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Detailed Project Report

for

Developing, Setting up and Management of the India Health Portal to promote Health Literacy

Constitution of the Working Group for the India Health Portal

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Context and Background

Recognising that the Internet constitutes a powerful and democratic source of information and knowledge, the National Knowledge Commission (NKC) deliberated on ways to create a series of web portals. These web portals are aimed at becoming a decisive tool in the popular movements that are in support of the right to information, decentralisation, transparency, accountability and people's participation. In order to increase openness and enhance accessibility, the NKC recommended the creation of web portals to aggregate, organise and present relevant and useful content in English and local languages, in a highly uniform, customisable, user-friendly and personalised way for several key areas related to basic human needs.

The country has undertaken major reforms in the health sector in the recent years. The rapid increase in quantum of public funding for the sector and operationalisation of decentralised innovations in rural areas has substantially altered the treatment seeking behaviour of communities in favour of public health facilities. Major reforms have simultaneously been undertaken to improve the health infrastructure, health human resources, drugs and diagnostics and referral transport options. In India, there is an opportunity for deploying IT to disseminate health information and present greater health choices before the citizens and help improve health status of the people. The proposal under consideration seeks to utilise IT-enabled protocols for improving access to health-related information and services so as to improve the quality of life of citizens specially the poor people living in remote rural areas of the country.

India is the second most populous country of the world and has changing socio-political, demographic and morbidity patterns that have been drawing global attention in recent years. Communicable diseases, which are preventable, dominate as one of the leading causes of morbidity in the rural areas. Lifestyle-related disorders dominate the urban scenario. Health problems are reflected in the life expectancy (63 years), infant mortality rate (80/1000 live births) and maternal mortality rate (438/100 000 live births). Therefore, the current situation

calls for addressing areas such as the burden of disease and health indicators such as maternal and infant mortality ratios and lifestyle-related diseases.

The developments in information and communication technology (ICT) have created new opportunities for enhancing the efficiency of health care delivery. Knowledge can be productively applied to promote change, enhance quality of life and facilitate reliable and regular flow of information. It has also come to light that the availability of information pertaining to traditional systems of medicine is lacking in the public domain. In a multilingual country, translation plays a critical role in making this knowledge available to different linguistic groups. Various champion organizations have been identified in promoting this cause such as the Centre for Science and Environment (CSE); on Teachers, championed by the Azim Premji Foundation; and on Biodiversity, championed by the Ashoka Trust for Research in Ecology and the Environment (ATREE). It has therefore become increasingly necessary to champion the cause of health literacy.

In the wake of this, the NKC had proposed to launch the National Health Information Portal which would serve as a comprehensive source on health information in India. This portal will provide information on healthcare for the citizens of India and the healthcare workers alike. This portal will serve as a single point of access for consolidated health information, application and resources on the sector and aim to cater to a wide spectrum of users from citizens, to students, healthcare professionals and researchers.

The proposal aims to create space for other portals, publishers, IT and non IT based interventions. As the portal evolves, cloud computing technologies could be incorporated with the central agency becoming the mentor for multiple interventions (thematic, geographical etc).

The India Health Portal is being proposed to be built in collaboration with a wide range of stakeholders from all sectors including Government, academic institutes, private sector and technology experts.

I.Problems to be addressed

Need for a National Health Information Portal

Health literacy is generally agreed upon as a means to find, understand, analyze and use information to make better decisions about health and to ultimately reduce inequities in health. Health literacy is about communicating health information in ways patients and families can understand. The diffusion and use of knowledge in society is arguably one of the most important factors in improving health outcomes.

However, although knowledge is often considered a prerequisite for change in attitudes and behaviours that lead to better health, that relationship is not always direct, positive, linear or even necessarily present (Andrew Pleasant, 2008). Health behaviour could be affected by multiple factors that operate at various levels including the individual, family, social, organisational and the community level (Deborah R. Sepinwall, 2002). Some of these factors include access to information, policies and regulations in place to address the health problem, the individual's perception of the problem and an understanding of the recommending behaviour for managing the problem.

Access to health information is one of the foremost rights of humankind. Inadequate or poor health information can increase the risk of hospitalization or even disease burden. Medical information that is not tailored for consumers can be confusing and deciphering this can be difficult. Therefore, availability of reliable, high quality health information is important for the promotion of health among the population.

In a study (by Tessa Tan-Torres Edejer 2000 - BMJ), it was found that in India, information technology (IT) has not been utilised systematically to improve the population's health. However, there is still an opportunity for IT to help improve the health status of the people, as the same can be used to publish health information and people could be presented with greater health choices. Studies have demonstrated throughout the world that the digital divide is creating huge

inequalities in health as information is not being used appropriately. Besides, the health information being published on the Internet currently is rather inconsistent and lacks validity. Today's technology needs to be utilised to provide greater interactivity and ensure that information is continuously being used to further the knowledge of the people. With the explosion of the Internet in India, it has become increasingly important for quality health information to be made readily available on the public domain via this medium. However, the challenges that need to be considered in India include the prevalence of illiteracy, multiple languages and cultures and poor access to the Internet especially in rural areas. These problems can be resolved by disseminating quality health information tailored for the population of our nation by using a wide range of Information and Communication Technologies (ICT) including fixed and mobile telephony, touch-screen kiosks, television and radio, besides the Internet.

