Health Systems

Sea-Change or Change Challenge? Health Information access in Developing Countries: The U.S. National Library of Medicine experience

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Abstract

Health professionals in developing countries want access to information to help them make changes in health care and contribute to medical research. However, they face challenges of technology limitations, lack of training, and, on the village level, culture and language.

This report focuses on the U.S. National Library of Medicine experience with access: for the international medical/scientific community to health information which has been published by researchers in developing countries; for scientists and clinicians in developing countries to their own literature and to that of their colleagues around the world; for medical librarians who are a critical conduit for students, faculty, researchers, and, increasingly, the general public; and for the front line workers at the health center in the village at the end of the line.

The fundamental question of whether or not information communication technology can make a difference in access and subsequently in health is illustrated by an anecdote regarding an early intervention in Africa in 1992. From that point, we examine programs to improve access involving malaria researchers, medical journal editors, librarians, and medical students working with local health center staff in the village. Although access is a reality, the positive change in health that the information technology intervention might produce often remains a mirage. Information and technology are not static elements in the equation for better access. They must function together, creating a dialectic in which they transform and inform one another and those whom their combination touches.

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Introduction

In 1992, a small satellite in a low earth orbit quietly delivered the first electronic version of a medical journal article[1] in sub-Saharan Africa. Published in the *New England Journal of Medicine*, the article concluded that "treatment with vitamin A reduces morbidity and mortality in measles, and all children with severe measles should be given vitamin A supplements".

At the time, measles persisted as a common killer of children in developing countries and vitamin A was readily available almost everywhere. Results of this research, carried out in Africa, had not reached African doctors who could have used it to save lives. The delivery of the medical journal article in sub-Saharan Africa provided a symbolic gesture, bringing home information that had belonged there all along. When the antennae on the ground picked up the signal of the satellite above, the article was transmitted from the sky to the computer at the ground station in Nairobi[2].

As difficult as it was to get all the technology to work properly to accomplish this simple exchange, the challenge of access had just begun. The article had been delivered into a void. There was neither a digital network to disseminate the article, nor a body of users (policy makers and health professionals) ready to receive it electronically and put the information to use. The technology succeeded - the first electronic delivery of a medical journal article in sub-Saharan Africa - but the transfer of bits, as yet, had no meaning[3].

Background

In the early 1990s, SatelLife's HealthNet system and information service was the first to address the challenge of health information access through the digital medium. In the intervening years, access to first the peer-reviewed literature through the National Library of Medicine's (NLM) PubMed and then an accurate and high-quality reliable consumer health

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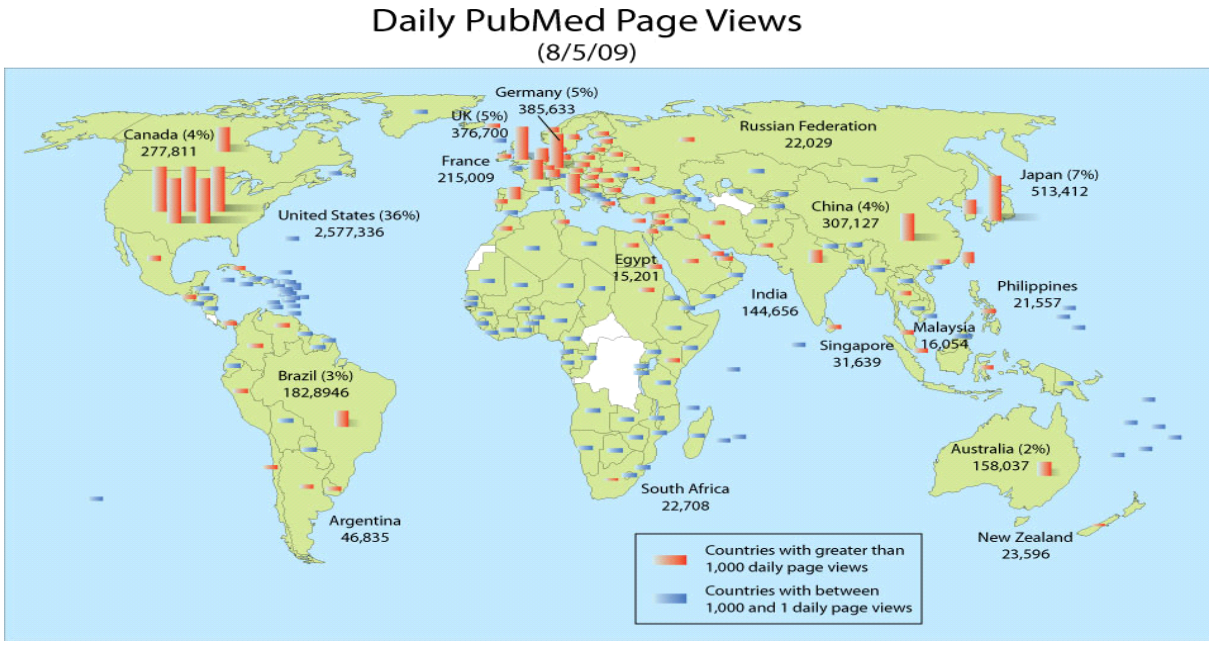
website, MedlinePlus, made health information more readily available. Access to the full-text peer-reviewed literature was eased through the development of PubMed Central's full-text archive and through WHO's Program for Access to Health Research (HINARI). The HINARI program provides a mechanism for publishers to make their collections of full-text journals available to institutions in developing countries. Table 1 provides a chronology of changes in electronic access to health information.

