Title: The chain of communication in health science: from researcher to health worker through open access

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**Abstract:** Open Access (OA), the concept that scientific publications, particularly those resulting from public funding, should be available online free for all users, is now a broadly accepted principle that is remodeling the landscape of scholarly communication and opening new opportunities for scientific discovery and collaboration.

However, this principle has yet to fully penetrate the field of public health communication, where open access could prove to have potentially transformative power. This paper documents the benefits of OA for health research and communication, and outlines the strategies for enabling OA and improved knowledge exchange between the researchers, policy makers, and the front line health workers. It provides evidence to show the significant progress already made in reaching information-deprived communities in the developing world and provides arguments as to why international health agencies should play a leadership role in integrating open access into the communication chain from research to application in public health.

### Introduction

Globally, the public and private sectors spend billions of dollars each year on biomedical and health-related research. Yet in many parts of the world, health care systems and health outcomes are still far below the target set by the Millennium Development Goals<sup>1</sup>. The causes for this disparity are complex, but one of the key factors that has been consistently identified is the failure to translate research into effective policy and practices. Not surprising then that health agencies and funding bodies around the world are paying closer attention to what is now generally known as "knowledge translation" and to develop mechanisms that would "strengthen communication between health researchers and users of health knowledge, enhance capacity for knowledge uptake, and accelerate the flow of knowledge into beneficial health applications"<sup>2</sup>.

At the same time, research funding agencies are recognizing that one of the key components of the "knowledge translation" process is the assurance that the primary research publications resulting from their funding are as widely disseminated as possible. As Robert Terry, a former Senior Policy Advisor to the Wellcome Trust said, "Just funding the research is a job only half done. A fundamental part of [our] mission is to ensure the widest possible dissemination and unrestricted access to that research." The Wellcome Trust believes that only through maximizing the access to the research they fund will they achieve greater health applications and benefits. As a result, beginning in 2005, the Trust made it a condition that all grant recipients deposit electronic copies of journal articles resulting from Wellcome funding into the UK PubMed Central open access repository no more than six months after publication.4

One of the first groups of organisations to require deposit of articles in open access institutional repositories was the UK Research Councils, including the Medical Research Council. More recently, the National Institutes of Health (NIH), the world's largest medical funding body, made it mandatory for researchers to submit final peer-reviewed journal manuscripts that result from NIH funding to PubMed Central. This requirement was made into law by the US Congress which passed the Public Access Policy

(Consolidated Appropriations Act, 2008).<sup>5</sup> Likewise, the Canadian Institute of Health Research (CIHR) enacted an open access policy requiring authors who received funding from CIHR to make their publications openly available within six months of publication<sup>6</sup>. In addition, CIHR grant recipients are required to deposit bioinformatics, atomic, and molecular coordinate data into the appropriate public database immediately upon publication of research results (e.g., deposition of nucleic acid sequences into GenBank).

These are prominent examples of agencies who understand that "Timely and unrestricted access to research findings is a defining feature of science, and is essential for advancing knowledge and accelerating our understanding of human health and disease<sup>6</sup>." A total of 62 major research organisations and funding bodies have now made similar requirements and are listed in the ROARmap database<sup>7</sup> with a further 11 such mandates under development. It is recognized that restricted access imposed by cost and/or copyright permission, leads to inefficiency and delay in discovery, isolation of researchers and, above all, a broken link between researchers and the research users. It is now becoming a requirement by funding organisations that the URLs to publications deposited by potential fundees in institutional repositories is made available in funding applications, since funders do not always have subscriptions to all the journals holding articles of potential applicants (Alma Swan blog, OptimalScholarship). As research users are not only other researchers, but also policy and decision makers, front line health workers, NGOs and the public, open access is vital to the overall health of the knowledge exchange process, as it vastly expands the opportunities for translating health research into improved health.

The remainder of this paper further expands on the public health benefits of open access, points to strategies for making publications accessible and reusable, provides examples of successes so far, and concludes with recommendations on how best to maximize the return on investment for health research.