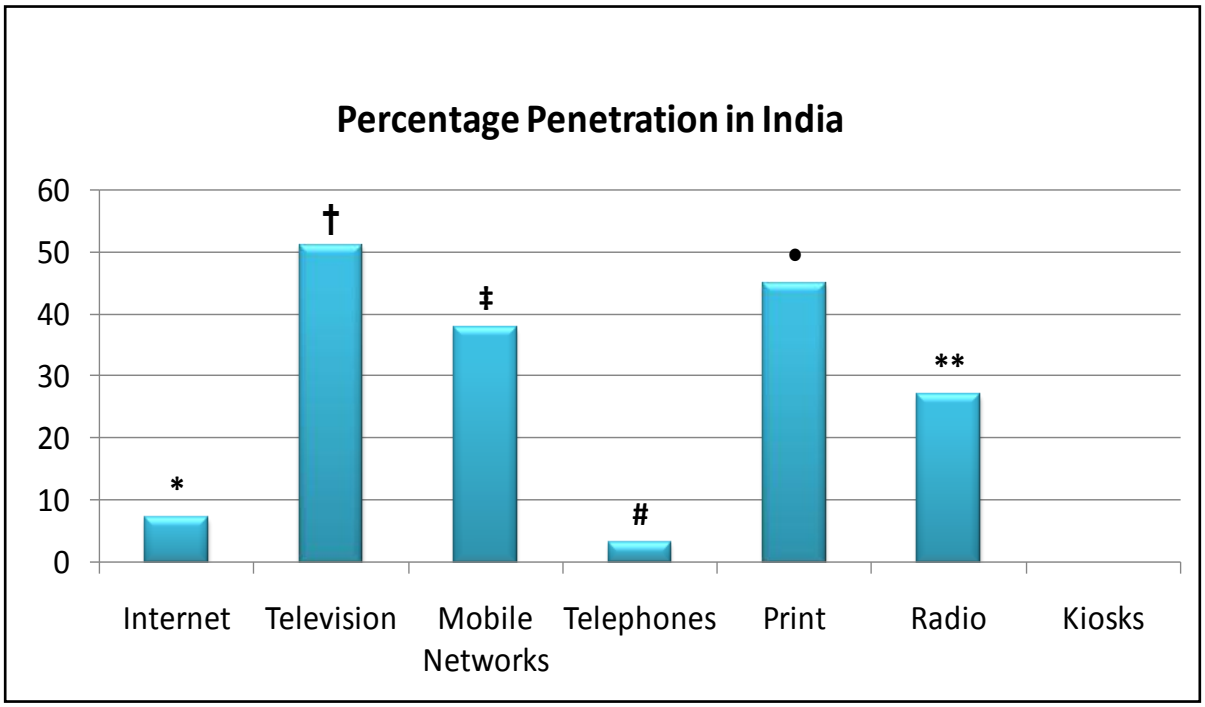


Figure II.1: Penetration rates (%) of various communication modalities in India

* **Internet** – World Bank, http://www.google.com/publicdata?ds=wb-wdi&met=it_net_user_p2&idim=country:IND:PAK:USA:GBR:KOR:CHN&tstart=631152000000&tunit=Y&tlen=18#met=it_net_user_p2&idim=country:IND&tstart=631152000000&tunit=Y&tlen=18

† **Television** – International Television Expert Group, http://www.international-television.org/tv_market_data/indian-pay-tv.html

‡ **Mobile –** http://www.trai.gov.in/WriteReadData/trai/upload/PressReleases/697/pr20aug09no64.pdf

 # Telephone – http://www.trai.gov.in/WriteReadData/trai/upload/PressReleases/697/pr20aug09no64.pdf

• **Print** – National Readership Survey, 2006, http://www.auditbureau.org/nrspress06.pdf

** **Radio** – National Readership Survey, 2006, http://www.auditbureau.org/nrspress06.pdf

There is also a need to provide health information to healthcare workers who in turn can share this information with the populations they serve. There is a need for healthcare professionals in India to access relevant updated medical information through a single window as part of continuing medical education, which would soon become a mandatory component for health professionals or an e-learning initiative.

A recent review (Magdalena Z Raban, 2009) found that there was a lacunae in the availbility of essential health information on Indian websites with regard to mainly non-communicable diseases and injuries. This is a significant gap as India is undergoing an epidemiological transition and non-communicable diseases now account for a major proportion of disease burden. This is besides the point that information on any health condition is less than required across the spectrum.

