

myself asking questions that my online 'family' needs to know. It's as if all these other people—the members of my group—are asking questions through me. And whatever answers I hear from my doctor, I know I'll share with them on line."

Much of what we have learnt in our collaborations with e-patients can be summed up in what has come to be known as Lester's law: "Medical knowledge is a social process: the conversations that occur around artefactual data are always more important than the data themselves."¹

Practical advice for doctors

Health professionals interested in observing e-patient dynamics can learn a good deal from going out into the self help neighbourhoods of cyberspace as observers. Find a few of the most impressive e-patient pioneers within your own areas of interest. Observe them, and if appropriate, communicate with them. See if you can find some low profile way to support their efforts, such as referring your patients to the group, answering group members' questions, or providing small scale sponsorships or grants. But please don't attempt to direct or control their efforts. And don't even think about attempting to put your advertising on their sites.

The things you learn from observing and communicating with the e-patients you find on line may prove invaluable in your future work. This has certainly been true with us.

One of us (DH) is a neurologist specialising in epilepsy. Having learnt about the value and dynamics of online groups through our e-patient research, he now routinely encourages all of his epilepsy patients to participate in a private in-house online support community. He participates in the discussions too, and as his patients get to know one another and become familiar

Summary points

Patients reach out and connect with others over the internet in a complicated, highly organised social support network

Doctors can find ways to help patient online communities and explore them without being intrusive

The impact and importance that online communities may have on patients should not be underestimated

with each group member's unique neurological conditions, he's working with them to develop and explore more sophisticated ways in which he and the group can collaborate. In the next phase of our e-patient research, we hope to explore these new types of online co-care in which e-patients, online support groups, and clinicians can collaborate in unprecedented ways.

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HINARI: bridging the global information divide

Srinivasa Vittal Katikireddi

The unequal distribution of health care is being addressed by an electronic initiative that makes medical journals available free of charge to health workers in developing countries

Health care is unequally distributed between the developed and developing worlds, which is matched by unequal distribution of health information. The information gap between rich and poor countries is so great it has been argued that "providing access to reliable health information for health workers in developing countries is potentially the single most cost effective and achievable strategy for sustainable improvement in health care."¹ So far, the most successful initiative to bridge this gap is the Health InterNetwork Access to Research Initiative (HINARI).

A short history

"In HINARI lies the seed of a knowledge revolution," said Gro Harlem Brundtland, director of the World Health Organization. "The knowledge gap between rich

and poor must be overcome if we are to reduce poverty. The information made available through HINARI will help developing countries in improving skills, developing research and, by extension, to save lives."²

In April 2000, a group of researchers from developing countries, convened by the World Health Organisation (WHO), concluded that the best way to help with their information problems was to improve their access to the published literature (Aronson B, personal communication). At that time, 56% of institutions in the lowest income countries had no current subscriptions to international journals and 21% averaged only two journal subscriptions.³

WHO realised that the recent revolution in information technology had opened up an opportunity for addressing information poverty. Compared