### Unfit for purpose

Throughout health care, the chain of knowledge transfer starts with the research laboratories in university departments, research institutes and health care companies where new research knowledge is generated. From there it is transferred through peer reviewed publications to the global community of end users. The chain can be broken at every link because of technical, social or fiscal problems, but if the first link in the chain – from original research to readers – is broken, nothing new emerges to support the health services around the world. The global investment made in research into the ever-present medical problems is wasted. As the WHO Bulletin Call for Papers rightly says, 'Communication is at the heart of public health'.

Traditionally, researchers, publish their findings in journals where the peer review process ensures authenticity and accuracy, but today this primary chain of communication from researcher to readers is not functioning well. It is no longer 'fit for purpose' because the cost of journals has risen far above the cost of inflation, disenfranchising readers in the poorer nations. As the WHO review of 2003 showed <sup>8</sup>, the poorest medical institutes often are unable to purchase any journals at all and so their researchers are working in a vacuum, isolated from the developments taking place in the rest of the world.

In 2003, the Wellcome Trust said 'the current market structure does not operate in the long term interests of the research community.' It follows that, if the essential first link in the communication chain is to be repaired, alternative communication routes must be established.

#### Global health concerns

Concerns at the lack of access to research information have stimulated many initiatives. If these efforts are to succeed they must build e-publishing capacity and lead to research independence. In1982, a UNESCO report stated that "assimilation of scientific and technological information is an essential precondition for progress in developing countries" and this has been widely accepted by many international bodies. The UN agencies, WHO and FAO, established the donation programmes, HINARI and AGORA9, by which partner commercial journals agreed to provide free access to registered libraries in countries with a GNP < \$!000/annum and, while these have filled gaps, they have a limited reach and can never serve to strengthen the national knowledge base in all disciplines of research.

Research communities everywhere need freedom to access the global knowledge pool as their research needs dictate and to make known their own research findings to the international research community. Only by closing the current north-south, south-north and south-south knowledge gaps can research accelerate to meet growing demands. The outbreaks of emerging new infectious diseases, the threat of avian influenza, the scourge of HIV/AIDS, the on-going infant mortality from malaria and other infectious diseases can only be addressed through the cooperative efforts of researchers. Climate change and environmental concerns, along with agricultural research needs are further examples of the incontestable importance of sharing research findings with those unable to afford ever-growing subscription costs.

# Health damage caused by inadequate access to current research

Many instances of the unfortunate consequences of information deprivation are emerging. The following reported examples highlight these dangers.

Gavin Yamey, in his article, "Excluding the poor from accessing biomedical literature: A rights violation that impedes global health" <sup>10</sup> provides many instances. Thus, a physician from southern Africa, engaged in perinatal HIV prevention, whose primary access to information was abstracts posted on the Internet, altered the perinatal HIV prevention programme . . . based on access to a single abstract. As Yamey reports, had he read the full text article he would have undoubtedly realized that the study results were based on short-term follow-up, a small pivotal group, incomplete data, and were unlikely to be applicable to their country situation. The decision to alter treatment based solely on the abstract's conclusions may have resulted in increased perinatal HIV transmission – but there were no funds to purchase the full text document. Similarly, a professor at Makerere University, Uganda, was asked to investigate research on the 'nodding disease', a mysterious illness affecting children in southern Sudan, but was unable to do so because of financial limitations on accessing relevant research.

Another instance of the importance of open access to both publications and data came to light at the Berlin 5 Conference at Padua, September 2007 <sup>11</sup>. Ilaria Capula, reported on her work with avian influenza and the development by her laboratory of valuable

sequence data to aid its containment, but disturbed the audience by reporting that she was initially discouraged from putting the data into the free and open access database, Genbank. Another reference to the broken link in the information chain came from Alayinka Ayankogbe, Nigeria, who stated in a message to HIFA2015 forum <sup>12</sup>: "Advances in treatment of major endemic diseases made in the North are "alien" even to most doctors in practice even here in Lagos. Take the example of HIV/AIDS. Information on the most recent and advanced therapies are at best confined to the few Professors specialising in HIV/AIDS treatment in the Universities. Most GPs do not know. The information gap is horrendous (if that word is strong enough) to say the least."

