Information in practice



Disseminating health information in developing countries: the role of the internet

Tessa Tan-Torres Edejer

During a visit to India in March President Clinton watched a woman enter a village health centre, call up a web page on the computer, and get information on how to care for her baby.¹ It is possible that this baby will have better health because of the availability of information on the internet. However, this possibility is underpinned by several assumptions, and the potential of information and communication technologies still has not been harnessed systematically to bring about important improvements in the health of populations, particularly among those who are poor and isolated in developing countries.

This article explores the potential of advances in information and communication technologies to disseminate information and describes the availability of access to technology in developing countries. It also discusses issues of accuracy and the relevance of content.

Methods

Sources for this paper were obtained by searching Medline using the term dissemination and from visits to websites and links to related organisations known to be working in the areas of health research and information and communication technologies in developing countries. Information was also provided by key informants working in international health research.

The digital divide: knowledge as power

Knowledge has been portrayed as a good that is available to the global public and as something that is not diminished after being used by an individual, and once provided it has been seen as difficult to restrict to a single individual or a group.² Advances in information and communication technologies make the global distribution of this good seem effortless. The technology, specifically the world wide web, enables information to be made available to multiple users the instant it is produced. Anyone can use it, whether an ordinary woman living in a village or a high ranking policymaker.

More importantly, users are not passive recipients. They can choose the type of information they wish to access. They can even produce or package the information themselves. As technology reporter John Markoff has said: "For very little money, and with a

Summary points

Information and communication technologies have not been harnessed systematically to improve the health of populations in developing countries

These technologies empower those who use information by providing them with a choice of information to be accessed in their own time and by allowing them to put their own information on the web

The current digital divide is more dramatic than any other inequity in health or income

The quality of health information available on the web is inconsistent, and the visibility of research from developing countries is limited

The way forward is to exploit the full interactivity of the internet, which allows rapid feedback and change to continuously mould information into useful knowledge

modicum of computer skills, virtually anyone can create his or her own website. Anyone with a modem is potentially a global pamphleteer."³ The vision that this conjures is both anarchic and democratising, and it emphasises freedom of expression and access to information. The power of technology has been described as revolutionary, and the Organisation for Economic Cooperation and Development has written of a new, knowledge based economy.⁴

However, it is rare for a woman in a developing country to have access to the internet. In Africa, which has a population of 700 million, fewer than one million people had access to the internet in 1998, and of this number 80% were in South Africa. Among the other 20% the ratio of people who have access to the internet to those who do not is 1 to 5000, in the United States or Europe the ratio is 1 to 6.⁵ According to the United Nations Development Programme: "There are more [internet] hosts in New York than in continental Africa; more hosts in Finland than in Latin America and the Caribbean; and notwithstanding the remarkable progress in the application of [information and Global Programme on Evidence for Health Policy, World Health Organization, 20 Avenue Appia, CH-1211 Geneva 27, Switzerland Tessa Tan-Torres Edejer scientist

tantorrest@who.ch

BMJ 2000;321:797-800

communication technologies] in India, many of its villages still lack a working telephone."6 That the digital divide is more dramatic than any other inequities in health or income is depressing because information and communication technologies have been hailed as one of the potential solutions to these inequities. The financial barriers to internet access are considerable, even just counting the costs of usage fees and telephone time which range from \$100 (£66) to \$1800 (£1200) annually and average about \$704 (£469) in Africa.⁷ During their meeting in April in Cuba the Group of 77, the largest formal coalition of developing countries within the United Nations, asked that efforts be undertaken to ensure that their countries would not be left behind by the rapid development of the internet.8

There have been some pioneering efforts to increase access to health information in developing countries. SatelLife uses the inexpensive but effective technology of the low earth orbit satellite to provide information to about 4000 health professionals in 30 countries in Africa and Asia.⁹ Aside from providing the technology and content, with funding from the World Bank, SatelLife is sponsoring a regional centre in Kenya to train health professionals to use information technology.⁵

At the Millennium Assembly of the United Nations in September 2000, it will be proposed that the right of universal access to information and communication services be added as a new component of the UN's principles and conventions on human rights and development. This will hopefully be implemented through a global initiative that will "provide access to the internet, especially through community access points, for the world's population presently without such access by the end of 2004."⁶

From information to action: the need for accuracy and relevance

Even if the woman in the village has access to the internet, she will not necessarily be able to use the information to improve her child's health because "trying to get information from the internet is like drinking from a firehose, you don't even know what the source of water is."¹⁰ Efforts are being made to devise a



