“Barriers to equitable access to quality health information with emphasis on developing countries

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Methodology

- The terms of reference of the study was defined by BIREME in the context of the objectives and expected results of the meeting on access to quality health information it is organizing with the support of the Rockefeller Foundation and as part of the series of conferences related to eHealth the foundation is leading and to take place in Bellagio in July-August 2008.
- The study was conceived and implemented under a vision favoring the promotion and achievement of equitable access to quality health information within developed and developing countries, with emphasis on the later. The following aspects and tasks drove the study:
- identification of main barriers to equitable access to quality health information
- highlight existing national, regional and global initiatives working towards equitable access to quality health information
- identification of solutions to remove barriers
- identification of current and emerging ICT tools enablers of smooth flow of information
- identification of partners for global solutions towards equitable access to quality health information
- lessen the “information divide” between rich-information and poor-information countries

Methodology

A bibliographic review was conducted in the NLM's PubMED, Google, Google Scholar, ALA, Cochrane Library, Global Health Library regional indexes, Wikepedia, etc

Comments/feedback were received from members of discussions groups such as HIF-NET, HIFA-NET, BOAI and IAMI (Indian Association of Medical Informatics)

This review confirmed the main barriers identified in the study and provided the basis for the description of each barrier, its understanding, and research conducted as well as solutions, proposals and ideas for their overcoming.

Some comments from professionals

Dr. Sridhar Bodapati, Bangalore, India – *When we talk about Barriers to Equitable Access to Health Information I will consider both Patients and Providers (Doctors, Nurses also)*

- ***For patients, barriers are:***
- ***Language:*** *Many patients don't understand English, which happens to be the main medium of communication in India. Sometimes the patient is from another part of the country and the doctor doesn't know his language. Interpreters are not available.*
- ***Jargon:*** *Patients don't understand jargon, which healthcare workers tend to use.*
- ***Assumptions:*** *Based on their own knowledge, past experience, advice from elders etc. patients have certain assumptions. In spite of getting the correct data, what they conclude is often wrong.*
- ***Information overload:*** *Some patients use the internet and get a lot of info, but are they getting the right information. How can they ever know which is the right source?*
- ***Cost:*** *Can they afford to get the right info from the right source. I don't really know what literature they can buy. Maybe a good h ealth magazine, maybe go to a good doctor who does give info.*

- ***Barriers for Doctors***
- ***Language:*** *So all of us know English. But, do we really know it. It's not our mother tongue. Moreover U.S English is not the same as U.K English.*
- ***Cost****: Can we afford the journals. Even single articles are so costly. Can all doctors afford the internet connection and the PC??*
- ***Information overload:*** *There are so many journals and so many online articles. It's tough to judge which one is correct. Are all the findings valid? Has enough research been done? Is the example size good enough*
- ***Assumptions:*** *Is there an underlying assumption in the reader's mind that research done in USA is better than that done in India. If the writer is a Nobel laureate can we assume that all his articles are of the highest quality?*
- ***Inability to use Computers/PDAs etc:*** *Many doctors and healthcare workers simply don't know how to use the PC or the PDA.*

I think its not just access to information to the problem but also the ability to sift the information and to make the right judgment. Not everybody can interpret statistics properly. All of us assume something or the other all the time (I assume that I have made some good points, maybe I am wrong). And frankly, I hope more and more of medical knowledge is available in local languages. Many of my classmates were very intelligent and hardworking, but simply couldn't understand English well enough. Also, a lot of good stuff is written by the Russians and the Japanese, we simply can't understand those.

Barriers, Their Status & Possible Solutions……..