Nowhere is the need to share scientific information openly more apparent than the outbreak of SARS in 2003. At the height of the epidemic, there was unprecedented openness and willingness to share critical scientific information immediately. As a result of collaboration of 13 major laboratories in 10 countries, the coronavirus responsible for the outbreak was quickly identified and its genome mapped within weeks<sup>13</sup>. In a news release by the WHO, Dr Klaus Stöhr, WHO virologist and the coordinator of the collaborative research network, remarked, "In this globalized world, such collaboration is the only way forward in tackling emerging diseases."

## A solution appears on the horizon

Since 2001, the global scholarly community has begun to take remedial measures and is widely adopting recommendations outlined in the Budapest Open Access Initiative <sup>14</sup>. Thanks to the opportunities made possible by the Internet, two recommendations were made that have the potential to release the essential information locked away in expensive publications. The two paths to reach this goal are:

- 1) to deposit copies of an author's final refereed accepted article in his/her interoperable Institutional Repository (IR) or
- 2) to publish in open access journals.

The IR option, already mandated as discussed above, is accepted by some 63% journals and requires the installation of free software that conforms to the internationally agreed OAI-MPH metadata harvest protocol that allows all IRs to be searched (by Google, Yahoo, and specialist search programs such as OAIster<sup>(15)</sup>)as though all were a single resource. This is a low cost option eminently appropriate for low-income countries.

The OA journal option requires the development of alternative funding models that allow free access to all 'readers' and the recovery of publishing costs by alternative economic mechanisms, such as an 'author pays' alternative —whereby authors or their organisations pay the document management costs - , or by providing other chargeable services, or by advertising or institutional support. All OA journals published in developing countries make no charge to either authors or readers; they recover costs through alternative means. It has been rightly argued that, even though a number of journals waive payment on request, switching to an author-pays model does not help researchers in low-income countries, but merely shifts the burden of cost from reader to author.

# Progress in development of OA Journals and OA Institutional repositories

A number of developments have taken place over the last few years leading to a significant boost to the volume of research material available to investigators without charge or other access barriers.

#### **OA Journals:**

The Directory of Open Access Journals<sup>16</sup> now lists some 3824 OA journals, ~19% of which are published in developing countries. The Bioline International 17 and SciELO 18 platforms are examples of services providing OA distribution of material from the developing countries, so providing greatly heightened visibility to essential regional research. SciELO began in Brazil and has been extended to other Latin American and non-LA countries. Bioline International is a Canada/Brazil partnership providing a distribution mechanism for publishers, currently from 17 developing and transitional countries. The MedKnow<sup>19</sup> publishing house in Mumbai, India, similarly provides free access to about 80 journals published primarily in India, focussing on biomedical research. These leading services, together with a number of society journals from the developing countries constitute some 20% of all OA journals. Unlike a majority of commercial publishers in the industrial parts of the world, these publishers have no concerns that OA will damage their journals – quite the contrary, as evidence is now accumulating that visibility leads to quality improvements, increased submissions, increased citations and even subscription growth for the printed versions of their publications. It is of significance that the British Medical Journal that experimented with full open access, and then reverted to toll access for non-research articles, has recently returned to being a fully open access publication<sup>20</sup>.

## **OA Institutional Repositories (IRs):**

The Registry of Open Access Repositories <sup>21</sup> lists 1243 open access repositories (the number increasing by an average of 1/day). Of these, ~16% have been established in institutes and universities in developing countries. The Directory of Open Access Repositories (openDOAR)<sup>22</sup> maintains a similar list. The low cost of establishing and maintaining IRs makes them a highly appropriate means of distributing local research findings and helping close the knowledge gaps. As outlined above, deposit of already published articles in interoperable IRs that comply with the internationally developed and accepted metadata protocols (OAI-MPH protocol), allows free and immediate access to researchers unable to afford the fee-based versions.

