

Moving from information *transfer* to information *exchange*: evaluation and production of electronic educational materials on dengue and Chagas's disease

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Introduction

Globally, infectious and parasitic diseases remain major contributors to morbidity and mortality, and disproportionately affect populations living in poverty. Between the interface of health, education and communication, we reflect on possible interventions that may increase the access and use of educational technologies in disease-endemic developing countries through modern *Information and Communication Technologies* (ICTs).

The problem of access to information is a major obstacle in the public health field, especially since this field focuses predominantly on the transfer and exchange of information. New communication technologies are a vehicle for a process of globalisation that takes place in unequal terms, and often increases social and economic inequality, between and within countries and people. *“The information gap between the rich and poor world is widening, both between and within countries. The digital divide is more striking than any other inequity in health income”* (1). At the same time, technologies can be an empowering tool for social mobilization, health promotion and development in the hands of people and organizations working for justice and equality through health information and promotion.

When the topic of ICTs and health information interconnects with neglected diseases in developing countries, the situation becomes even more urgently addressed. On top of the “digital gap”, or the lack of access to ICTs that affects most developing countries, there are the many neglected diseases that also affect these countries in a disproportionate manner. Despite the promises of the information revolution, and some successful initiatives, there is little evidence that the majority of health professionals in the developing world are any better informed than they were 10 years ago. Lack of access to accessible, relevant, accurate and up-to-date information remains a major barrier to knowledge-based health care in developing countries (2).

We now know that less than 10% of health-research funding is targeted at the health problems that account for 90% of the global disease burden (3). This “10/90” gap is a fundamental cause of lack of access to relevant health information. It is exacerbated by problems of getting developing world research published, indexed, incorporated into systematic reviews and integrated into accessible learning reference materials. The “10/90” gap in research probably translates into a “1/99” gap in health information (2).

Research has shown that, although access to information is necessary, it is not sufficient to change practice. This “know-do” gap is a problem in both developing and developed countries, and is by no means simple and remains a major challenge in the information-rich industrialized world (4). Therefore, ICTs may have considerable impact on global health promotion, disease control and health care, as well as on education, management and research for health (5).

Lee & Garvin, analysing the practices of information dissemination in health settings, express how practices in information transmission are insufficient because they are rooted in a one-way model of information transfer (6). Utilizing this same notion in electronic publishing, specifically in CD-ROM production, we argue towards a new approach where both developing and developed countries may share information, knowledge and experiences and benefit from each other mutually. We demonstrate that sharing information is not only theoretically desirable in health promotion but operationally possible under careful planning and collaboration.

Background

There is a need to move beyond traditional practices in information *transfer* (one-way monologue), toward a more appropriate notion of information *exchange* (two-way

dialogue). Information transfer has typically been conducted in a 'monologue' format where information flows in one direction – from provider (developed countries) to recipient (developing countries). *“Health communication practices and frameworks ... imply unidirectional, uncomplicated and linear flow from information creator to information user...They likewise assume that merely providing information is sufficient to produce improved health outcomes in individuals and populations and that individuals, regardless of social context, have the power and agency to implement change and act on information as it is made available”* (6).

Lee & Garvin (6) outline the limits of such approaches by criticizing three key problems inherent in health information transfer: (a) a focus on the individual; (b) the privileging of expert over lay perspectives, and (c) the assumption that a one-way flow of information, from provider to recipient, is appropriate. For the scope of this article, we will concentrate on the third aspect of information transfer and demonstrate how we are moving towards new methodologies, which shift paradigms in health communication by privileging the exchange over transfer of information.

By establishing an innovative collaboration between the Wellcome Trust, Publishing Group-International Health (Wellcome-PGIH), UK and CPqRR-FIOCRUZ, Brazil, this project constructs a two-way flow of information between North and South, where shared experiences and technologies open new channels of dialogues. We implement this collaborative strategy, by collectively evaluating a CD-ROM on dengue, produced by Wellcome-PGIH and by designing a new CD-ROM on Chagas's disease. Both discs will be translated to the local language (Portuguese) and evaluated with the target population (health professionals).