Identified Barriers	Current Status	Possible Solutions
Connectivity - how to expand and maximize the availability and use of different and new media to communicate health information, knowledge and evidences to health researchers, practitioners and the general public. Particularly, how to serve the last mile so the flow of information and knowledge becomes ubiquitous	As per 2008 March statistics portrayed by Internet World Statistics (http://www.internetworldstatistics.com), Asia has 512 million internet users, followed by Europe (374 million), North America (243 million), Latin America/Caribbean (127 million), Africa (45 million), Middle East (34 million) and finally Oceania/Australia (19 million). Though, Asia topped the figures with the highest Internet users, with a low internet penetration of 13.6%; Latin America was fourth in the number of Internet users but with 22.1% internet penetration. Africa figured 45 million Internet users with only 4.7% internet penetration. The top 20 countries with maximum internet users reveals that the United States toping with maximum users of 211 million and least Philippines with 14 million.	✍Intermediation - public spaces, infocentres, public terminals, radios, TV, etc. ✍Use of emerging mobile Health tools ✍Improving broadband connectivity to the under developed areas ✍Possibility of tie up with Internet service providers to establish a smooth flow of information and knowledge.

Identified Barriers	Current Status	Possible Solutions
Critical Appraisal / Medical Writing – how to ensure quality information; lack of training in high quality medical writing and lack of training in critical appraisal feeds into this too; lack of good facilities for conducting trials and lack in time (as in developing countries the doctor sees more patients than his counterpart in developed countries)	Many doctors believe that if one has learnt how to use a computer, he/she should know how to use medical information resources. The seniors think that younger doctors could manage information retrieval simply because they have learnt to use a computer. The doctors who are "computer / Internet savvy" do manage to find a good number of useful resources and references. This comes with their basic intelligence and practice in using computers and information resources. Many "net-savvy "doctors who initially wondered what was so special about searching, and then on watching demonstrations of correct search techniques, admitted that they were not aware of these Training programs in these in areas of Critical Appraisals are also sporadic and rare. All these are the result of language barriers as well as lack of time in addition to an unbalanced doctor: patient ratio in developing countries.	• Special training programs for medical researchers in medical writing • Creating awareness to the resources available. This would ensure "better" quality health information. • Also required are regular training programs in literature searching, library usage and critical appraisal. • Time needs to be devoted to review the information already available for producing quality research papers.

Identified Barriers	Current Status	Possible Solutions
Language Barrier - Contextualization and appropriate up to date translation of scientific knowledge - how to develop instances that review, adapt and put in context knowledge already available in order to lessen the know do gap among the health systems workers, patients and citizens?	Information in published in non-English journals does not reach the English speaking users. Medline indexes more than 48,000 non-English journals in 56 languages. Some International MEDLARS Centers, including those in Germany, Japan, Brazil, and France, as well as other national medical information centers have long produced translations of MeSH to make the vocabulary useful for non-English users. Various translations of Medical Subject Headings (MeSH) enable users not familiar in English to identify articles that are of sufficient potential interest to warrant further effort to ascertain if the article addresses their concerns. Known translations of MeSH in UMLS – French, German, Finnish, Portuguese, Spanish, Russian, Swedish and Japanese. Other complete translations– Arabic, Chinese, Czech, Greek, Thai and Turkish (all details of 2004). MedlinePlus Health Information is now available in 40 languages (Arabic, French, German, Urdu, Portuguese, Spanish, Somali, Thai, Russian, etc). NLM also offers health information in Cambodian/Khmer Chinese, Filipino/Tagalog Hmong, Japanese, Korean, Laotian , South Asian (Asian Indian), Thai and Vietnamese.	✍Reliable translation services should be provided by agencies/organizations. ✍There is need for multilingual health information in different formats. ✍New technologies offer solutions to providing consumer health information despite problematic issues. • Libraries can play a key role in making multilingual materials available to their constituent populations and the world. ✍Explore potential use of Internet translation tools

Identified Barriers	Current Status	Possible Solutions
Copyright – how to enrich the approach to intellectual property towards the formation of common digitals and public goods on health information, knowledge and evidences	This is an obvious barrier which restricts access and distribution to peer reviewed journals. To further the development of knowledge, researchers, scholars and even the layperson requires access to relevant scholarly literature. Increasingly, this literature is interdisciplinary, global, expensive, digital, and hidden behind technical walls to comply with license restrictions. Access is limited and free distribution of the information is restricted. Copyright laws prevent free distribution of peer reviewed health information; use of literature is mostly restricted to use for research purposes and cannot be freely distributed to the user community. Permissions from journals' publishers lead to further delay in the distribution of quality health information. In a paper on Intellectual property and networked health information: issues and principles, it has been felt that government must provide particularly important health information to the public, and facilitate that information's accessibility and reliability, while avoiding unnecessary competition with private information providers. Both producers and users of information must work with the government to educate the public about the availability of health information and the rights of and limitations upon users under copyright law.	✍Pursue Open Access to health information resources ✍Promote open access and self archiving culture.