Waystation at the British Council in Surabaya, Java, Indonesia

system for grading the quality of information provided by websites but, realistically, only a few sites can be graded.¹¹ It is the quality of the processes used to select the information that can be evaluated. The information itself can only be evaluated at certain points in time because of the dynamic nature of websites. Some consumers who use the internet feel that their only recourse is to search sites run by government agencies, medical journals, or evidence based groups; on these sites it can be legitimately claimed that the information has passed through a quality filter.¹²

Despite retrieving accurate information, the woman in the village still has to decide if the information is relevant to her situation. Much of the guesswork about generalisability would be unnecessary if the data came from her own country or a similar one. However, there is an insidious problem associated with the availability and visibility of health research from developing countries, particularly in printed media and its electronic counterparts.

Few reports of health research from developing countries are published in journals indexed by Western services such as Medline. Western indexing services cover some 3000 journals, of which 98% are from the developed world.13 The whole of Latin America accounted for 0.39% of the total number of articles referenced by Medline in 1996, down from a "high" of 2.03% in 1966.14 Because only a small number of journals from developing countries are indexed by Medline, research from these countries is almost invisible. Thus, for example in the 1994 Science Citation Index articles from Singapore accounted for 0.18% of the total compared with 30.8% for the United States, 7.2% for Germany, and 8.2% for Japan.¹⁵ The problem is complex, and possible explanations range from the difficulties encountered by researchers in developing countries in gaining funding for research-only 10% of funding is spent studying problems relevant to developing countries¹⁶-to the existence of "ethnocentrism at its worst"¹⁷ in biomedical publishing circles.

Some effort has been made to address this problem by including indexed, full text articles from journals in developing countries on services such as ExtraMED or ExtraSCI,13 but the very names of these services reveal their "alternative" nature: these are articles not included in the mainstream of Medline and the Science Citation Index. This is not bad in and of itself, but because these products are only available on CD Rom distribution and accessibility are limited. But now, with the availability of publishing software that can be coupled with powerful internet search engines, it is possible for authors or local scientific societies to bypass traditional avenues of scientific publishing. They can post their research directly on their own websites or, for example, on websites that focus on international health¹⁸ or on general health and clinical research websites like PubmedCentral¹⁹ or other electronic servers operated by biomedical journals.18 20

There are also the twin barriers of literacy and language. Many internet postings are in English. This is the point where local intermediaries, on the web or on the ground, can read, translate, and convert the information into content that is relevant to the local context. These "staging posts" might be governmental or non-governmental public service organisations or health workers in the village health centre. It has been recognised that "local conditions matter for the success of programs, that people on the ground have the most knowledge of local conditions and that the challenge of knowledge for development is to combine local knowledge with the wealth of experience from around the world."²

Interactivity on the internet: steps towards the future

MacLuhan, the man who recognised the power of the medium in delivering the message, accurately predicted that "the new electronic interdependence recreates the world in an image of a global village."²¹ That global village will be led by a younger generation that is more adept at using technology and, because of the nature of that technology, they will be more inclined to interact with it, to be responsive to feedback, and open to change. For the younger generation, relevant knowledge evolves through a process of adding value to which they themselves contribute.²² The distinction between users and producers of information will be blurred.

In the near future, wider global access to the internet will be facilitated by the development of less expensive technology. Greater mobility in using the technology will be made possible through the use of pocket sized wireless devices such as internet enabled mobile phones.²³ Extensive tailoring of the volume and style of presentation of information can already be done using hypertext and multimedia links. This can convert any material to accessible formats that cater for different audiences.

How can we "fast forward" to the future?

To ensure that the envisioned future does not remain merely commercial hype, a systematic effort should be made to exploit the advances of information and communication technologies for use in developing countries. Already many small efforts are being made to bring these technologies to developing countries. In Africa there are hundreds of initiatives developed by donor agencies: some are intended to increase access to these technologies in remote areas by establishing "waystations" (resource centres that provide access to health information on CD Roms and on line) and others are dedicated to increasing the use of these technologies in specific areas like health and agriculture. $^{^{24}\ 25}$ The long list of initiatives is impressive but has any effort been made to get them to work synergistically? This role is most appropriate for the nations themselves with the cooperation of international organisations and donor agencies.