This study approaches the problem of providing information of quality for health professionals and schools about neglected diseases, specifically dengue and Chagas disease. We aim to evaluate and produce two CD-ROMs to help bridge the gap between the need for health educational materials about neglected diseases adapted to the local culture and language, and lack of production in the public health field. The first CD-ROM evaluated will be on the topic of Dengue, originally produced in English, by the Wellcome Trust in collaboration with TDR. We are translating this CD-ROM into Portuguese and will evaluate it in Brazil. We seek to evaluate its reach and its cultural appropriateness in the Brazilian setting, trying to see how it may be better incorporated and utilized.

Dengue and dengue haemorrhagic fever have emerged as a major public health problem, with 100 endemic countries throughout the Americas, South-east Asia, the Western Pacific islands, Africa and the Eastern Mediterranean. Dengue is the most important arboviral disease in the world and in terms of mosquito-transmitted viral diseases; it has the highest attack rates of morbidity and mortality. The WHO Global Strategy for Prevention and Control of Dengue Fever/DHF (7), as established in 1995, comprises five major elements. Our project aims to address two of the five elements, specifically:

- Emergency preparedness - requires the development of emergency and contingency plans, including *education of the medical community*, hospitalisation plans, case management and emergency vector control are required.
- *Capacity building and training* – for surveillance, laboratory diagnosis, case management and vector control at professional, supervisory, technical and field levels.

All countries in dengue-endemic areas need to develop and implement new emergency control strategies for dengue epidemics. The education of the medical community and health workers is a vital step for disease prevention and control. Not only in the case of treatment of the disease, but also as in all aspects of emergency preparedness, where capacity building and training of health workers in general will help create awareness of the disease and possible steps to control it.

Given its sources, most transactions in the information economy are carried out principally in the English language. This means that much of the software needed for being a digital citizen requires familiarity with the English language, mother tongue of less than 10% of the world's population. This implies that non-English countries should invest either in generating software in the vernacular, or in developing English skills, or both, which further increases cost in “catching up” (8).

By translating the dengue CD-ROM into Portuguese, we intend to test its use and impact with the target audience, identify and overcome barriers to the use of information in different settings, such as with health care professionals and schools in developing countries. We also aim to distribute the translated disk in Brazil, using some channels of distribution already in progress in FIOCRUZ and consequently making the

CD more widely available in the local language to health workers and other health professionals in the country.

The second aim of this study is to produce an interactive educational CD-ROM about Chagas disease in Portuguese. This CD-ROM will be produced in collaboration with The Wellcome Trust-PGIH in the UK and CPqRR-FIOCRUZ in Brazil. Chagas's disease or American trypanosomiasis, caused by *Trypanosoma cruzi*, is a major public health problem in Latin America (present in 18 countries), where it constitutes one of the largest parasitic disease burdens. The morbidity and mortality associated with Chagas's disease in Latin America is more than an order of magnitude higher than those caused by malaria, Schistosomiasis or leishmaniasis (9). Control strategies for the disease have proven effective and elimination is being planned in many countries in South America. As part of TDR/WHO's research focus for Chagas's disease, the focus is concentrated on the improvement and wider dissemination of existing tools and strategies, and risk avoidance.

Traditional information flow: why still a "monologue"?

As suggested by Godlee et al (2), "pull" is better than "push" when it comes to health information. Also, as suggested by Lee & Garvin (6), exchange is more appropriate than transfer in health information dissemination. "*People in the developing world should be given the chance to say what they want rather than simply be sent information*". Even so, "*despite the growing understanding of the need for exchange of knowledge between countries and within regions, there is a continuing tendency to push information to people rather than strengthening and responding to the pull of their informational needs*" (2).