With the passage of time there has been a shift in the role of the patient from being a passive recipient to becoming an active consumer of health information (McMullan M, 2006). Patients today are expected to and also feel like playing an active role in their own medical care and treatment.

The development of reliable, relevant, usable information in an agreed-upon fashion requires cooperation among a wide range of stakeholders including health-care providers, policy makers, researchers, publishers, information professionals, indexers, and systematic reviewers (Godlee F, 2004). However,

concerns have emerged regarding the quality of health information documents contained on the World Wide Web and this requires introspection.

Health information published on the Internet lacks review, and there is no means by which the user can check the validity of the information. Often the information present on the Internet is inaccurate and misleading. It was felt that for those seeking easy ways to identify high-quality and reliable information, rating systems to evaluate the quality of health information on the Internet should be provided and developed (Aeree S, 2001).

Burden of Disease

When compared to the South Asian Region averages on life expectancy and mortality (Life Expectancy: 64 years, Infant Mortality: 52 per 1000, Maternal Mortality 4.5 per 1000)[1] India is just about at the average level on these parameters. Therefore, a focus on these areas needs to be continued.

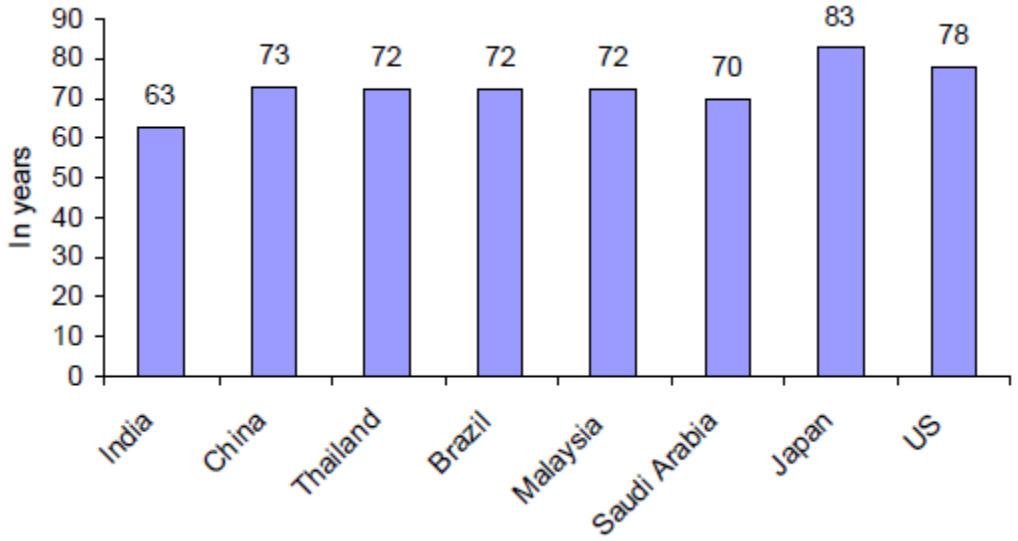


Figure II.2: India life expectancy comparison[2]

[1] World Health Organisation report on World Health Statistics, 2008
[2] World Health Organisation report on World Health Statistics, 2008

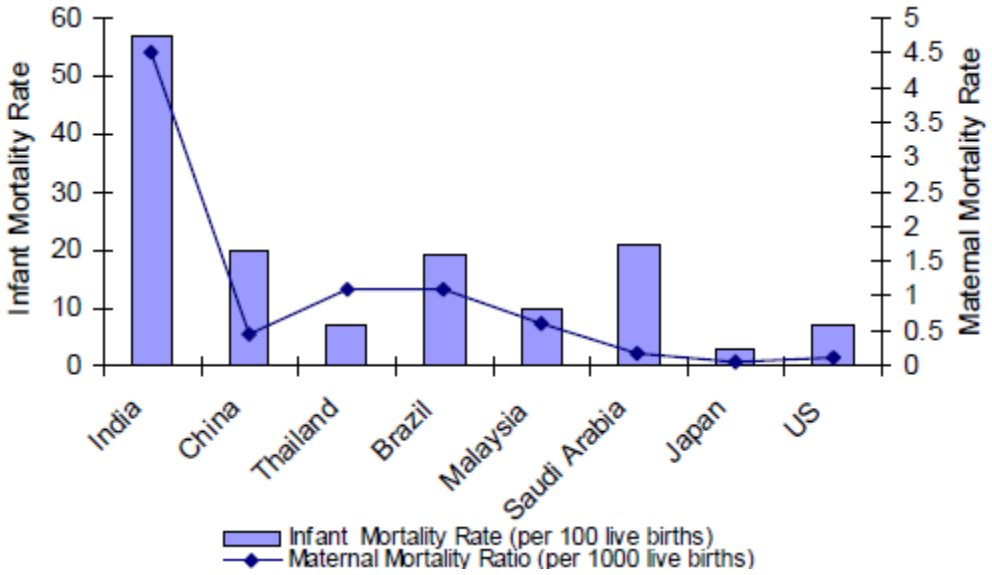


Figure II.3: India mortality rate comparison[3]