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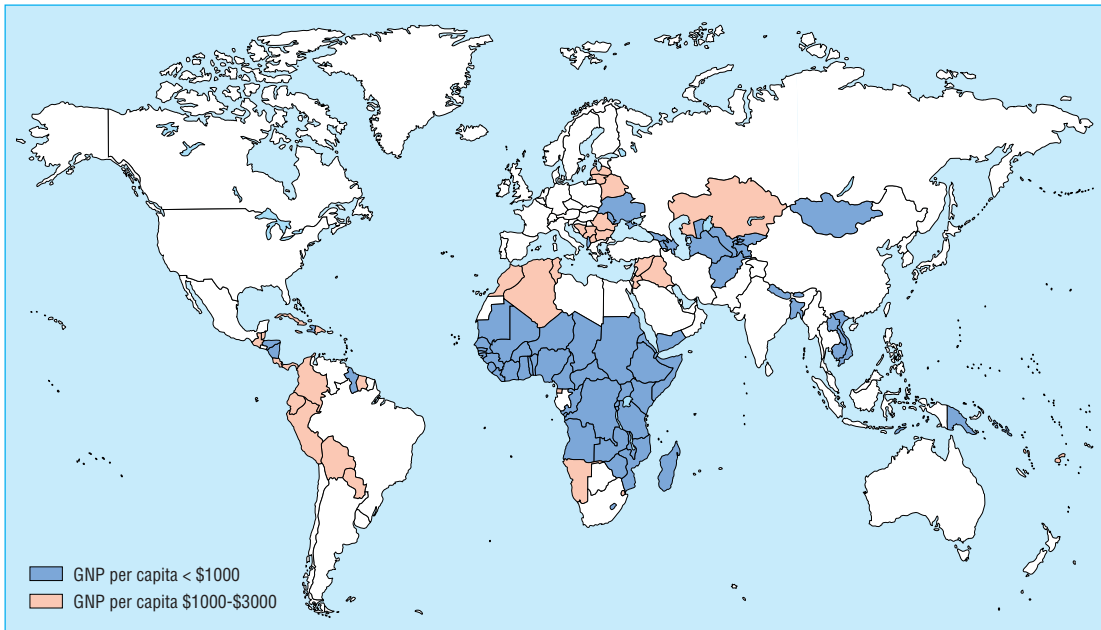


Fig 1 Countries with access to HINARI

with the £50 or more that it costs to send a paper copy of a weekly journal to an institution in Africa for a year, it costs publishers virtually nothing to give that same institution free access to an electronic edition of a journal.⁴ Publishers in the developed world are unlikely to incur significant financial loss by offering free or reduced price access to their online material, but they may benefit from the raised exposure of their journals and an improved public image.

The WHO, in collaboration with the BMJ Publishing Group, approached the world's six largest medical journal publishers to try to improve access to scientific information for researchers in the developing world through online provision.⁵ In a meeting at the United Nations in March 2001, the six publishers (Blackwell, Elsevier Science, Harcourt Worldwide STM Group, Wolters Kluwer International Health & Science, Springer Verlag, John Wiley) agreed to provide access to all of their online journals for free or at deeply discounted rates through HINARI.

HINARI was launched in January 2002 and initially allowed not-for-profit institutions in countries with a gross national product (GNP) per capita of less than US\$1000 (£556; €825) per year (as calculated in the World Bank's report in 2001) to receive free online access to more than 1500 journal titles. In January 2003, the initiative expanded to allow institutions in countries with a GNP per capita of between \$1000 and \$3000 per year to access the online material now available through HINARI, estimated to be worth more than \$750 000, for \$1000 (fig 1). Money raised from these small fees is being used to train librarians and researchers in information technology so that the best use can be made of the information now available to them. The number of publishers involved in HINARI has enlarged to 50, providing access to more than 2400 journals and other full text resources. HINARI can now be used by more than 1100 institutions in 102 countries (out of a total of 113 eligible countries).

How HINARI works

HINARI allows health and medical institutions to join the initiative by filling in a simple online form.⁶ After processing and authentication, WHO staff issue the institution with a password. Individuals at the institution wishing to use HINARI then approach their librarian (or equivalent) for the password. Through the HINARI web portal, they have free access to full text biomedical and related social science articles supplied from publishers' websites (fig 2). The portal also allows users to conduct PubMed (Medline) literature searches through the National Library of Medicine, search for journals based on subject, and access the full text papers directly through HINARI.

Has HINARI worked?