Why is this still taking place? Since knowledge, as a commodity, is power, the hierarchical, one-sided relationship assumed exemplifies what Freire calls the 'banking concept' of education (10). Knowledge is bestowed by the knowledgeable (the teacher as subject) upon the ignorant (the student as objects). The teacher regards not only the students as objects, but also as individuals considered to know nothing. Thus, students become 'containers' to be filled by the knowledge of the teacher, and information becomes 'deposited' into the empty 'receptacles' of the students through the process of memorizing and repeating (10). Most health information transfer is based on this banking approach and presupposes a social relationship based on a one-sided

monologue from expert to layperson, and from knowledge creator/communicator to knowledge user (5). In this way, *“those sending information risk being paternalistic, patronizing and wrong”* (11).

These underlying problems of information transfer have many implications. It ignores the social context of the information receivers and denies the agency and adaptive powers of recipients. Therefore, communication flow in health and health care are related to issues of power (5). Experts have the power to define the ‘truth’ or ‘best practices’. The North (here understood as developed nations) continues to transfer knowledge to the South (developing nations), repeating the historical imperialist trade of goods where knowledge becomes a commodity.

This power could be thought of, not only in the economic sense, but also through the ownership of information and its dissemination. *“The structures and practices of information transfer gave information providers – ‘the experts’ – the power to define ‘truth’ ... Knowledge dissemination can have more impact if it is based on two-way communication – a dialogue – between researchers and those who implement health promotion programs”* (5). Thus, *“information empowers and those who work with information flow in the rich world should find ways to enhance flow, recognizing that the flow, like good communication, must be two way”* (1).

Electronic publishing: sharing experiences between North and South

Our innovative partnership of CD-ROM production combines the field research experience of FIOCRUZ with the expertise and know-how in CD-ROM technology production of the Wellcome Trust. In doing this, this project forms a new link between health research and educational multimedia production, incorporating both the “pull” (health demands) and the “push” (health delivery).

Local health information providers are best placed to create and adapt health information for local healthcare workers. They are best placed to understand their health information need, use of language and education level. They understand best the context of how the information will be used: socio-economic factors that affect health care interactions, levels of available resources, health system logistics, cultural factors and the local disease profile. Consequently, a recognized priority area for action is to strengthen the local production, translation, adaptation and dissemination process in the resource-poor countries. In this view, joint initiatives that involve local producers and end-users thought the publication cycle, from initial needs assessment and planning

through to evaluation of use and impact assessment is the aim between the collaboration formed between Wellcome-PGIH and FIOCRUZ.

The Wellcome Trust, Publishing Group-International Health (PGIH) has an ongoing mission to develop multimedia products, principally CD-ROMs, in partnership with organizations working in international health. The PGIH team is an experienced group in producing series of educational materials for medical and life sciences students, their teachers and other healthcare professionals. More than 17,000 discs have been distributed in more than 70 countries.

The Oswaldo Cruz Foundation – FIOCRUZ, linked to the Brazilian Ministry of Health, is the biggest biomedical research institution in Latin America. FIOCRUZ develops actions in the area of science and technology in health, including activities in basic and applied research, teaching, reference hospital and ambulatory assistance, strategies formulation in public health, information and diffusion, personnel training, etc.

Even though FIOCRUZ is a well-qualified research institute, it still lacks in some research areas, specifically on the development and production of electronically published interactive IEC (information-education-communication) materials. Presently, FIOCRUZ has to interact with private contractors to produce CD-ROMs. Several technical constraints exist in developing multimedia applications, such as CD-ROMs. Software requirements for multimedia development consist of one or more authoring systems and various editing applications for text, images, sounds and video. Therefore, due to lack of skills, human resources and technical IT infrastructure, FIOCRUZ is still deficient in development of this type of computer-assisted learning.

In this way, this collaboration brings together the multimedia development expertise of the Publishing Group with the disease and country-specific knowledge of CPqRR-FIOCRUZ. We aim with this collaboration to begin CD-ROM production in FIOCRUZ with the help of PGIH, and in return we offer the Wellcome Trust CD-ROM distribution channels in Brazil, translation of some of their CDs and evaluation of their materials in Brazil with health professionals.

