



Access to Information and Health: ICT's Transformative Impact

From Silos to Systems

Chapter 4

Information and communication technologies (ICT) combined with wireless and mobile devices, are strengthening the production, dissemination and global use of health information. The increasing capacity of information producers, intermediaries and users is triggering the explosive growth of easily accessible information. However, to take advantage of opportunities created by these technologies, it is imperative to overcome important inequities in access. Referred to as the digital divide, access inequalities dampen the power of open knowledge exchange and thwart improvements in health, health systems and health care, particularly in developing countries.

Key barriers inhibiting equitable health care information access, particularly in developing countries, include connectivity, language, copyright, economics, visibility, technological literacy, and culture (the need for information to be culturally acceptable and relevant within different settings and domains).¹

BIREME, the Latin American and Caribbean Center on Health Sciences Information, convened *Access to Information and ICT*, part of the Rockefeller Foundation's *Making the eHealth Connection: Global Partnerships, Local Solutions* Bellagio Center conference series. Participants identified catalytic ingredients for the establishment of equitable national and international policy. They also identified new strategies for promoting the inclusion of developing countries in global information flows.

Access to Information and Knowledge Sharing: Key Issues and a New Paradigm

As e-solutions to better and more equitable knowledge sharing are identified, key questions are emerging. These include:

- ▶ How can information access inequalities best be addressed? Does this require focused priority setting or a multipronged strategy?
- ▶ How can open-access information resources be more optimally leveraged and promoted?
- ▶ What strategies result in quality and consistency when it comes to online health information?
- ▶ How can flexible, user-focused, access models and tools be developed that incorporate unique national, local and cultural needs?

To address these and other challenges to enhancing eHealth, *Access to Information and ICT* conference participants agreed that a new environment is needed. Such an environment should enable producers, intermediaries and information users to develop and share content, methods and technologies for the global public good. The essential ingredients of such an environment include the following:

- ▶ Open-access tools
- ▶ Collaborative and social network-based approaches to information and knowledge sharing
- ▶ The development of greater national capacity, with recognition of culture and context
- ▶ Integration with primary health care activities
- ▶ Interoperability through the use of the most appropriate standards, methodologies and technologies

This enabling environment must encourage cooperative development and operation globally, increasing health information use and promoting actionable knowledge. To do so, it must include these elements:

1. OPEN-ACCESS INFORMATION AND KNOWLEDGE

TOOLS ⇒ Online information knowledge sources and tools developed and adapted by eHealth should be openly accessible and interoperable in order to fully achieve the objectives

of improving health. The mass digitization of information brought on by digital technologies has been accompanied by an expansion in intellectual property rights, such as copyrights, patents and trademarks.² This expansion makes it difficult and complex to fulfill the ideal of equitable access to information and knowledge. However, the growth of the open-access movement is managing this trend, helping to create a freer environment for innovation in health. Open access is defined as “free availability on the public Internet, permitting any users to read, download, copy, distribute, print, search or link to the full texts of these articles, crawl them for indexing, pass them as data to software, or use them for any other lawful purpose, without financial, legal, or technical barriers other than those inseparable from gaining access to the Internet itself.”³

An open-access article, which is available to anyone with an Internet connection, is highly visible because Web search engines index open-access repositories and journals.⁴ Open-access articles are therefore more likely to be read and cited than articles in subscription-based journals that come with costs attached to them. This is particularly important for developing countries, whose scientific production faces barriers in becoming visible and accessible in the classic mainstream indexes.



Several initiatives in the developed world promote open access in the health-sciences domain, including the Biomed Central Public Library of Science and PubMed Central, which is spearheaded by the U.S. National Institutes of Health. Developing countries have also put into practice initiatives that promote open access. For more than a decade, in Latin America and the Caribbean, the Latin American and Caribbean Center on Health Sciences Information (BIREME) has been developing the Virtual Health Library (VHL), which includes several networks based on open access. A prominent effort in this regard is the Scientific Electronic Library on Line (SciELO) which enables developing countries to have free, full text access to scientific journals. Another important initiative promoted by the World Health Organization (WHO) in cooperation with private publishers is the HINARI (Health InterNetwork Access to Research Initiative) program, which provides free, or very low cost, online access to major biomedical literature related to local, not-for-profit institutions in developing countries. Nations entitled to free access to HINARI are those with a GNI per capita below US \$1250 (World Bank figures). Institutions in countries with GNI per capita between US \$1250 and US \$3500 pay a fee of US \$1000 per year per institution.