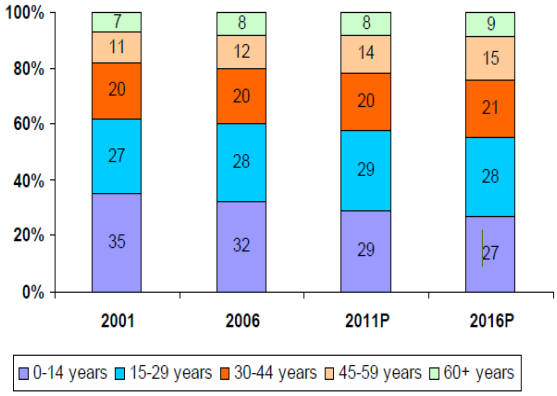
Changes to the age demographics mix of the Indian population indicate an increase in the working age group population. This has also brought with it a change in the disease profile and an increase in the incidence of diseases to which the population in the working age group is more prone towards.

India is facing an epidemiological transition accompanied by health transition, which has resulted in an epidemic of NCD's (Non Communicable Diseases). In India, deaths from NCDs are projected to almost double from about 4.5 million in 1998 to 8 million by the year 2020. In the year 2005, 53% of all deaths were due to NCDs and this is projected to increase by 18% over the next 10 years[4].

While NCDs are usually expected to occur in old age, their peak occurrence in India is a ***decade earlier than western countries***. Hence, the issue is not only the burden, but also its prematurity and the resulting socioeconomic consequences. With changing socio-economic mix in India, the share of lifestyle diseases is likely to surge. The figure below indicates that lifestyle diseases like Cardiac ailments, Oncology and Diabetes accounted for about 13 percent of the total hospitalization in 2006. Projections for these diseases in the future indicate that

[3] World Health Organisation report on World Health Statistics, 2008
[4] http://www.ncd.in/need.html

the share of these might rise to more than 15 percent by 2011 on account of a change in dietary habits and a more sedentary lifestyle led by people. These lifestyle diseases are more expensive to manage and control.



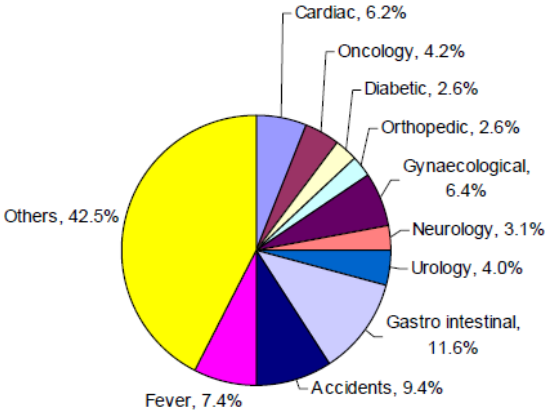


Fig II.4: Age and Demographic Shift[5]

Fig II.5: Hospitalized Cases in India[6]

In middle-income countries[7], around one quarter of YLL per 1000 population are due to communicable diseases, maternal and perinatal conditions, and nutritional deficiencies. The major cause of YLL here would be NCDs. The figure below depicts the Years of life lost (YLL) due to deaths occurring at younger ages. It is evident that lower-middle income economy such as ours, the YLL per 1000 population is almost twice when compared with high income economies.

[5] World Health Organisation report on World Health Statistics, 2008
[6] Policy Paper – The emerging role of PPP in healthcare sector
[7] World Bank Report http://data.worldbank.org/about/country-classifications/country-and-lending-groups#Europe_and_Central_Asia

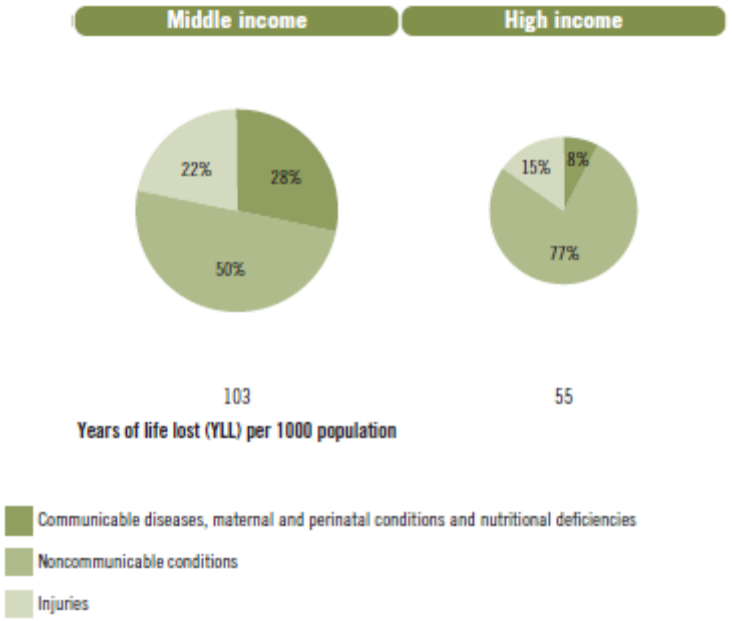


Figure II.6: Years of life lost (YLL) due to premature mortality by broad cause and country-income group – 2004[8]