This collaboration started in 2004 under funding of UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) for a one year placement at the Wellcome Trust in London for a *Career Training fellowship in interactive learning*. A fellow stayed in the Publishing group for a year and four months where many experiences were shared. This capacity training aspect was fundamental for

the fellow to be able to go back to her country of origin, not only to apply what was learned, but also to link the two institutions in collaborative dialogues and future project. Collaborations may be a simple, but effective aspect of information dissemination, where it is key in assuring the sustainability of projects. Sustainable development is achieved only through building local capacity (2).

With the production of these two CD-ROMs - the translated dengue CD and the new production of a CD-ROM about Chagas's disease, we intend to contribute to the improvement and strengthening of human and IT resources in interactive learning and educational multimedia publishing for health professionals and schools in Brazil.

The Wellcome Trust's multimedia products seem to lie between two extreme models:

- a) Course-specific model: materials are specifically developed for a specific course – ('deep and narrow') or 'generic' (in the sense that general materials are distributed on the open market – 'shallow and wide') - the relationship with end-users comes built in;
- b) E-Talc approach: materials are distributed worldwide, where the sheer number of users makes it very hard to build up a meaningful relationship with all end-users.

The consensus of building up relationships between the Wellcome Trust and end-users seem to lie middle ground in which key contacts or 'trainers' may be conducts building relationships with teachers using CDs in the courses. By sharing experiences on the production and application of CD-ROMs for healthcare professionals in developing countries there could be many ways to discuss ways forward and maximize their impact.

Yet, important questions remain to be answered, such as: how is CD used as a educational resource – who uses it, do they do so alone or in training setting? Is it used didactically by a lecturer or used interactively by a group?

Evaluation of ICTs is another important aspect that has traditionally been overlooked in health. Without scientific evaluative information of ICTs, we are unlikely to reap the greatest benefits from these powerful tools. According to Hutchinson (12), members of the medical profession seem reluctant to value research and evaluation into the effectiveness of educational interventions. One reason for this reluctance may be

that there is a fundamental difficulty in addressing the questions that everyone wants answering: what works, in what context, with which groups and at what cost? Any attempts to overcome barriers to use information should be based on good research into the nature of the barriers and evaluations of planned interventions (2).

Although new technologies are often welcome, they require criteria in the choices and use of these materials. To say that these new resources configure themselves as one more revolutionary didactic tool, or even as something revolutionary to education, without evaluating them is a technological risk that could generate future problems. According to Brandão (13), for a long time researchers of many countries occupied themselves trying to define educational *software*, although few of them paid much attention to the elaboration of necessary instruments to evaluate them scientifically. Therefore, standardised evaluation criteria may help producers conform to common standards in electronic publishing.

By building partnerships, skills, understanding and ownership between these two institutions, the use and distribution of interactive educational CD-ROMs may be potentially increased. The possibility of designing and producing the Chagas CD-ROM as a collaborative process will enable both parties to grow considerably. With the premise that good research can be done in any part of the world – not just in developed countries – given the right resources and skills, by exchanging experiences and knowledge, both institutions will gain from this project. By evaluating the CD-ROMs with the target audience, the Wellcome Trust-PGIH also seeks to gain a newfound knowledge not previously available to it. It is with project that the Wellcome Trust will, for the first time, be able to gain detailed and rigorous scientific experience from the use of their materials in a developing country. This will greatly benefit the range of multimedia production activities in which the Trust is engaged.

Concluding remarks: towards information exchange

Production and evaluation of CD-ROMs are linked and intertwined processes. We evaluate the CD-ROMs qualitatively and quantitatively. By producing the content in Brazil with experts in FIOCRUZ and other Latin American institutions, and by evaluating the disk with the target population, we strive to create an end product more in tune to, and reflecting better the reality of, the location where the diseases are

endemic. By building partnerships, skills, understanding and ownership between these institutions, this collaborative process enables both parties to grow considerably, where this approach strives to expand the frontiers of health information, education and promotion.