Table 1: Milestones in electronic acccess to health information

1992	SatelLife's delivery of Vitamin A article to a ground station in Kenya and subsequent publication of HealthNet News (www.satellife.org)
1997	Free MEDLINE on the Internet (www.pubmed.gov)
1998	Free MedlinePlus on the Internet for the public (www.medlineplus.gov)
1998	Multilateral Initiative on Malaria Communication Network (MIMCom)
2002	WHO's HINARI Access to Research Initiative for full text journal access – free to many developing countries (www.who.int/hinari/en)
2002	Development of PubMed Central full text archive – free (www.pubmedcentral.gov)

Within relatively few years, the prevalence of electronic journals, the availability of free access to MEDLINE, and the development and expansion of the Internet have changed the landscape dramatically. The private sector through HINARI[4] and other nongovernmental organizations have made great strides in addressing access to biomedical literature. By late 2009, a single day snapshot of PubMed page views shows most countries within sub-Saharan Africa accessing the database between 1 and 1,000 times per day (figure 1). While there is greater availability of medical and scientific literature through the Internet, there is also greater availability and prevalence of non-medical information including entertainment, videos, images, games and business.

Figure 1: Daily PubMed Page Views, 5 August 2009



This growing desire for more bandwidth is taking place against a backdrop of limited Internet access and reliable electricity. Africa has 15% of the world's population with only 5% of the world's Internet users (table 2). Lack of internet access is compounded by inadequate and unreliable electricity supply. Seventy-five percent of the sub-Saharan Africa population does not have access to electricity and that figure is on the increase as the population grows but the ability to generate power declines. Ten sub-Saharan African countries experience 30 or more days of power

outages per year, causing loss of productivity and equipment damage for businesses[5].