Inadequate health literacy was an independent risk factor for hospital admission among elderly.[9] Inadequate health literacy also contributes to disproportionate burden of disease among disadvantaged populations as evidenced by studies conducted in other countries[10]. It has further been proven in studies that respondents with inadequate health literacy knew significantly less about their disease than those with adequate literacy. Statistical analysis indicated that health literacy was independently related to disease knowledge[11].

Health literacy has a significant impact on lowering the maternal and infant mortality. In the Swasthya Sakhi program (under the Rajiv Gandhi Mahila Vikas Pariyojana), conducted in 22 Blocks in Amethi, Uttar Pradesh, one Swasthya Sakhi (or Community Health Activist) was assigned to a village to spread health literacy and create awareness. Every pregnant woman in these villages was identified and connected to the public health facilities. 1550 pregnancies and

[8] WORLD HEALTH STATISTICS 2010
[9] Am J Public Health. 2002;92:1278–1283 http://ajph.aphapublications.org/cgi/content/full/92/8/1278
[10] JAMA 2002;288:475-482
http://hss.ucsf.edu/PDF/article_AssoHealthLiteracy%20Schillinger%20JAMA%202002.pdf
[11] http://www.pec-journal.com/article/S0738-3991(02)00239-2/abstract

deliveries before the program (May 2009 to November 2009) were compared with subsequent 1532 pregnancies after the implementation of the Swasthya Sakhi program (November 2009 to July 2009), in the same 256 villages in 22 blocks. The study also demonstrated a significant reduction in the maternal and infant deaths. MMR has decreased from 645 to 65 and IMR from 40 to 9.7 (there is a margin of error in MMR due to small sample size)[12]. The maternal deaths after the study was just 1, compared to 10 before the study. The infant deaths after the study was 15, compared to 63 before the study. Through this Health literacy there was also improvement in the personal hygiene. The number of families who adopted personal hygiene habits was 48,349 and before the study 14,575 had followed personal hygiene habits. This study goes on to demonstrate the impact of health literacy on maternal and child health.

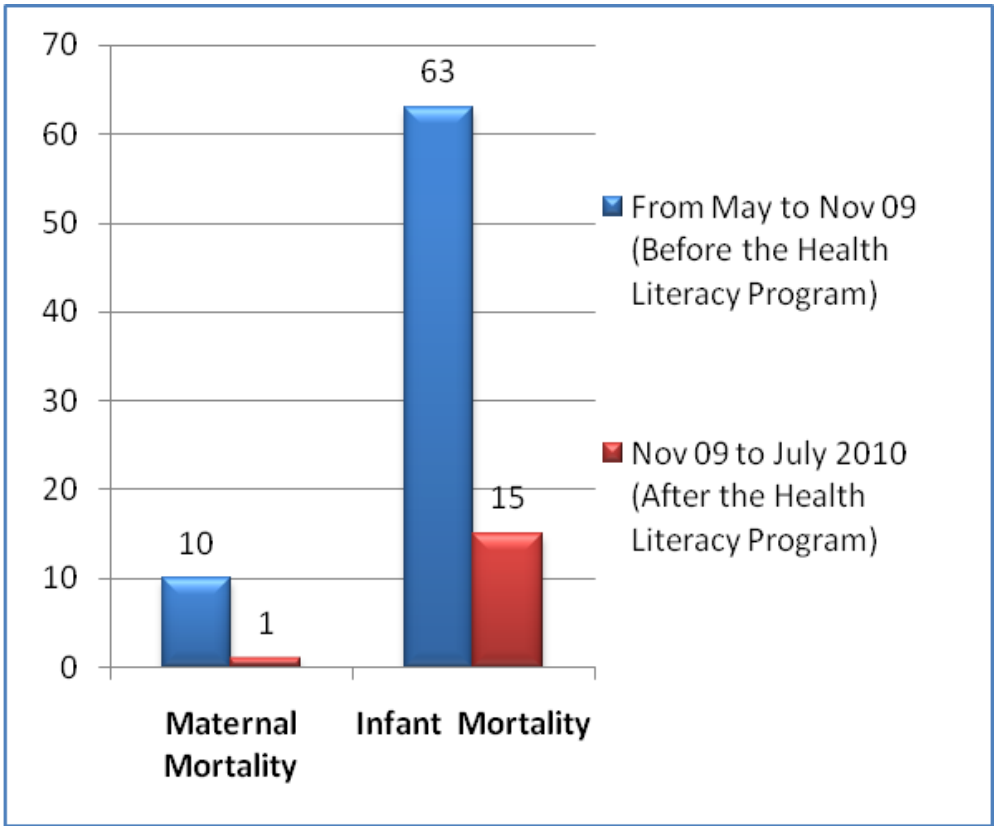


Figure II.7: Maternal & Infant Mortality Rate before & after the Literacy Program