Genuine partnerships and mutual trust is a prerequisite for the sustainable exchange of technology and knowledge. *“Local conditions matter for the success of programmes, 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 a round the world”* (14). As a result, there is a need to address the cultural dimensions of information dissemination. The solutions proposed are mainly technical, but more challenging is the problem of cultural barriers to access and use of new information technologies.

Local producers are best place to construct their own material, where information may be generated by the countries themselves and in exchanged in productive dialogue with developed nations. This flow of information is beneficial for both parties involved where *“using the concept of exchange as opposed to transfer is a powerful first step in redirecting current health communication relationships to a structure that is more attentive to social relationships and contexts, and to the agency of information users. Further, information exchange may be a powerful tool for ensuring that health information is not simply received, but also acted upon”* (5).

In summary, the process of local content creation and sharing may be best supported by including the possibilities of:

- a) Training and technical support (writing, editing, adaptation, evaluation, etc.);
- b) Access to and the application of information technologies;
- c) Joint initiatives that involve local producers and end-users throughout the publication cycle (from initial needs assessment and planning through to evaluation of use and impact assessment).

Information technology is of limited value on its own. What is of enormous potential value is the opportunity to link with partners around the world and to disseminate locally created or adapted resources. As Pakenham-Walsh (15) affirms: *“international organizations have spent an increasing amount of time to try to understand the needs of end user and tailoring their own publications accordingly. But*

is this the best approach? Should international organizations in fact spend more time trying to understand the needs of local 'health information providers', if local providers are best placed to create and adapt locally relevant information...". Thus, the dialogue and exchange between North and South, local and global may be the best way to open channels of new possibilities in health information dissemination, and consequently, health promotion.

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References

1. GODLEE F. Global information flow. *BMJ* 2000;321:776-777.
2. GODLEE F. et al. Improving access to health information in the developing world: a position paper for WHO [draft paper]. Available at: http://www.who.int/rpc/meetings/en/improving_access_draft.pdf
3. WHO. World Report on knowledge for better health. 2004. Geneva: World Health Organization. Available at: <http://www.who.int/rpc/meetings/en/WR2004AnnotatedOutline.pdf>
4. HAINES A & DONALD A. 2002. Getting research into practice. 2nd edition, London: BMJ books.
5. GLOBAL FORUM FOR HEALTH RESEARCH. 2004. 10/90 report on health research 2003-2004. Available at: <http://www.globalforumhealth.org/pages/index.asp>
6. LEE RG. & GARVIN T. Moving from information transfer to information exchange in health and health care. *Social Science & Medicine* 2003; 56:449-464.
7. WHO. 2001. Strengthening implementation of the global strategy for dengue fever/dengue haemorrhagic fever. Available at: http://www.who.int/csr/resources/publications/dengue/WHO_CDS_D_EN_IC_2000_1/en/print.html (Accessed Oct 2004)
8. CHANDRASEKHAR CP & GHOSH J. Information and communication technologies and health in low income countries: the potential and the constraints. *Bull WHO*. 2001; 79(9):850-855.
9. MOREL CM. Neglected diseases: under-funded research and inadequate health interventions. *EMBO reports*. 2003;4:35-38.
10. FREIRE P. *Pedagogia do oprimido*. 17 ed. Rio de Janeiro. Paz e Terra, 1987.
11. KALE R. Health information for the developing world. *BMJ* 1994;309:939-942.

12. HUTCHINSON. Evaluating and researching the effectiveness of educational interventions. *BMJ*, 318:1267-9.
13. BRANDÃO EDJR. Repensando modelos de avaliação de software educacional. Universidade de Passo Fundo, 2004. Available at:
in:<http://www.minerva.uevora.pt/simposio/comunicacoes/artigo.htm> (Accessed on 23 of July, 2004).
14. WORLD BANK. World development report 1998: knowledge for development. Washington DC: World Bank, 1998.
15. PAKENHAM-WALSH. Local capacities to create and adapt information for healthcare workers in developing countries: an information explosion – with little impact? *Bulletin von Medicus Mundi Schweiz*. 85, 2002.