2. COLLABORATIVE AND SOCIAL-NETWORK APPROACHES TO INFORMATION AND KNOWLEDGE SHARING⇒

Traditionally, the processes of production, dissemination and utilization of information and knowledge were developed separately, in different locations, by diverse agents and institutions. A transition to a proposed social network-based enabling environment with intensive utilization of ICTs is recommended. This would:

- ▶ Allow a more effective integration of these processes
- ▶ Promote the establishment of flexible cooperative networks among producers, intermediaries and users of information and knowledge

The impact on health of collaborative spaces and online communities of practice is markedly changing the face of knowledge

dissemination and ICT-enabled communication.⁵ Knowledge is not static, but is a living entity that is continually being refined, revised and supplemented, requiring open access and social interaction. Social intelligence and collaborative spaces play a critical role in promoting knowledge exchange and knowledge building, helping to develop and implement culturally sensitive and contextually appropriate health interventions. To move beyond stovepipe approaches to global health improvement will require a plurality of solutions in meaningful contexts, a weaving of the empirical with the experiential, an integration of the vertical with the horizontal and vested community participation.

Among good examples of collaborative spaces and communities of practice for knowledge networking and exchange is the Global Alliance for Nursing and Midwifery Community of Practice (GANM), which includes more than 1,500 nurses, midwives, birth attendants and others from 132 different countries.⁶ Healthcare Information For All (HIFA), administered by the Global Healthcare Information Network based in the United Kingdom, is another case in point. HIFA's goal is to ensure that by the year 2015, every person in the world will have access to an informed health service provider and that "people will no longer be dying for lack of knowledge."⁷ Online Web conferences and meetings are also becoming a practical solution to bring people together online regardless of their geographic locations. Some solutions such aslluminate Live!™ Web conferencing software have been used successfully even in contexts with limited connectivity.

Each of these collaborative spaces has had significant impact on knowledge dissemination in the health realm.

3. DEVELOPMENT OF NATIONAL CAPACITIES⇒

The complexity and diversity of health problems in the developing world require a myriad of solutions. These challenges are local and context specific, strongly related to social determinants, such as economic and cultural factors, living and working conditions and individual behaviors.

A one-way importation of knowledge, frequently from the developed world, will not achieve the desired health improvements in developing countries, since knowledge dissemination as a unidirectional process fails to deal with diversity and disregards the importance of cultural and societal context. Altering the behavior of individuals, communities, and policy makers requires multi-directional considerations and involves flexibility and compromise.

The need to find adequate solutions according to local context requires developing countries to strengthen national capabilities and insert themselves in a conscious and sovereign way in the global flow of information. It is imperative that these nations become involved in international cooperative networks to produce, analyze and adapt this information to their specific needs. *Access to health information, as a social determinant of health, is a basic tenet of national growth and development.*

Instead of the unilateral transfer of knowledge, international and multilateral agencies should focus on technical cooperation activities in supporting national efforts to develop these capacities.

4. INTEGRATION WITH PRIMARY HEALTH

CARE⇒ Information and knowledge-sharing initiatives that implement a social networked enabling environment should be supported by wide community participation, appropriate technology and the integration of health promotion, disease prevention and medical care. Together with universal access, equity and social justice, these are the basic principles of primary health care (PHC), making PHC settings, actors and activities an ideal environment for the development of these initiatives.

The proposed social network-based enabling environment can help update the PHC strategy by supporting the following:

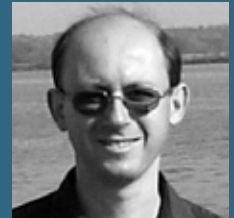
- ▶ The production and dissemination of information, knowledge and scientific evidence pertaining to local historical, geographic and cultural conditions

- ▶ Proactive participation by different segments of society in defining public policies and in generating, adopting and using health innovations through new forms of social organization such as networks of professionals and communities

As eHealth grows in its reach and sophistication, the ability of these tools to support health equity and to level the information and knowledge playing field is limitless. If used thoughtfully and in a context that recognizes national, regional, educational, cultural and other differences, knowledge sharing can expand in the health care sector, improving care through international cooperation.