It is estimated that HINARI users downloaded more than one million articles in 2003. Usage depends on

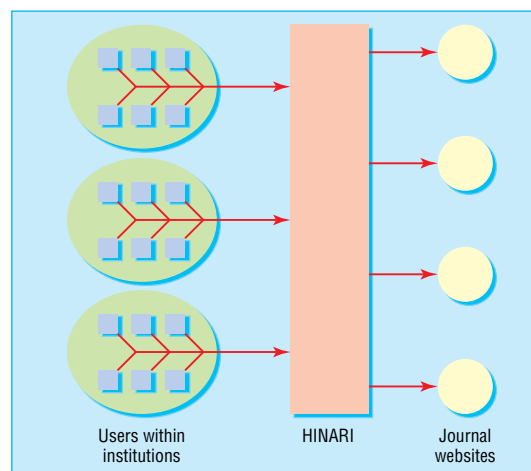


Fig 2 How HINARI works. Individuals receive a password from their institution which allows them to log on to HINARI; through the HINARI web portal they can access publishers' online journal websites

good internet connectivity rather than the economic strength of the country, with some very low income countries, like Ethiopia, being among the biggest users.³ The high cost of reliable internet access has limited the expansion of services, but some institutions have been able to use their eligibility for HINARI to support their applications for funding from donors.

No formal evaluation of HINARI has yet been done; one will start at the end of 2005. Anecdotal feedback has been positive. The box outlines some potential benefits of HINARI, but methodological difficulties in evaluation mean that a direct connection between improved access to scientific information and an improvement in health is unlikely to be proved.

Continuing problems

HINARI cannot reach everyone who might benefit. In many countries internet access is slow, expensive, and unreliable. Many poor institutions carrying out valuable research in countries with a GNP per capita of over \$3000 per year are not eligible to use HINARI. Information is often not available in electronic format—especially if it has been produced locally. The electronic format may be unsuitable for certain uses—for example, medical students in the developing world may benefit more from printed textbooks than from virtual textbooks that are only accessible from an unreliable internet connection at medical school.

HINARI may also pose problems to researchers and health professionals working in the developing world. Allowing unrestricted access to much of the world's medical literature may produce an information overload and lead to valid and relevant information being difficult to find.⁷ This is particularly important for people who are not experienced in using information technology and reading primary research (but this problem occurs in the developed world too).

Some valuable journals of specific relevance to the developing world (tropical medicine journals, for example) may not be available through HINARI as this may compromise publishers' commercial viability. Also, in a few countries, publishers withhold some journals because the sales of these journals are significant in these countries. However, institutions in these few countries are still able to access at least most of the key general medical and scientific journals without restrictions.

Other free initiatives

Alternative approaches for providing free or highly discounted rates to online journals exist. They include the Programme for the Enhancement of Research Information (PERI; www.inasp.info/peri/) managed by the International Network for the Availability of Scientific Publications (INASP); Electronic Information for Libraries (eIFL; www.eifl.net/); and the Ptolemy Project (www.utoronto.ca/ois/myweb9/).

The BMJ Publishing Group offers free access to its journals for users in the world's 118 poorest countries.⁸ This differs from HINARI in offering countrywide free access without the need for passwords. Many other journals sharing the group's electronic publisher, Highwire Press, provide a similar service (see <http://highwire.stanford.edu/lists/devecon.dtl> for a list of these publications).

What might HINARI achieve?

- Reduce feelings of isolation among scientists in the developing world
- Enable researchers in the developing world to improve the quality of their research
- Help stop or slow the "brain drain" of scientists from the developing world to the developed world
- Improve teaching and training of current and future health professionals and scientists
- Allow developing world scientists to provide more accurate and informed advice to policy makers
- Reduce the "publishing gap" between researchers in the developed world and developing world by improving the likelihood of publication in international journals
- Improve quality of locally produced journals
- Help create an information culture that uses an evidence base rather than inherited knowledge

A sister initiative

Access to Global Online Research in Agriculture (AGORA; www.aginternetwork.org/) is HINARI's sister initiative, which aims to improve food security by providing free or low cost access to major scientific journals in agriculture and related biological, environmental, and social sciences to public institutions in developing countries.⁹ AGORA was launched in October 2003 and provides access to over 400 journals related to nutrition.

