

# Dr Neil Pakenham-Walsh: On Increasing the Availability of Healthcare Information

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Coordinator and Director at HIFA, Dr Neil Pakenham-Walsh, talks about his organisation's vision of enabling universal access to healthcare information.



*Coordinator and Director at Healthcare Information For All (HIFA), DrNeil Pakenham-Walsh, talks about his organisation's vision of enabling universal access to healthcare information and the role of mHealth therein.*

**You have a really interesting background that brought you to your current role. Tell us a bit about that and the founding of HIFA.**

Over the years I've found myself in a number of professionally isolated health worker roles, from being a medical officer on an expedition in cloudforest in Ecuador to aiding a large archaeology project in Peru – all of which had a big impact on me. A couple of years later I went into medical publishing, where I started as Deputy Editor for the free health journal for doctors in Africa, *Medicine Digest*, and then went on to become an Editor at the [Wellcome Trust](#) where I worked on Topics in international Health, a series of CD-ROMS for health professionals in low- and middle-income countries (LMICs).

In 1994 I attended a conference at the British Medical Association (BMA) in London which focused on the question of how to improve the availability and use of health information in LMICs. From that moment on I realised that was my personal niche and mission. I then got a job with the international development charity [INASP](#) as their first Health Programme Manager, where I remained for the next nine years.

In 2004 I was invited by [Fiona Godlee](#), the current Editor in Chief of the *BMJ*, to co-author a piece that had been commissioned by the World Health Organisation ([WHO](#)) around this issue of how to improve the availability of health information in LMICs. In that piece, we called on WHO to take the lead in championing the goal of Healthcare Information For All. This was published as an article in *The Lancet* called: “Can we achieve health information for all by 2015?”.

Meanwhile, I left INASP with an increasing interest around the information needs – not only for scientific journals, which was the main focus of INASP at that time, but also the information needs of ordinary citizens and front-line health workers. Together with a couple of colleagues who had a similar interest in this area, I set up small non-profit called [Global Healthcare Information Network](#) that became the registered framework for the HIFA project.

We went on to launch HIFA with help from the *BMJ* in October 2006. At that time we were supported with a letter from the WHO which basically said that our work is important and that HIFA is an ambitious goal, but it can be achieved if all stakeholders work together.

Indeed, this is what HIFA is all about; it’s trying to bring all the stakeholders together in a global community and campaign.

### **Tell us more about the importance of HIFA.**

HIFA supports global health discussion forums, so you can think of it as a 24/7 virtual conference. Our network includes thousands of health information providers who are all working in different capacities, languages, countries, with different levels of health workers, in different parts of the global healthcare information system. We have large numbers from Africa – in South Africa there are around 300 members and in Nigeria we have 1,300 members. Our main forum is in English but we also run HIFA-French (mainly francophone Africa) and HIFA-Portuguese (mainly Brazil, Angola, Mozambique and other Portuguese-speaking countries in Africa). On each forum we have the full range of stakeholders: health professionals, policy makers, researchers, publishers, information professionals, social scientist, citizen representatives. We share a common interest in empowering citizens, health professionals, and policymakers with the information they need to protect their own health and the health of others.

One of the things that HIFA is trying to do is to bring together stakeholders from each of those areas to try and work out the issues and support each other so that we can better understand the drivers and barriers and what can be done about them. But it is a complex business – there’s no quick fix.

### **What sort of information is most useful to healthcare workers in Africa?**

We did a review in 2009 that suggested that across Africa there is a gross deficit in the availability of information and therefore healthcare knowledge among front-line health professionals. Because of the weak health information system and the fact that they’re not getting the information that they need to learn and use as a reference for healthcare, they are putting African citizens in danger.

In Africa and across all LMICs, many citizens are being exposed to healthcare from front-line health professionals who are not adequately supported. We look at this support, not just in terms of information because if you just increase the availability of information that in itself is not going to change everything, but health professionals have a whole range of different

needs that must be met, and if they are they will be empowered to deliver safe and effective healthcare to citizens. We use the acronym SEISMIC to describe these needs: Skills, Equipment, Information, Systems support, Medicines, Incentives (including a decent salary for what they do) and Communications facilities.

### **What do you think are the biggest barriers to providing health workers or patients with health information?**

The availability and use of healthcare information is dependent on the integrity of the global healthcare information system. This includes everyone and all processes that are involved in the creation, exchange, dissemination and making available of relevant and reliable healthcare information. There are weaknesses and issues at all stages in the cycle system, which range from low capacity for health research and publishing; indexing, systematic reviewing and international guideline development; national policy development and implementation; production of end-user materials (ranging from formularies for prescribers through to health articles in newspapers); and difficulties in finding and obtaining information in the right language that may exist, but may not be accessible for various reasons.

For example, [MEDLINE](#) – the bibliographic database of life sciences and biomedical information – is Anglo-centric and fairly US centric as well. Therefore, WHO is needed to oversee and support the Global Index Medicus, which aims (with inadequate funding) to balance and make visible content from research from LMIC.