In terms of health, attention would be best directed to improving access to accurate and relevant information. Credible agencies or organisations that provide evidence based health information can increase the speed with which users are able to download information by constructing mirror or replica sites in different geographical areas. For example, health information on a busy site based in New York can be downloaded faster in London from a European mirror site. Agencies or organisations can also participate in efforts to judge the accuracy of information on health oriented websites by providing a time limited "mark of good housekeeping" to a website or by offer-



ing indirect endorsement by linking their own website to those of other groups. They can create up to date databases of information sources. For example, the European Union funds the website of Scientists for Health And Research for Development (www.shared. de/sharedhome.html). This website lists potential donors, ongoing projects, and resources available to researchers in developing countries or their partners in the developed world. Medical journals that have their own websites can follow the lead of the *BMJ* and provide free access to their articles.²⁶

The relevance of information can be improved partly by increasing the visibility of health research from developing countries. Technical assistance in designing websites could be provided, preferably through the creation of templates which could be easily adapted by different users. Alternatively, some agencies might offer to host other organisations on their websites, absorbing the costs of developing and maintaining the sites. For example, Kabissa (www. kabissa.org/index.html) provides low cost domain hosting for non-profit non-governmental organisations in Africa, including the Network on Equity in Health in Southern Africa (www.equinet.org.zw/), a network of research, non-governmental, and health sector organisations seeking to influence health policy in southern Africa.

Addressing the cultural dimensions of change

The solutions that have been proposed are mainly technical. More challenging is the problem of acculturating individuals to new technologies. Interactivity will not be exploited if users do not come near the technology. A well known approach to inducing attitudinal change is to familiarise people with, in this case, technology through repeated exposure. Guidance should be provided when needed so that the intended users are satisfied with their results and their confidence increases. Staging posts (dissemination centres that adapt information for local use) can easily be modified to fulfil this role. Initially, there will be some passivity on the part of the users, and they will merely access and download information, treating the internet as an online health library. But as they spend more time on the internet, gain access to different sites, and notice consistencies and contradictions, they will search for opportunities to pose their own questions and apply their own knowledge. Such opportunities for interaction with users should be exploited by health policymakers and researchers. Information generation and policymaking need not be one way processes but can, on the internet, be interactive, and policies and research may benefit from early feedback from users. Subsequent revisions can then be tailored to users' needs. In this way, the internet can provide a mechanism for users to become active partners in the dissemination of information and in policymaking. As one futurist said, "Above all else in bringing about the information society is the necessity of partnership between the builders of the information infrastructure and the representatives of society."27

This article reflects the author's personal views and not those of the organisation for which she works.

Competing interests: None declared.

- 1 Williams M. G8 to meet developing nations on digital divide. www.cnn.com/2000TECH/computing/07/19/g8.divide.idg/index.html (accessed 8 September 2000). World Bank. World development report 1998: knowledge for development.
- 2 Washington, DC: World Bank, 1998
- Markoff J. If the medium is the message, the message is the web. New York Times 1995 Nov 20: A1, C5. 3
- Organisation for Economic Cooperation and Development. The knowledge-based economy. Paris, OECD, 1996:7-8. Lown B, Bukachi F, Xavier R. Health information in the developing
- 5 world. Lancet 1998;352(suppl II):34-8S.
- 6 United Nations Development Programme. Report of the Meeting of the high-level panel of experts on information and communication technol-ogy, New York, 17-20 April 2000. www.undp.org/info21/new/necosoc.html (accessed 3 July 2000).
- 7 Jensen M. African internet connectivity: African internet access costs. www3.sn.apc.org/africa/afrmain.htm#six (accessed 5 June 2000).