Table 2: World Internet usage and Population statistics

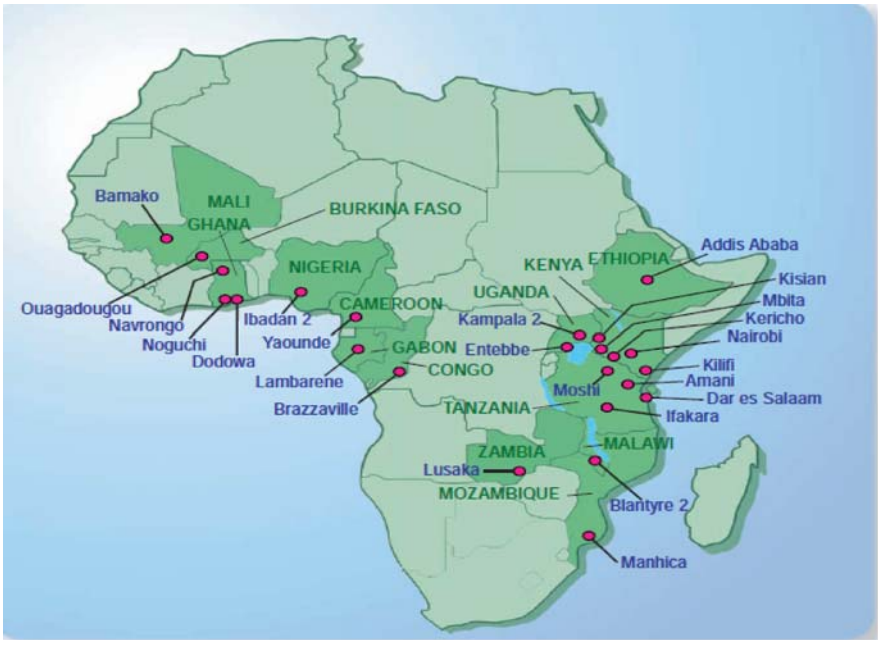
World Regions	Population (2009 est)	Pop % in World	InternetUsers, Latest Data (2009)	Penetration (% Population)	Users % of Total
Africa	991,002,342	14.6%	86,217,900	8.7%	4.8%
Asia	3,808,070,503	56.27%	764,435,900	20.1%	42.4%
Europe	803,850,858	11.88%	425,773,571	53.0%	23.6%
Middle East	202,687,005	2.99%	58,309,546	28.8 %	3.2 %
North America	340,831,831	5.04%	259,561,000	76.2 %	14.4 %
Latin America/ Caribbean	586,662,468	8.67%	186,922,050	31.9 %	10.4 %
Oceania/Australia	34,700,201	0.51%	21,110,490	60.8 %	1.2 %
World Total	6,767,805,208	100%	1,802,330,457	26.6 %	100.0 %

Table from Internet World Statistics. http://www.internetworldstats.com/stats1.htm

Multilateral Initiative on Malaria Communication Network (MIMCom)

To meet the real needs of scientific researchers, NLM made possible enhanced access to the Internet and to medical literature at the request of African researchers. Starting in 1998, the Multilateral Initiative on Malaria Communication Network (MIMCom) eventually reached 27 research sites in 14 sub-Saharan African countries (figure 2). When a study examined the use of MIMCom supported information technology (IT) by scientists, students, and administrative personnel to facilitate communication, retrieve information, obtain documents, write proposals, and prepare papers for publication, it was shown that this intervention made a positive contribution to the professional performance of malaria researchers and support staff at the sites reviewed by improving e-mail exchange, access to published literature, and research proposal development and submission. By providing full access to the Internet and the resources of the World Wide Web, MIMCom was shown to be invaluable to malaria researchers and their institutes in Africa. This access increased visibility of scientists in their respective institutions and supported opportunities for stronger engagement with the international scientific community[6].

Figure 2: MIMCom Communications Network



African Medical Journal Editors Partnership Program

The MIMCom offered lessons for subsequent projects in Africa: enhance existing resources for a dedicated purpose and build human capacity and infrastructure within country in order to create research products and services that are competitive beyond African borders. The African Medical Journal Editors Partnership (AJPP) follows this model.

The goal of this program is to build the capacity of African journals, so that they are accepted into MEDLINE. Once the journals are indexed in MEDLINE, their research becomes available to and archived for the international medical and scientific communities. The program ensures that its editors have the knowledge and resources to develop an adequate production and quality review system. By strengthening the editorial and technical functions of developing country journals not currently in MEDLINE, the project can, over time, make a major contribution to creating an inclusive and enriched information highway for the medical/ scientific community.

The inaugural meeting of AJPP was held in September of 2003 in London at the British Medical Association. Working hand in hand with the Forum for African Medical Editors (FAME), the Program includes journals associated with sites where the NLM and the U.S. National Institutes of Health (NIH) have projects - in Mali, Ghana, Uganda, Malawi, Zambia, and Ethiopia. The AJPP comprises editors of *Mali Medical, Ghana Medical Journal, African Health Sciences, Malawi Medical Journal, Medical Journal of Zambia,* and *Ethiopian Journal of Health Sciences;* editors of *The Lancet, British Medical Journal, The Journal of the American Medical Association, Environmental Health Sciences, Annals of Internal Medicine, The New England Journal of Medicine*; and the Council of Scientific Editors. Three institutes of the NIH (NLM, Fogarty International Center, and National Institute of Environmental Health Sciences) have supported the program. In addition, NLM has supported technical capacity building, providing site visits by experienced information technology experts from Africa and purchasing equipment, including computers, printers, scanners and software. Staff from each African journal visits the offices of its partner journal for one to two weeks. African editors report these site visits to be extremely useful for observing the editorial and publishing practices of another journal[7].