# Do these open access developments make a difference?

Since research scholars do not take time and effort to download articles unless they have a need for the information contained within them for their own research purposes, the proof of the value of OA comes from usage statistics. While it has always been difficult to measure the real impact of specific research findings on the progress of science, it is now being shown that the numbers of articles downloaded from an information resource is a measure of future citation, and by extension impact, see recent articles by Brody et al <sup>23</sup>. Norris et al <sup>24</sup> and a recent paper by Thomas V Perneger, professor of health services evaluation on the value of full text downloads from the British Medical Journal <sup>25</sup>.

**Usage of OA journals** published by developing countries was shown to be significant from the start, and is growing steadily as more material becomes available.

Bioline International has statistics to show the volume of usage, including full text downloads, from 2002 to 2008. In 2008, the total full text requests was >4.2 million, indicating the very significant need for previously unavailable research information. As the overlay map from the Bioline site indicates, usage was largely – though by no means exclusively - from the developing regions, showing repair of the broken links between neighbouring developing countries often facing similar health and environmental problems.

Year	Article Titles	Abstracts	Full-text	Info Pages	Search	Total Hits
2002	44,548	105,189	26,961	7,682		224,137
2003	116,364	149,211	45,944	26,315		445,679
2004	121,546	288,548	157,809	33,895		854,467
2005	86,097	434,935	1,100,615	34,204	33,637	2,723,472
2006	162,622	1,097,370	2,496,511	79,334	66,318	5,749,149
2007	364,529	2,574,886	3,255,156	146,576	180,293	9,671,469
2008	626,544	3,629,160	4,214,709	300,192	207,504	12,154,807

Usage of developing country research publications available from the Bioline International platform, 2002 – 2008.

Similar high volume usage is shown for the SciELO journals as the number of hits over a 4-year period from the SciELO Chile site indicates:

Again, in India, the MedKnow journals show consistently increased usage of the OA online versions and steadily improving impact factors, as shown by the chart for the Journal of Post Graduate Medicine, below.

While some publishers have shown concern that the OA publishing strategy could lead to a loss of subscription income vital for the survival of their journals, evidence is now available that shows this not to be the case<sup>25</sup>. In physics, the major journals publishing research in this discipline have seen no adverse effect from the widespread use by the physics community of the OA arXiv <sup>26</sup> repository. Similarly, in India, the MedKnow publisher of biomedical journals reports an increase in subscriptions since the online versions of the journals were made available on an OA basis. Results showing subscriptions for nine MedKnow biomedical journals since converting to open access for the online versions in 2002 are shown below.

Moreover, the quality of local journals has improved as a result of increased visibility, with increases in submissions, impact factor and in international contributors being recorded.

**Usage of Institutional Repositories** is now becoming recorded as IRs incorporate recently developed statistical packages into their repository system. As with the OA journals, usage of repository deposits is growing dramatically. The following table gives a summary of usage by just four countries of deposited material held in four repositories – two from the industrial world and two from the developing world:

Repository	(NZ)		Africa)	Bangalore
Institutional		Strathclyde		Science,
	University	of	Cape	Indian Inst of
		University	Western	
			of	
			University	
			Online,	
			Education	
			Higher	
			African	

Full text downloads during 2008									
No. of records in IR	677	6033	417	11850					
Usage from Canada	3542	2479	157	2931					
Usage from India	6786	6746	94	9354					
Usage from UK	11282	24069	759	3581					
Usage from Sth Africa	1453	344	2698	331					
Total Usage from Jan-	135,584 from 196 countries	145,722 from 172 countries	14186 from 149 countries	66514 from ~60 countries					

If the usage from this small sample is any indication, then papers deposited in the 1243 IRs worldwide have a significant level of usage.. While apparent repository fluctuations are difficult to interpret (causes may be sudden workshop usage, new partnership developments, launch of specific programmes or implementation of new OA training materials, for example), the very high usage recorded is incontestable evidence of the value of archived material that was previously inaccessible.