- 8 Third World Leaders meet in Havana. CNN.com. 13 April 2000. www.cnn.com/2000/ASIANOW/south/04/13/cuba.summit/ index.html (accessed 6 July 2000).
- 9 Groves T. SatelLife: getting relevant information to the developing world. BMJ 1996;313:1606-9.
- 10 McLellan F. "Like hunger, like thirst": patients, journals, and the internet. Lancet 1998;352(suppl II):39-43S.
- 11 Kim P, Eng TR, Deering MJ, Maxfield A. Published criteria for evaluating health related websites: review. BMJ 1999;318:647-9.
- 12 Jadad A, Haynes B, Hunt D, Browman G. The internet and evidence-based decision-making: a needed synergy for efficient knowledge management in health care. Can Med Assoc J 2000;162:362-5. 13 Zielinski C. New equities of information in an electronic age. BMJ
- 1995;310:1480-1. 14 Rosselli D. Latin American biomedical publications: the case of Colombia in Medline. Med Educ 1998;32:274-7.
- 15 Sundram FX. Scientific publication is dominated by First World countries. Ann Acad Med Singapore 1998;27:147.
- 16 Global Forum for Health Research. The 10/90 report on health research 2000. Geneva: GFHR, 2000.
- 17 Gibbs W. Lost science in the third world. Scientific American 1995;August:92-9.
- 18 McConnell J, Horton R. Lancet electronic research archive in international health and eprint server. Lancet 1999;354:2-3.
- 19 National Institutes of Health, PubMed Central; an NIH-operated site for electronic distribution of life sciences research reports. www.nih.gov/ about/director/pubmedcentral/pubmedcentral.htm (accessed 7 July 2000).
- 20 Delamothe T, Smith R, Keller MA, Sack J, Witscher B. Netprints: the next phase in the evolution of biomedical publishing. BMJ 1999;319:1515-6.
- 21 Philips Research. Networks: linking people and information. www.research.philips.com/generalinfo/shaping/networks.html
- (accessed 7 August 2000). 22 Deane J. Information, knowledge and development. www.oneworld.org/
- panos/ (accessed 6 July 2000). 93 Fraser H, McGrath SJ. Information technology and telemedicine in sub-
- Saharan Africa. BMJ 2000;321:465-6. 24 Partnership for Information and Communication Technologies in Africa
- (PICTA). AI-AIMS: African ICT activity information management system. www.bellanet.org/partners/picta/aiaimshome2.html (accessed 4 September 2000).
- 25 Jensen M. African internet connectivity; summary of international ICT development projects in Africa. www3.sn.apc.org/africa/projects.htm (accessed 4 September 2000).
- 26 Delamothe T. The BMJs website scales up. BMJ 1998;316:1109-10.
- 27 Greenop D. A partnership of industry and users. In: Inventing the future: communities in the information society. www.partnerships.org.uk/itf/ itfsum.html (accessed 3 July 2000).

A memorable patient Addressing men's health issues

I used to think it was a cheek. Surely my free time was my own? I enjoy playing squash, but as the other members discovered that I was a GP, I would be asked by more and more of them about health related issues. In reality they had accepted me as a member of the club and asked my advice as they would the carpet fitter, builder, or plumber.

When one of my own patients casually mentioned to me that he had been bleeding from the back passage, I suggested that he should come and see me in the surgery. A couple of weeks later he appeared on my booking sheet for the morning surgery, but he cancelled the appointment at the last minute.

When I next saw him at the club, I asked him why he hadn't come for his appointment. He said that he had been busy and anyway he had always been able to make himself bleed if he strained excessively. I wasn't so sure about his explanation, and I had a sixth sense that things might be more serious. We shared a joke about how difficult it might be for me to examine him in the showers and the danger of the headlines, "Doctor caught in compromising position in shower with patient."

Next week in the surgery the story unfolded. He had been passing fresh blood intermittently for a couple of months and just didn't feel quite right. A rectal examination was unremarkable, but in view of the history a prompt referral requesting sigmoidoscopy was sent. We are lucky in Exeter to have a fast track clinic, and he was seen a month after initial referral where a tumour was discovered and biopsied. Two weeks later he was admitted for an anterior resection and defunctioning ileostomy. As an extremely fit 50 year old he made a rapid and

uncomplicated recovery-he was even walking the day after his surgery and still plays squash to a high level.

What have I learnt from this? Men's health is something of a forgotten subject-men do not access health care as they should. Perhaps by offering a peripatetic clinic in a unofficial capacity I am allowing people to use me as a sounding board for their health concerns which I can listen to and direct them back to their own GP if appropriate. When people ask me for advice, I no longer feel annoyed (well, just a little) but see it as a mark of respect that they trust me and my opinion.

At a practice level, we offer at least one late surgery per partner, and these appointments are usually taken by people at work during the day. We are also open on a Saturday morning when we see any patient without an appointment.

At the last Devon and Cornwall trainers conference there was a talk on men's health issues, which highlighted the growing mortality from suicide and prostate cancer but also raised the point that there were no screening programmes for prostate and testicular cancer. As a practice, we have raised our awareness of men's health problems, and when men come to the surgery we offer a general health check as well as having a low index of suspicion of underlying disease.

I am glad that I followed up the non-appearance of my own patient who had "found" an explanation for his symptoms. The early referral and prompt surgery have allowed full resection of the tumour and I hope have given him a good prognosis.

Alexander Williams general practitioner, Exeter