With the support of the Partnership Program, African journal editors have organized a series of training workshops for editors, authors, reviewers, researchers, and journalists. The workshops have provided hands-on experience and lectures emphasizing international standards for writing and a systematic approach for reviewers. International trainers have helped facilitate some of these workshops, and an element of training the trainers was incorporated into many of them. Workshops have been well attended and feedback has been positive from both participants and facilitators. Some of the editors have already noticed improvements in the quality of their contributors' work.

Three of the original four journals are currently indexed in MEDLINE and the program is now in a second phase with the inclusion of the *Medical Journal of Zambia, Ethiopian Journal of Health Sciences, The New England Journal of Medicine*, and *Annals of Internal Medicine*. Essential to the success of this phase will be a diversity of funding, including contributions from publishers. Also, the program will need to assess from the experience thus far how most effectively and efficiently to build capacity in African journals. Strategic forward movement will both help the journals achieve sustainability as well as stronger editorial and technical bases. Not one strategy or time frame will fit all journals, so care will need to be taken to work with the particular strengths and challenges of each.

MedlinePlus African tutorials: focusing on disease issues in developing country contexts.

In this program, NLM brought together the existing machine of its consumer health website, MedlinePlus, with medical school faculty and students at Makerere University in Uganda where the faculty had recently implemented a case-based curriculum and a community-based education and service program. The challenge was to leverage the delivery platform of MedlinePlus and work with two teams of players from the US and Uganda to a successful local outcome that could be shared internationally.

This project is another effort by NLM to reach the consumer/end user, no matter where that user is located in the rural districts of Uganda. The first two tutorials on malaria and diarrhea[8] were developed with the Faculty of Medicine at Makerere University in Uganda. In coordination with the Dean of the Faculty of Medicine, NLM worked with African doctors, artists, medical students, and translators to create two original tutorials. The tutorials were field tested as part of the medical students' curriculum and have been translated into

local languages of Luganda, Rukiga, Luo, Japadhola, Kinyrurwanda, and Kiswahili. The project leaders reported that the students enjoyed using the tools and were especially pleased.

The project inserts another layer of health care education in the field and in the medical school, connecting those two worlds in ways whereby each can inform the other. The project leverages existing methodologies (MedlinePlus and the concept of health information for consumers) to create a new product for an African context, bringing together local health and language experts and a respected university with the cultural context and artists who can reflect that particular context through their use of imagery.

As the medical students field tested the tutorial they had created, they were able to witness tangible results of their success in integrating the messages of the tutorials with the life of the village (i.e. villagers cleaning up areas of their yards which had previously been breeding grounds for mosquitoes). The testing, in turn, increased their desire for working in the field and being, as they put it, "agents of change."

Students, health workers and staff of clinics are now able to use the tutorials in both electronic and hard copy formats (booklet, poster, and audio versions) to educate the general public. Through the Community Based Education and Service Program (COBES), students have taken the lead in distribution of these materials to district health offices, local health centers, youth centers, trading centers, churches, NGOs, internally displaced people camps, and schools in 20 districts in Uganda.

The students have carried out a baseline survey (over 100 respondents) on knowledge about malaria in Mifumi village outside of Tororo in Eastern Uganda. This survey has been analyzed and will be critical in determining whether an information intervention in electronic and hard copy formats can make a difference in the morbidity and mortality of malaria in this community.

The MedlinePlus African Tutorials project brings together Makerere University/ Faculty of Medicine's case-based curriculum and its field work component with a locally designed version of a highly successful NLM product, enabling it to serve the cause of health education in developing countries. For the Faculty of Medicine in Uganda, the project provides an innovative way to engage and harness the enthusiasm of young medical students. The success of this pilot project demonstrates the ability of the large institution NLM to reach end users who can effect behavior change in developing country contexts.

