

Thousands dying every day for lack of health information



Information isn't just power – it can save lives too. But how do you get vital information about quality research, resources and treatment options to frontline health workers wherever they may be in the world? Simon Crompton talks to the founder of a campaign that is addressing just that.

Some words spoken by the late James Grant of Unicef have been the inspiration for Neil Pakenham-Walsh, founder of the Healthcare Information for All by 2015 (HIFA2015) campaign. "The most urgent task before us is to get medical and health knowledge to those most in need of that knowledge," said Grant in 1993. "Of the approximately 50 million people who were dying each year in the late 1980s, fully two thirds could have been saved through the application of that knowledge."

That statistic is still shocking, and still holds. "Tens of thousands of people die every day, often for the simple reason that the parent, carer or health worker lacks the information and knowledge they need to save them," says Pakenham-Walsh. "Basic healthcare knowledge isn't being implemented. But in the past few years, for the first time, it's become technologically possible to bring together large numbers of people from different countries all over the world, so that they can explore how to change things, and make the available information better used."

In October 2006 he launched HIFA 2015 – a web-based campaign and knowledge network. Its members – more than 3000 in 150 countries – interact and communicate with the aim of bringing about the HIFA 2015 goal:

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“By 2015, every person worldwide will have access to an informed healthcare provider.” It has support from 77 leading health and development organisations, including the British Medical Association, its main funder.

The campaign itself does not act as a provider of healthcare information – instead it wants to enable providers and users of healthcare to find ways to make information more widely available and implemented. One recently posted comment, for example, came from a charity which sends information about health to workers in under-resourced regions, requesting addresses of libraries of nursing schools and other professional training programmes in Africa. Another pointed out studies indicating the reduced mortality rates in villages if trained midwives were on hand to provide information.

There are three strands to the HIFA strategy. The first is an already well-established network of like-minded people who contribute thoughts and ideas to all other HIFA members by email. The other two strands are, by Pakenham-Walsh’s own admission, still awaiting development because of lack of resources. One is to harness all the expertise in the network into an online knowledge base about the information needs of different healthcare providers and how to meet them: “It’s the sort of information that appears in our online discussions, but disappears too quickly” says Pakenham-Walsh.

The other aim is to obtain a commitment to support the spread of health information from a major funding agency. The campaign needs money to take it to the next level.

Pakenham-Walsh, a doctor by training, has worked for various organisations which support international health information since 1990, but became increasingly aware that the emphasis was often on improving access to information among researchers and policy makers. What needed more attention was the lack of information getting to frontline health care providers.

In 2004, he was asked to help write a report on global access to health information for the World Health Organization. A short version was published in the medical journal *The Lancet* laying down the challenge: “Can we Achieve Health Information for All by 2015?” The enthusiastic response led to Pakenham-Walsh, along with a Kenyan cardiologist and a software expert, setting up the website and the campaign, which launched in Mombassa in October 2006.

Now he wants physical therapists around the world to become more involved in the campaign. He’s very aware, he says, that continents like Africa are chronically underserved with physical therapy due to lack of resources. Their scarcity makes it even more important that these individuals’ information and learning needs are met effectively. “We’d certainly like to complement our existing membership of physical therapists with more from developing countries. There’s already discussion about developing open access resources for physical therapists, such as *Physiopedia*.”

But doesn’t Pakenham-Walsh worry that information overload is increasingly becoming a problem as much as information deprivation? Joining HIFA’s network results in sometimes as many as a dozen emails arriving in your in-box every day.

“Yes, information overload is a really important problem. But the issue is not so much about how many emails you might receive through HIFA2015 - at least I hope not. HIFA members receive an average of two or three a day, and very few people choose to unsubscribe once they have joined. Also,



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members in developing countries are least likely to unsubscribe, despite their slower and more expensive internet connections, and many of them write to us to say how useful the messages are, how they feel less isolated.”

“The real issue of information overload is increased exposure to irrelevant or unreliable healthcare information. HIFA2015 members are very aware that this is an increasingly big issue. The difficulty of sorting reliable from unreliable sources of information is key. We hope that through our networks, we will help people to know where to go to find the information they really need. It’s not our job to police the information available, but we can help people discuss how to address these issues.”