Identified Barriers	Current Status	Possible Solutions
Economic – how to make quality health information, knowledge and evidences open and accessible in the global south? How to enhance business and economical models towards the development and operation of digital goods in health information, knowledge and evidences?	High cost of journals' subscription charges restricts the access to these journals. Electronic publishing has made these journals available on their websites, but again is fee based. A study examined the rates of print journal subscription price increases according to the type of available electronic access. The types of access included: electronic priced separately from the print, combination print with "free online" access, and aggregated, defined here as electronic access purchased as part of a collection. The findings revealed that the increases of print prices for their sample of titles were higher if a type of electronic access was offered. According to the results of this study, aggregated collections currently represent the electronic option whose percentage price increase for print prices was lowest. However, the uneven fluctuations in rates of subscription prices revealed that the pricing of journals with electronic access is still evolving.	o Create Open Access start-up Journals from developing countries to make information electronically available; the cost of publishing would residual

Identified Barriers	Current Status	Possible Solutions
Local, national and regional visibility and accessibility - how to strengthen the visibility, accessibility and credibility of developing countries scientific production and contents?	Lot of information is available in local language in national or regional level journals. This does not disseminate to a wider community of readers/users, hence posing as a barrier. The information found in international journals is often not relevant to the developing world. National and regional journals attempt to fill the void by publishing robust and relevant information. However, these journals face difficulties in sustainability and local access.	o Develop Regional and national consortia to ensure the visibility, accessibility and credibility of developing countries scientific production and contents. o Encourage interlibrary loan and document supply among entities
Information technology literacy- How to facilitate the use of technologies to access health quality information by using commonly used devices, interfaces, packaging of information, language of communication, etc.?	Lack or poor knowledge of IT tools poses another barrier to access to health information. More than 70,000 websites disseminate health information; in excess of 50 million people seek health information online, with likely consequences for the health care system. A paper reports of a study to identify the extent of postgraduate nursing students' information literacy skills in relation to electronic media and health information and barriers to accessing this information. The study was conducted through questionnaires and it concluded that the development of nursing competencies in accessing and using online resources is a key precursor to supporting patients and families' use of the medium. Access to Internet resources at work, along with training and time for searching, is necessary for the development of skills enabling effective use of information technology.	✍Training in upgrading the IT skills of medical community. ✍Awareness of the IT tools available should be an essential part of the medical education curriculum.

Identified Barriers	Current Status	Possible Solutions
Cultural - how to make information that is culturally acceptable and relevant within the different settings and domains, keeping the end-user in mind? How to popularize the search for scientific evidences amongst the general public? How to make information a trigger towards behavioral change? How to develop information flows that support healthy life styles?	Use of health facilities by due to cultural reasons leads to bad health life styles. Information is not disseminated to the end user highlighting the benefits of health care and facilities, thus leading to non-use of these facilities. Also, ethnic, language and other cultural barriers impede the flow of information. In one study, the literacy levels among older patients, the readability and the cultural sensitivity of written information used in an anticoagulation management clinic was investigated. It was found that the average self-reported for highest grade completed in school was twelfth grade; however, the actual mean reading skills were between seventh and eighth grade. The readability of the written information was three to four grades higher than patients' reading abilities. None of the patient education materials were culturally sensitive. Another study was aimed to identify and document access barriers to health care services for the indigenous population in Rabinal, Guatemala.	✍Cultural barriers can be removed by out-reach of IT and remove the digital divide. ✍Also ensuring access to online technologies and developing educational programs that build health information and technology efficacy in underserved populations.