[12] Unpublished data - Courtesy: Rajiv Gandhi Mahila Vikas Pariyojana, http://rgmvp.org/core-programmes-cbhc-overview.asp

Events	May 09 to Nov 09 (Before the Health Literacy Program)	Nov 09 to July 10 (After the Health Literacy Program)
Number of pregnant women followed	1,550	1,532
Maternal deaths	10	1
Infant deaths	63	15
Number of families who adopted personal hygiene habits	14,575	48,349

Table II.1: Statistics before & after the Literacy Program

There is no lack of information in the system about healthy lifestyles, but the manner of communication of risk and the level of support for lifestyle change need improvement. Action also has to be taken to address inequalities in health and to focus on securing better access to healthier choices for people in disadvantaged groups or areas. Accordingly, one randomized controlled trial examined whether access to a purpose-built health portal for heart disease could enable patients to manage better their heart conditions. The results of this study indicate that the there was significant changes in the way they managed their diets, thereby improving their lifestyle[13].

Efforts should focus on developing and evaluating interventions to improve diabetes outcomes among patients with inadequate health literacy. There are many opportunities to improve patients' knowledge of their disease(s), and efforts need to consider their health literacy skills.

[13] http://www.ncbi.nlm.nih.gov/pubmed/15923772

With all these problems being encountered in finding reliable and relevant health information, it has become increasingly necessary to create a window of information that will help the common man in his need for basic health knowledge.

II.Project Objectives

I Development Objectives:

1. The Project aims to improve the health literacy of the masses in India.
2. It aims to improve access to health services across the nation.
3. It aims to decrease the burden of disease by educating the people on the preventive aspects of disease.

II Outputs to be achieved:

The Project has following key Outputs:

1. Improve access to services through IT enabled cataloguing of service providers.
2. Create a comprehensive web based National Health Portal to make available comprehensive health related information to the community using IT and analogue or Non-IT methods.
3. Create protocols to enable the masses to access reliable, easy to understand, multilingual health information from the interactive National Health Portal.
4. Create protocols for wide dissemination of health information in public domain using the Internet and other pertinent communication modalities.
5. Create databases to enable citizens to seek, locate and access health care providers across the country.
6. Create platforms to provide health information and health resources for the healthcare workers, NGOs, student communities, and health professionals.
7. Create a transparent resource on regulatory and statutory guidelines pertaining to healthcare in India.

III Key Outcomes of the Project:

1. Wider awareness of validated information on health, common diseases and health services.
2. Improved health status of citizens through better access to services.
3. Improved financial status of citizens through optimized allocation of resources.
4. To enable the masses to access reliable, easy to understand, multilingual health information from an interactive National Health Portal.
5. To make health information readily available on the public domain using the Internet and other pertinent communication modalities.
6. To enable an average citizen to seek, locate and access health care providers across the country.
7. To provide health information and health resources for the healthcare workers.
8. To provide information to organizations who wish to contribute to public health and welfare (NGOs).
9. To provide health information to cater to the needs of student communities including educational/career opportunities.
10. To cater to the body of health professionals and meet their information needs, networking, and learning.
11. To provide a transparent resource on regulatory and statutory guidelines pertaining to healthcare in India to the public.
12. To provide information on National/State Health Programmes and schemes to the public

IV Deliverables for the Objectives:

The scope of this project would mainly include but not limited to the following:

- Building the health portal with all its features and functionalities
- Dissemination of information on the portal through various modalities

The portal will be updated with content in a phased manner. Although there may be certain overlaps between the phases, it is planned that the portal would be developed over 4 years.

These Years would be as follows:

1. Year 1
2. Year 2
3. Year 3
4. Year 4
5. Maintenance

The portal will be updated with content in a phased manner. Although there may be certain overlaps between the Years, it is planned that the portal would be developed over a period of 4 years and thereafter regular updates would be performed under maintenance phases.

IV.1 Year 1

This year will mainly focus on collecting and collating information and static content (non-vetted) from existing sources, both from the government and private/ third party agencies. Information thus collected would presumably be in various styles and formats. It therefore becomes necessary that all such information be converted into a single standardized format. The institutional mechanism that will be responsible for standardizing the content has been described later. The various types of content that would be collected and uploaded on the portal would include the following:

IV.1.1 Health Content

During the first year, Information Education & Communication (IEC) and health information material that is already available with various government (including state governments) and non-governmental agencies will be collected and compiled by the CHI and handed over to the CDCs. The CDCs would be responsible for converting the information thus gathered into a standard format to unify the look and feel of information available on the portal. The information available will cater to both the rural and urban populations alike. This section will consist of health information that will be presented in a format that is succinct and addresses key points of interest or concern. The design will be fairly minimalist and aesthetic which will convey the most relevant information in the least amount of space. The purpose of such a design is to reason in the concept that facts proliferate in an ever-increasing number while the time available to review and comprehend them diminishes. These fact sheets will attempt to solve this problem by condensing information into an easy-to-read, straightforward, portable and modular form of knowledge. This will aid in the process of promoting health and hygiene amongst the masses.