AGORA is spearheaded by the Food and Agriculture Organisation of the United Nations and has received funding and support from Cornell University Mann Library, the Rockefeller Foundation, the UK Department for International Development, WHO, and the US Agency for International Development.¹⁰ It builds on the work of The Essential Electronic Agricultural Library (TEEAL), a collection of key agricultural journals distributed to developing countries on CD-ROM, which is available for institutions without adequate access to the internet for AGORA.

AGORA operates in a similar way to HINARI. By 1 March 2004, 200 institutions in 47 countries had registered.

The future

Publishers have committed to the current form of HINARI and AGORA until 2006, when they will be reassessed. It is hoped that they will continue, with the list of eligible countries being reviewed regularly. More publishers and users are being encouraged to take part in HINARI, and in AGORA.

HINARI has already held training workshops to help maximise the value of the newly available information. Joint training workshops run by HINARI and AGORA are planned for the future.

HINARI and AGORA show what can be achieved in effective public-private partnerships. These initiatives, along with other complementary approaches, are likely to eventually make a real difference to the health of many people in the developing world. Innovative use of information technology is finally beginning to bridge the information gap, to the benefit of the developed and developing worlds.

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Digital bridges need concrete foundations: lessons from the Health InterNetwork India

Shyama Kuruvilla, Joan Dzenowagis, Andrew Pleasant, Ranjan Dwivedi, Nirmala Murthy, Reuben Samuel, Michael Scholtz

The World Health Organization's Health InterNetwork pilot project has shown that national and international partnerships can use information and communication technologies to strengthen the public health system and bridge the digital divide in health

Information and communication technologies (ICT) are often promoted as bridges to better governance, economies, and health,¹⁻³ but examples of how these bridges can be successfully built are rare.² In this context, the United Nations' secretary general, Kofi Annan, launched in 2000 the Health InterNetwork in the Millennium Action Plan "as a concrete demonstration of how we can build bridges over digital divides."⁴ The initiative proposed to install computers and internet connectivity at thousands of hospitals and health centres in developing countries. The private sector pledged to provide the millions of dollars needed, but the "dot com" bubble burst and the funding never materialised.

The challenge of improving the flow of timely, relevant, and reliable health information remained, however. The World Health Organization (WHO), along with other United Nations agencies, technical experts, non-governmental organisations, and national governments, developed a strategy to implement and evaluate a series of pilot projects to better understand and meet those needs, as a basis for expansion.⁵

An early Health InterNetwork pilot project—to improve access to scientific publications for researchers in developing countries—grew quickly as agencies and publishers formed the Health InterNetwork Access to Research Initiative (HINARI). Coordinated by WHO and the BMJ Publishing Group, HINARI now provides public and non-profit health institutions in 113 countries with free or low cost access to over 2300 biomedical journals from more than 40 of the world's major publishers.^{6,7}

A second pilot project, Health InterNetwork India (HIN India), aimed to show the value of integrating ICT into public health practice. This article describes the Health InterNetwork approach and focuses on lessons from the HIN India pilot project.

The "digital divide"

The term digital divide often refers to unequal access to the internet in and between countries (table 1).⁸⁻¹⁰ But the divide also refers to inequities in ownership and use of technology, content, and telecommunications infrastructure.^{2,3,11}

The Health InterNetwork initiative focuses on four main components: connectivity (facilitating information access and use through ICT); content (providing timely, relevant, and high quality information); capacity building (developing skills in ICT management and use); and policy (lowering the barriers to ICT integration into public health practice).

Background to HIN India

India was selected for a Health InterNetwork pilot project because of its public health programmes as well as the availability of resources and skills needed to test the process of establishing, using, and scaling up ICT in a complex environment.

A wide range of agencies provides health services in India. Primary and secondary health care—available through a network of government health facilities (table 2)—is free or highly subsidised. Tertiary health care is provided through government medical college hospitals and specialised institutions. A rapidly growing private sector exists alongside traditional systems of medicine and major public health programmes organised by international agencies.¹²

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