Notes

- 1 Pandita N, Singh S. Barriers to Equitable Access to Quality Health Information with Emphasis on Developing Countries. In: *Making the eHealth Connection: Global Partnerships, Local Solutions*. Rockefeller Foundation's Bellagio Center in Bellagio, Italy, July 13 to August 8, 2008. [cited 2008 Nov 27]. Available from: http://www.ehealth-connection.org/files/conf-materials/Barriers%20to%20Equitable%20Access_0.pdf
- 2 Wilbanks J. Intellectual Property and Access to Information. In: *Making the eHealth Connection: Global Partnerships, Local Solutions*. Rockefeller Foundation's Bellagio Center in Bellagio, Italy, July 13 to August 8, 2008. [cited 2008 Nov 27]. Available from: <http://ehealth-connection.org/wiki/images/a/a3/WilbanksJohn-2008.pdf>
- 3 Open Society Institute Budapest Open Access Initiative Definition. Available from: <http://www.earlham.edu/~peters/fos/boaifaq.htm>
- 4 Lyon B. Access to Equitable Access to Quality Health Information with Emphasis on Developing Countries (narrative, with case studies). In: *Making the eHealth Connection: Global Partnerships, Local Solutions*. Rockefeller Foundation's Bellagio Center in Bellagio, Italy, July 13 to August 8, 2008. [cited 2008 Nov 27]. Available from: <http://ehealth-connection.org/wiki/images/2/21/RoyalJulia-LyonBecky-20080717.pdf>
- 5 Abbott, P, Urra P. Knowledge Networking: Social Networks to Share, Create, Disseminate and Use Information, and Knowledge to Enhance Health. In: *Making the eHealth Connection: Global Partnerships, Local Solutions*. Rockefeller Foundation's Bellagio Center in Bellagio, Italy, July 13 to August 8, 2008. [cited 2008 Nov 27]. Available from: http://ehealth-connection.org/wiki/index.php?title=Knowledge_Networking:_Social_networks_to_share_%2C_create%2C_disseminate_and_use_information%2C_and_knowledge_to_Enhance_Health
- 6 Abbott, P., Coenen, A. Globalization and Advances in Information and Communication Technologies: The Impact on Nursing and Health. *Nursing Outlook*, 56:238-246.
- 7 Healthcare Information For All. Available at: <http://www.hifa2015.org>.



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*“Information is necessary
to make informed
decisions about health.*

*The importance of
technology to aggregate
information for the
patient is so important
for safety and efficiency.*

*This is not spending
money but investing
money [in technology]
to get a return in health
and efficiency.”*

Bellagio Center Declaration on Access to Information and Knowledge Sharing

Making the eHealth Connection: Global Partnerships, Local Solutions, a month-long conference series at the Rockefeller Foundation Bellagio Center in Italy, in 2008, addressed key issues for advancing eHealth and improving health in the developing world.

We, the participants of the conference on the theme of Access to Health Information and Knowledge-Sharing, organized by the Caribbean, the Latin American and Caribbean Center on Health Sciences Information (BIREME) with the support of the Rockefeller Foundation, during the week of July 20 to 24, agreed to the following summary report on the conclusions of the meeting.

Recognizing that:

- 1) Health information and knowledge are social determinants of health since inequities in access to information and knowledge generate and/or increase health inequities. This creates unjust, unnecessary and avoidable differences in the health conditions of individuals and population groups.
- 2) Health information policies should be part of health policy in order to strengthen the use of information, knowledge and evidence in decision making.
- 3) eHealth comprises health promotion, disease prevention and care to improve health conditions and equity. Involving different stakeholders with different interests and needs, this requires a plurality of solutions in meaningful contexts.
- 4) National and global research programs are essential to identify information needs, to recognize barriers to the access, translation and use of information and to evaluate the impact of information and knowledge-sharing interventions on health outcomes.
- 5) The implementation of global eHealth initiatives should be based on partnerships involving various national and international players.
- 6) eHealth must be used to overcome barriers to access and barriers to the use of quality health information. It must also be used to facilitate the convergence of initiatives, products and solutions.

- 7) Priority should be given to settings where the production of information and knowledge is weak, and where access to it is limited.**
- 8) The information and knowledge sources and tools developed and adapted by eHealth should be openly accessible and interoperable via adequate methods and technologies.**
- 9) Information and knowledge sharing should be implemented through community participation, appropriate technology and the integration of promotion, prevention and care as a primary health care approach.**
- 10) Human resource capabilities should be expanded to incorporate skills for health information and knowledge management and sharing that meet the needs of different users, applying appropriate standards, methods and technologies.**

We commit ourselves to mobilizing efforts and resources toward the creation of an environment that will serve the global public good and that will enable producers, intermediaries and users to develop and share content, methods and technologies. This new environment will increase the use of health information and promote knowledge sharing with a focus on international cooperation for the development of health-information infrastructure and human resources.

We call for the creation of a task force with representatives from key stakeholders and donors. This task force should establish a plan of action for the implementation of this health information and knowledge sharing.

We urge national and international organizations, funding agencies, the private sector, governments and institutions to become our partners in this endeavor.