As part of improving outreach of IEC material to health workers in the field, the team will compile the existing health promotion material and make it available through the portal.

IV.1.2 AYUSH Content

It's also being proposed AYUSH content will also be made available on the portal. The Department of AYUSH would be responsible to collect and compile health information that's already available for the masses and transfer this data to the portal development team which will be responsible to present the information in a standard format.

Along with health content, the AYUSH section would also consist of information regarding the AYUSH department (structure & function, offices, etc), courses that are being offered and the institutes where these courses are being offered. This would help prospective students to reach out and make informed choices

regarding carer options in AYUSH. Also part of this year, the portal will link-out to the Traditional Knowledge Digital Library (TKDL) database which will serve to foster modern research based on traditional knowledge.

IV.1.3 Regulatory Information

It is also proposed that the India Health Portal will provide information regarding regulations, standards and policies as described above in section V.5. This aspect seems important as the healthcare industry would need to comply with several such regulations, standards and policies. The insurance schemes of state governments in the areas of health will be listed here and links to appropriate sites will be provided.

IV.1.4 Disaster Management

In year 1, it is also being proposed that the India Health Portal will provide links to the various resources specific to disaster management and preparedness that are available on specific Government websites such as the National Disaster Management, Government of India http://www.ndmindia.nic.in, National Disaster Management Authority http://ndma.gov.in/ndma/index.htm and the National Institute of Disaster Management http://nidm.gov.in/. This will help masses in better understanding the anatomy of both natural and manmade disasters and help them to be better equipped to manage these unfortunate incidents.

It is proposed that during this year the India Health Portal should contain comprehensive information and listing regarding national health programs that have been initiated by the government and that are aimed at improving the reach and delivery of healthcare across the country.

IV.1.5 Directory Services

This service will provide a database of all healthcare providers in the country. This list will contain vital information such as address and contact details of health care providers such as registered hospitals, nursing homes, private clinics,

government hospitals, primary care health centres, etc. Data would be taken from MoHFW, Infrastructure development division which is updated annually. Accordingly the states will be required to update the portal annually.

IV.1.6 Deliverables in Detail for each Year

Year 1

Task Name	Resource Group	Clearing House
Year I		
IEC Material Collection & Integration	NIHFW	CHI
Health Information - Already Available (Collect & Collate)	NACO+IDSP+DGHS	CHI
AYUSH Content	Dept. of AYUSH	CHI
Directory Services	WHO	CHI
Regulatory Issues	MoHFW, Legal Experts	CHI
National Health Programmes	NIHFW	CHI
Disaster Management	NDMA/ NIDM	CHI
Standardizing Content	CDC	CHI
Dissemination	**Information and Publicity**	
Enabling CSCs with content for dissemination		
Identifying Vendors for Kiosk, booklets & DVDs		

Table III.1: Deliverables for Year 1

IV.2 Year 2

This year will see the creation of pristine content. The CHI will enable the CDCs to create new content that would be vetted by health care professionals. Along with new content creation which will include AYUSH topics. The CCDC would create interactive modules & online health widgets. This phase would also consist of translating content that was uploaded in year 1 into 11 major Indian languages. Deliverables of this phase have been described in the following paragraphs.

During this phase, the following content would be uploaded onto the portal:

- ✓ Patient Information Fact Sheets/ Interactive modules

- ✓ Directory Services
- ✓ AYUSH/ Complementary and Alternative Systems of Medicine
- ✓ Online Health Tools and widgets

IV.2.1 Patient information sheets/ Interactive modules

This section will contain information in the form of static text pages, interactive modules, illustrations, animations and downloadable patient information sheets that can either be viewed on the portal or could also be downloaded on to a computer, burnt on a CD/ DVD or can be printed in the form of patient information hand-outs.

This section will consist of health information that will be presented in a format that is succinct and addresses key points of interest or concern. The design will be fairly minimalist and aesthetic which will convey the most relevant information in the least amount of space. The purpose of such a design is to reason in the concept that facts proliferate in an ever-increasing number while the time available to review and comprehend them diminishes. These fact sheets will attempt to solve this problem by condensing information into an easy-to-read, straightforward, portable and modular form of knowledge.

The areas that will be covered in this module include the following broad categories:

- ✓ Blood
- ✓ Bones & Joints
- ✓ Child Health
- ✓ Heart Health
- ✓ Mental Health
- ✓ Pregnancy
- ✓ Respiratory
- ✓ Sexual & Reproductive Health
- ✓ Travel Health

At the end of each module, there will be an optional quiz which the user can take that will evaluate the extent to which he/ she has understood the module. Short films will be embedded within select modules which will make the information dissemination more efficacious.