Identified Barriers	Current Status	Possible Solutions
Lack of government support/funding and lack of public policies – government funded research needs to get more publicity and wider access; such research is lying "closed" to the medical community; right to information act proposed that would enable the general public to have access to the rules and policies	As research becomes increasingly global, data intensive, and multifaceted, it is imperative to address national and international data access and sharing issues systematically in a policy arena that transcends national jurisdictions. Lack of government support/funding and lack of public policies – government funded research needs to get more publicity and wider access; such research is lying "closed" to the medical community; right to information act proposed that would enable the general public to have access to the rules and policies. Access to and sharing of data are essential for the conduct and advancement of science and publicly funded research data should be openly available to the maximum extent possible. In one study in India, the aim was to explore the route map for employing efficient e -governance so that at least existing resource and infrastructure are better utilized and deficiencies are tracked for future planning.	o Public funded research should be made available to the public. This research remains "locked up" and for this the government has to revise the policy. Support to information flow should also be ensured o Support a Right to Information

Role of Stakeholders at Global, Regional and National Level to remove Barriers

- Generating quality content for access
- Ensuring availability of quality health information in accessible format (web-based or CDs)
- Information should be available in local language (if feasible)
- Non-English research publications should be made available in proper translated form or English abstract must be compulsory
- Availability of information in Open Access format
- Information should be made available from single as well as multiple servers (mirror servers should also be made available)
- Reliable connectivity reaching the last mile that would ensure access in remote areas

Potential Partners/Stakeholders for Information Dissemination and Funding

- NLM
- WHO – SciELO, SEARO….
- BIREME/PAHO & other South American Partners
- Africa Online and related initiatives
- HINARI
- Virtual Health Library
- Global Health Library
- HELLIS
- Government Departments
- National/Regional Health Libraries
- Internet Service Providers

Discussion & Trends

There exists a digital divide not only between the developed and developing countries, but also within developing countries themselves. Lack of proper infrastructure facilities leads to disparities within a country; this invariably leads to poor access to health information inevitably leading to poor quality health care facilities.

Eight main barriers to equitable access to quality health information in developing countries were identified during the course of the study undertaken. These were Connectivity, Medical Writing Skills, Language, Copyright, IT skills, Economic, National/Regional Resources, Cultural and Government Policies.

The primary barrier to access can be seen in the disparity in outreach of Internet access; though Asia has the highest Internet users, yet it lags behind in the reach of Internet which means that access to Internet is limited to major cities and towns. Another important barrier to access is copyright which prevents free distribution to health related information. This is followed, not necessarily in any order, by the high cost of journals, language, cultural, non-availability of regional/national information resources, restricting government policies and lack in training in medical writing and IT skills.

Discussion and Trends....

Internet growth has been ten-fold in the last ten years, from the approximately 147 million Internet users reported for year-end 1998 to the current 1,407 million users in 1 quarter of 2008. World Internet penetration rate is now 21.1%, based on a 2008 population estimate of 6,676,120,288. Asia has the largest population of Internet users, currently at 529,701,704 and the largest potential for growth. Future Internet growth will be substantial in Asia considering the current low penetration rate of 14.0%. Following in size is Europe with 382,005,271 Internet users, where the penetration rate is high, currently at 47.7%. North America, mainly Canada and the United States, represent the third largest group of Internet users in the world with 246,402,574 people. The Internet penetration rate in that region is the highest in the world with 73.1%. Another region with very high Internet penetration rate is Oceania, mainly Australia and New Zealand, with 57.0% and 19,353,462 users. Latin America and the Caribbean house the fourth largest group of Internet users, currently numbering 137,300,309 and growing at a fast rate. Internet penetration is 23.8% in this region. The smallest Internet usage regions in the world are Africa with 51,022,400 and the Middle East with 41,939,200 people. Although current Internet penetration rates are low, both regions have exhibited substantial Internet growth rates in the last few years (**http://www.internetworldstats.com/pr/press005.htm**).