The following map from the SHERPA web site <sup>27</sup> shows the wide geographical location of the global IR network:



Usage of developing country IR deposits is well exemplified by the overlay map of usage of the Universidad de Los Andes, Venezuela, showing that there is high usage of the scholarly output from the university by both neighbouring Latin American and more remote developing countries, as well as from Europe and North America. The statistical reports shown on the ULA IR site <sup>28</sup> states that, for example, 10,000 files on Health Science were downloaded in the first 7 days in August 2008. Little further evidence is required to demonstrate the overwhelming need for such information, previously inaccessible to those with economic constraints. Moreover, it is clear that this IR has clearly placed the ULA 'on the map' in the eyes of the international research community, to the benefit of the status of the university.

The statistics outlined above are a very strong indication that the old communication mechanisms failed by barring many researchers and health workers from the information they needed. The serendipitous benefits arising from the re-established links to the initial chain of communication are largely immeasurable, as it is not possible to judge the consequences arising from chance meetings and partnerships, or from the encouragement that grows from a feeling of inclusion.

### Infrastructure

In the meantime, while BOAI routes to international sharing of publications and data continue with some speed, a number of infrastructure projects are already underway. In Europe, the Digital Repository Infrastructure Vision for Europe (DRIVER) <sup>29</sup> has been established to support and develop EU IRs and a similar programme, ORCA, has been set up in Australia. Many groups are working on new software tools to advance the functionality of the IR network – for example the SWORD software has recently been made available to allow easy transfer of files between IRs. Other software for metrics of value to institutes, authors and publishers are well advanced and the Joint Information

System Committee (JISC) <sup>30</sup> funds a raft of projects relating to institutional repositories and metrics.

# Soldering the links in the chain – what must be done?

It follows from the statistical evidence and personal stories now available that a sure way to achieve equitable access to the world's published biomedical research literature is through the rapidly emerging OA developments. But it is clear that awareness of opportunities is still limited in the poorer countries and much effort should continue to be made in informing policy makers, research administrators and practitioners.

As the Open Access Directory <sup>31</sup> shows, the Events link records much global activity, but it is limited in the main to the industrial world. Whereas dedicated groups such as the Electronic Information for Libraries network (eIFL)<sup>32</sup>, the Electronic Publishing Trust for Development (EPT)<sup>33</sup>, the development agencies, the publishers and repository managers in the developing countries, as well as the recently funded Open Access Scholarly Information Sourcebook<sup>34</sup> are all making sterling efforts to inform and train in order to provide OA-capacity, these efforts would be much strengthened by support from the major international agencies. In the health area, the WHO has a leading role to play in supporting the establishment of OA repositories and journals and it is good to note that in its Global Strategy and Plan of Action report it lists as an objective, '- *promote public access to the results of government funded research, by strongly encouraging that all investigators funded by governments submit to an open access database an electronic version of their final, peer-reviewed manuscripts.*' <sup>35</sup>

While other problems remain to be solved (connectivity, strengthening the links further down the communication chain, education, translation – both language and content - and training), there is a surge of activity in efforts to resolve communication difficulties. As discussions on the HIFA2015 forum show, mobile communications and other technologies are starting to make an impact on the transmission of information to remote areas, and the connectivity infrastructure is an on-going priority in the developing world (see reports from the *Balancing Act* newsletter <sup>36</sup>).

Krishnan Ganapathy, a Chennai-based neurosurgeon, and the former president of the Neurological Society of India and current president of the Apollo Telemedicine Networking Foundation, said in an interview for the Bytes for all forum<sup>37</sup> "We really started using mobile phones very recently...... If you take India, for example, 750 million

Indians live in suburban and rural areas where you just don't have specialists. Now I, as a neurosurgeon, am able to provide neurosurgical, if not care, at least advice to these people. Similarly, all other specialists are able to do the same. This is what we have been doing fairly successfully for the last nine years. . . . In India, the growth of mobile phones is exponential...... In the city where I live [Chennai], between 1998 and 2008, mobile phone penetration has increased by a factor of 133."

With the great efforts underway by dedicated policy makers, researchers, computer experts and development professionals, it is clear that a way has at last been found to provide a level playing field for all with a need to access health information. Restoring the link between primary research and the end users is a fundamental need to maintaining the knowledge chain intact.

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