These modules will be built using contemporary software, and the modules will require minimal plug-ins so that the content can be accessed with ease.

IV.2.2 Directory Services

Health care provider information will be updated during this phase. This phase will aim to include the smaller health facilities and individual providers who have been missed out by the mechanism applied in Year 1. During this Year, online registration forms will be made available. With the help of this, providers will be able to upload their information such as specialty name, range of services, contact details etc. This process will however require validation to prevent misuse. For this purpose, external validators will be hired who will be responsible for the accuracy of the information provided. The directory services could also include 24-hour pharmacy and blood bank locations.

The mechanism for online registration and validation would be as follows:

Individuals who seek to upload their details will need to register online with the portal. This may either be a free registration or a nominal fee can be charged from the individuals who wish to do so.

- Data that will be collected from individual care providers would contain their address and telephone number and GIS coordinates if possible.
- The validators will be responsible to call back these individuals and confirm location and identity.
- Once the validation has been performed, the webmaster can then give authorization for the information to become public.

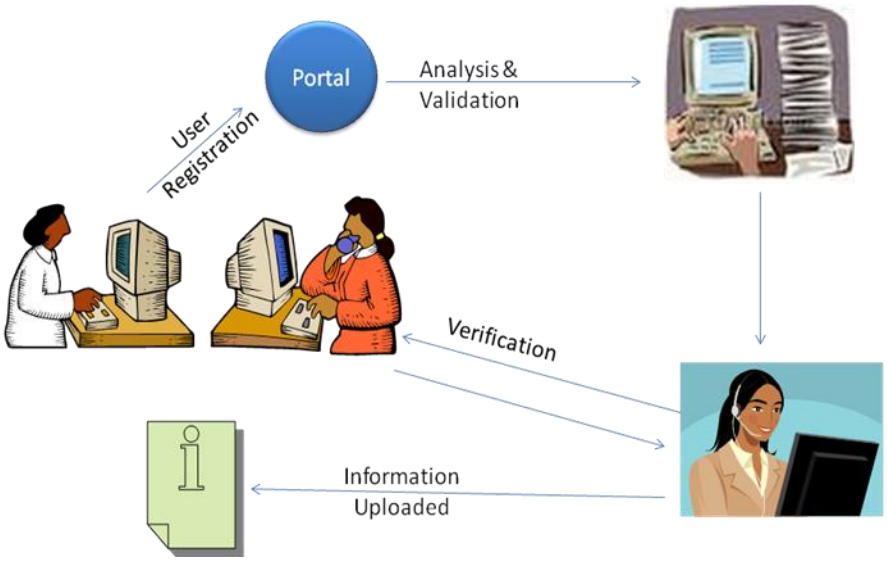


Figure III.1: Individual Health care provider Registration Mechanism

This information will be made available when the user selects key information such as name of state, city, village etc in the form of dropdown options or search as you type feature. Based on his selection, the portal will be able to display the closest matches to his selection as indicated in the figure below.

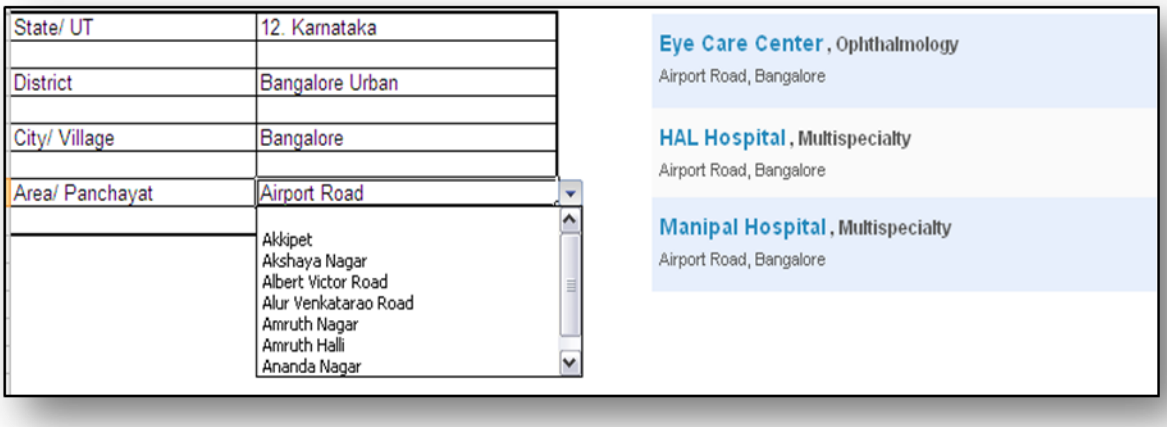


Figure III.2: Proposed Directory Services User Interface

The directory services module in Year 2 will incorporate advanced features that have been discussed in the sections below.