Recent advances in Internet enabled mobile devices have paved the way for remote patient monitoring applications programmes are being conducted to train of medical professionals to ensure retrieval of relevant information. In India, National Informatics Centre (Department of Information Technology) has extended Internet connectivity through Community Information Centres to remotest North Eastern areas of the country and Orissa. This has enabled the common man and the medical professionals to access information sitting in their town/district. Through the CICs, distant CME programmes have been conducted for doctors in these areas as well as tele-referral services are being provided. NLM's Medical Subject Headings is being made available in languages other than English and NLM has also made available consumer health information in more than 40 languages. The cost of journals is spiraling as seen by samples taken from a hospital library and Elsevier, BMJ and Oxford Publishers price lists. There is a trend to adopt Open Access technology for publishing of journals and providing free access to health literature. Also, Open Journal System is being used by several publishers that enable online publishing of journals free of copyright restraints. NLM's Medical Subject Headings has been available in languages other than English, thus facilitating translations of published papers; NLM has also made available consumer health information in over 40 languages

Conclusions and Recommendations

Ensuring reliable connectivity and Internet access to the last mile: Setting up effective broadband connectivity to the remotest areas and also ensuring back up power supply.

Effective training in IT skills and information retrieval techniques: Medical professionals / researchers/information professionals need to be trained to improve their IT skills and be more IT friendly. Training in searching for information and critical appraisal is also essential so that relevant information can be retrieved and used effectively. Training in effective searching of PubMED and other MEDLARS databases, Google, Google Scholar and other resources has to be made essential and possibly part of a regular curriculum.

Strengthening of Medical libraries: Provide resources (books, journals, etc) and trained manpower; provide connectivity and networking of libraries for interlibrary loan and document delivery systems.

Consortium building at National, Regional and Global Levels: Interlinking of existing initiatives to the Global Health Library and funding of new regional/national initiatives. Sharing and exchange of information between consortia members to be encouraged through interlibrary loan and document delivery systems.

Conclusions & Recommendations..

Promoting Open Access Publishing and Building of Institutional Repositories: Encourage more journals in areas of biomedical/medical/health sciences to publish in open access mode utilizing tools like Open Journal System. Institutions to be initialized in creating knowledge based repositories and researchers/professionals to be sensitized on self archiving benefits.

Availability of online, web versions of journals/information sources: Publishers should enable access to journals' articles free of cost after a certain time period. Presently access is restricted to current subscribers or is fee based.

National and Regional level information to be disseminated in proper and effective mode: Support production of information for a local audience through increase of local information publication using suitable local human resources and promotion of quality accreditation of websites. Availability and dissemination of locally produced information onto a more international platform is essential. Effective translation services to be made available from agencies that would enable information to be made available to English/non-English speaking users.

Government Policy: Government funded research results should be made available to the medical community and the public. Right to information should be made mandatory law thus enabling the common man to access information.

Indian Medlars Centre's initiatives at National Level

IndMED – bibliographic database of peer reviewed over 70 biomedical journals (free access)

medIND – full text of 40 IndMED journals (free access); includes 2 Medline journals

OpenMED – Open Access Archive with over 1100 registered participants and over 2100 submissions; uses MeSH for indexing

Training in searching Internet tools/resources

Proposal....

Develop institutional repositories in specific subject areas.....

Form consortium of participating institutions for data sharing and data input for IndMED/medIND databases

Metadata harvesting...at NIC, New Delhi

Assisting /Training in Online journal publication using PKP's OJS software..

http://www.oksociety.org/whatwedo

Google

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Open Knowledge Society aims to facilitate all forms of Open Access to Knowledge.

It includes:

- Supporting creation of Institutional Repositories
- Supporting publication of Open Access Journals
- Supporting conversion of print journals into online versions
- Supporting making online journals OAI-PMH complaint
- Supporting automation of libraries
- Supporting Digital Libraries
- Supporting Open Courseware and Open Data
- Other activities that promotes open access to knowledge.