Training

In 2001, NLM added an international associate to its highly successful Associate Fellows program. The Associate Fellows Program offers recent library science graduates a year-long residency at the National Library of Medicine, with time spent in curriculum, working on projects and developing as leaders through mentoring, self-assessment and structured educational opportunities. One of the goals of adding an international associate from sub-Saharan Africa was to develop a cohort of African librarians over time. This goal has been partially met in that since 2001, five African Associates have joined the U.S. and Canadian Associate Fellows for this immersive experience at the National Library of Medicine. These librarians, from Kenya, Zambia, Mozambique, Mali, and Nigeria, joined by other close colleagues from Zimbabwe and Uganda, have formed the African Network of Medical Librarians and Deans.

The Network held its first organized meeting through an NLM-sponsored event in July 2009 at Kenyatta University in Nairobi. The medical librarians used this opportunity to design and outline an information literacy course for integration into the curriculum at their respective medical schools. To promote dialog among the librarians and the curriculum decision-makers at their institutions, the librarians' deans were also invited. The presented outline and proposed strategies for implementation was met with enthusiasm on the part of the Deans.

Also at that meeting, a series of interviews with the African librarians were conducted by an NLM staff person. The interviews were intended to aid in an evaluation and redesign of the international component of the Associate Fellows program. In the process of conducting the interviews, though, the impact of the program on the African librarians was clearly career-enhancing.

Conclusion

Access to the Internet is only one step in the process of making health information available and accessible to all who might make use of it. Online access meets challenges of unreliable electricity and a lack of widespread Internet penetration throughout sub-Saharan countries. Even with enhanced support for information technology, western programs that aim to assist African researchers, clinicians, and health care

workers must plan to collaborate on African-identified information needs and meet them where they are in their own research, education and careers.

In particular, medical libraries and librarians are an essential part of the equation as they reinvent themselves to serve the new world that information technology makes possible, bringing together the needed information resources, training users to find the most relevant information to meet a specific need, and providing a place – virtual or actual - where health professionals can pursue information toward better health outcomes.

We have reached a crossroads where the change challenge is in the active, innovative, and interdisciplinary engagement of users at all levels – whether in medical schools, the research community, medical libraries, district hospitals or the village. There are visible examples already, not quite 20 years after that first electronic delivery of a medical journal article in Africa:

African medical librarians are reaching beyond the borders of academia with experimental programs – in the districts of rural Uganda and a new model of health information center in a Masai community in Kenya.

African medical students are spending weeks of each year of medical school in rural communities and some are even taking on small research projects which challenge the assumptions of the larger research and funding communities. They use innovative IT applications to gather data and then take their research findings directly back to the community in village meetings where dialog takes place. Even if they don't pursue research professionally, they will never again view patients in the clinic in the same way after visiting their homes as part of a research project.

African journal editors aim for inclusion in PubMed/MEDLINE, advocating open access and often eschewing the expense of traditional paper publishing and looking to digital distribution to carry content instantly across continents and oceans.

Rather than following only the large funding interests in infectious disease, these new professionals also will study and implement prevention and treatment measures for chronic diseases of hypertension, diabetes, and the myriad of mental health issues – exploding the myth that chronic disease is not a part of the landscape in developing countries.

Further, effective support for research, prevention and treatment efforts will require an interdisciplinary team of health professionals as well as the talents of artists and input from the local communities. One such research team has developed a community education approach that has produced a pictorial informed consent, posters on why people do not seek treatment for their condition at the health center, as well as a video and tutorial on the research itself. The materials have been vetted on all levels with a dialectic taking place between the artists and medical personnel.

Research needs to be presented to policy makers in language and formats which are useful to them. Only then can the voices of the academy and the community be heard and policy informed to benefit health for all. This is an area in need of much development.

Engagement, exchange, and interchange are critical if major strides are to be made in improving the health of all through better access to information. The potential is here to create a healthy blur, lacking so many silos, among the arenas of medicine, public health, and the communities they serve. This new meeting ground can encourage teaching and learning and sharing of information among health professionals, policy makers and the community – a two way street that will enable people to take more control over and responsibility for their own health. The means of distribution will become more digital and more mobile, with these new professionals encountering one another and those they serve in person and in cyberspace, creating new meeting grounds that are ultimately more equitable.

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