offered to the poor, if any
  - Cost for hospitalization (per day basis)
  - Consultant's cost per visit
  - Indirect & other costs of the Facility, if any.
- iii. *Beneficiary Population:* Tentative information areas are:
- a. Awareness levels
- Awareness, symptoms and causes of various NCDs (specifically CKD, CVD & Diabetes)
  - Knowledge about preventive techniques and treatment available/ known about each NCD
  - Sources of information on the above (spontaneous & aided) and type of information gathered from each source of information
  - Type of service facilities available for each NCD
  - Recall of any IEC material on any NCD (CKD, CVD & Diabetes), message from the same and any change in behaviour post exposure to the IEC material
- b. Diagnosis, Treatment & re-habilitation procedure
- Initial symptoms experienced and age at which disease was diagnosed
  - Duration of illness
  - Type of doctor, service facility first visited and techniques used first time for diagnosis or details of referral given
  - Counseling/ guidance/ advice/ type of treatment offered post-diagnosis
  - Type of service facility for final treatment – Govt. or Private (at primary, secondary or tertiary Level) & details of frequency of visits required

- Details of any other health problem along with the core disease and the treatment sought
  - Type of in-home care required for the post-treatment & availability of medication nearby.
  - Details of rehabilitation offered, if any
  - Details of IEC material provided to patient – if possible to observe & record the same
  - Any other alternate therapy being followed
  - Reasons or barriers for not seeking treatment or stopping it midway, after diagnosis of NCD, if any
- c. Satisfaction and expectation from type of service received
- Expectation from the service facility when first diagnosed with the disease
  - Satisfaction levels on various parameters (e.g. medical personnel, facilities available, promptness in response, therapy/ treatment being offered/ undergone, etc.)
- d. Cost of care – Direct & indirect
- a) Cost of the treatment – all types to be recorded
  - b) Cost for hospitalization (per day basis)
  - c) Details of any subsidized cost offered
  - d) Consultant's cost per visit
  - e) Indirect and other costs such as wage loss, transportation etc.