Governments are legally obliged to ensure adequate access to health information

Access to reliable, relevant, and implementable health-care information has been identified as one of the key determinants for reaching the Millennium Development Goals (MDGs). In 2006, Pang and coworkers noted that the challenge is to “ensure that everyone in the world can have access to clean, clear knowledge—a basic human right, and a public health need as important as access to clean, clear water, and much more easily achievable.” However, this challenge has repeatedly been put on the sidelines. The world has seen several high-profile investments including the Global Fund to Fight AIDS, Tuberculosis and Malaria and The Global Alliance for Vaccines and Immunization, but no big investment has been made in the domain of making health information available for all. The issue of availability of relevant, reliable health information for all domains including education for patients and health-care providers, research accessibility, and application of available knowledge into best practices has not been adequately addressed by the international community. The Healthcare Information For All (HIFA) 2015 campaign was launched in 2006 with the shared goal that “by 2015, every person worldwide will have access to an informed healthcare provider.” Since its launch, HIFA2015 has grown to more than 6000 members representing 2000 organisations in 167 countries. External evaluation of the HIFA2015 programme concluded that HIFA2015 has achieved “an extraordinary level of activity on minimal resources from which many people around the world benefit.”

Article 25 of the Universal Declaration of Human Rights states that “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.” So then, when a child dies of pneumonia because eight in ten caregivers in developing nations are unaware of the key symptoms, are we guaranteeing any “standard of living adequate for health?” When four in ten general practitioners in Pakistan prescribe sedatives as first line drugs for treatment of hypertension because they do not have adequate information about medicines, what standard of medical care are we guaranteeing? Mismanagement of malaria, the third stage of labour, and sick children (at district hospitals) have all contributed to an unacceptably large burden of avoidable morbidity and mortality because proper health information was not available or implemented. The National Family Health Survey in India reported that even after decades of access to oral rehydration therapy, only 8% of children in India received increased fluids and continued feeding during diarrhoea, whereas about 40% actually received decreased fluids. Evidently, it is not an exaggeration to state that people are dying for lack of healthcare information—a social injustice that the global health community cannot afford to ignore.

Should governments be held responsible for ensuring that every citizen and every health professional has access to the information they need to protect their own health and the health of those they care for? Should governments be held to account for, and to stop, any action that denies the availability of health information, or that misinforms the public or health professionals contrary to scientific evidence? The answers to these questions are yes and yes, as clearly stated in international human rights law.

A 2012 analysis by the New York Law School and HIFA2015 concluded that “health information is an essential component of many identified and established human rights. States party to treaties such as the International Covenant on Civil and Political Rights must provide and guarantee access to health information.” Sadly, however, many examples show that governments are getting away with failure to improve availability of information, failure to reduce misinformation, and, occasionally, deliberate, harmful misinformation. For example, public health researchers estimated that more than 330,000 people died unnecessarily because of the South African Government’s failure to accept HIV as the cause of AIDS, thereby delaying the introduction of antiretroviral drugs. HIFA2015’s new initiative, the HIFA-Watch campaign, is now monitoring examples of apparent progressive and regressive action by governments.
A UN Educational, Scientific, and Cultural Organization case report clearly explains that “access to health information is also an essential aspect of the right to health. Health information enables people to promote their own health and to claim quality health facilities, goods and services from the State and others.” Thus, we call on governments worldwide to publicly acknowledge the fact that they are, under international human rights law and treaties, legally obliged to take steps to improve the availability and use of health-care knowledge for their citizens and health professionals. Governments should provide a public statement on what they are already doing and what they expect to achieve in the next 5 years to promote the availability and use of health-care knowledge for health professionals and citizens. Mandates reinforced under current laws could be used to bring in specific actions according to the local need for health-care information, so that the obligation of governments to protect the health of their citizens with regards to health-care knowledge is made a priority with respect to MDGs and in the post-MDG era.

We thank Molly Land (School of Law, University of Connecticut) for comments on the first draft of the Comment. SB, PC, and TB are country representatives of HIFA2015 for India. The position of country representative of HIFA2015 is a voluntary unpaid position. NP-W is the coordinator of HIFA2015 and CHILD2015 networks and codirector of Global Healthcare Information Network. We declare that we have no other conflicts of interest.


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