There is also the issue of how guidelines are produced, and it's only in the last eight years that WHO, for example, which is the most important producer of international guidelines and recommendations, has had a systematic approach to developing guidelines. Up until 2007, guideline development at WHO was largely based on expert opinion as opposed to systematic reviews.

Then there's the whole problem of how guidelines are then used to inform the development of health policy at country level, integrating inputs from local health research, and how such policy is (or isn't) actually implemented. This requires all frontline staff have access to up-to-date, point-of-care information such as prescribing formularies. Most prescribers in LMICs continue to rely on information that is passed to them by the pharmaceutical industry, whose primary motivation is to sell their products, as opposed to independent, reliable formularies (such as the British National Formulary) that we're used to in other countries. That's an area that interests us at HIFA: access to reliable information on medicines for both prescribers and users.

Then of course there's the whole area of how people find information amongst the information overload that happens as soon as you have an internet connection. You suddenly have access to lots of information but then the problem becomes one of identifying and finding the information that is relevant to you, that is in the right language, and at the right technical level to understand and implement.

The whole issue of the availability of health information in different languages and for different levels of health worker and for different citizens is a big issue. So is the issue of misinformation and myth, which was a driver in the [Ebola](#) crisis of 2014 and 2015. An internet connection (or mobile phone) dramatically increases access not only to information but also to misinformation, and there are powerful commercial drivers that promote

misinformation and biased information, ranging from claims from quacks to be able to cure cancer or HIV, through to exaggeration of benefits of specific drugs, and systematic downplaying of harms of tobacco, alcohol and junk foods.

**Tell us about the mobile HIFA (mHIFA) project, which promotes the use of mobile phones to share health information.**

Like other projects, mHIFA has risen through discussions on the HIFA forum that highlighted the importance of mobile phones in healthcare, for both health workers and citizens. As a result of those discussions, a working group has formed out of HIFA volunteers who meet every couple of months via Skype. Together with the wider HIFA community, we have articulated what we call the mHIFA goal: at least one mobile handset manufacturer in at least one LMIC will provide access to essential health information free of charge by 2017. We consider pre-loaded information would be ideal in this context, and examples of essential health information for citizens include Red Cross's first aid app and Where There is No Doctor. However in reality it seems like we're not going to achieve that goal – not through lack of trying.

The mHIFA project is particularly focussed on the information needs of citizen's, parents and children. We have hosted two consecutive student internships in association with the San Jose State University. The first did a survey of mHealth projects in general, which found that only a tiny percentage of overall global mHealth projects were actually providing practical healthcare information for citizens. The second survey looked at health education videos for citizens and identified huge potential but many gaps in content coverage. We have a third project planned for 2017 where we'll bring in a third student to look at ways to promote the availability and use of the Red Cross app in LMIC.

**How would you motivate mobile operators or device manufacturers to get involved in this work?**

One way of looking at this is to try imagine a world that whenever there is an emergency such as a road traffic accident, ordinary people on the scene will have access to basic information in their local language on their mobile phone to help guide them on what to do in that situation (most accidents are initially attended by ordinary citizens – ambulances and professional care happens later, if at all). At the moment, the vast majority of mobile phones do not have such information. The same is true for child illnesses – imagine a world where every child, if they were to become ill with diarrhoea or develop a high temperature, their parents would only have to look on their mobile phone to get the information they need to make the decisions as to what to do in the home, and when to make the journey to the nearest health facility.

We've personally written to 20 of the leading mobile network operators and mobile handset manufacturers about this vision, and tried to impress on them that part of their corporate social responsibility is to meet the needs of their customers – these are very real needs. It's also in their commercial interest to serve the basic needs of their customers. However we've had zero response and it is difficult to understand why.

**How does HIFA engage with policy makers to help them make informed decisions?**

We have a lot of policy makers, including Ministry of Health staff and WHO staff at HQ, regional and country level on HIFA. We're currently running a project called Evidence Informed Policy in Practice, which is being supported by [TDR](#), the Special Programme on Tropical Disease Research, WHO and *The Lancet*.

We have run two 6-week thematic discussions in 2016; the first one was on evidence informed country level policy making, which was presented at the Cochrane Colloquium in Seoul in October. The second was on implementation research. By and large we're learning that it's evident that policy makers have different kinds of needs. It's also evident that, as compared with researchers and health professionals, evidence informed policy making is not a major, or even in some cases, a minor part of policy making in the real world. There are lots of other factors that impact it, but there is scope for increasing awareness among policy makers about the importance of taking into account evidence in policy making – and helping them to find the information they need, in the right format.

There is also a growing awareness of the importance of what evidence informed policy making actually is. Up until quite recently it's been widely regarded that if you find a piece of evidence – in other words a piece of research – that fits what you want to do, then you might cherry-pick it to help you to put it into practice. More and more policy makers are recognising that evidence in informed policy making is around the accumulation of existing evidence around a topic. There's more understanding of what a systematic review is, and why that's important.

Also, there is more awareness about how systematic reviews, which are typically global in their scope in terms of geography, can be synthesised and understood side by side with local research. There is a lot of importance afforded by most policy makers on local research as opposed to global research. That's quite understandable, but it's also important that decisions aren't just made on the basis of local research – the global research on the same kinds of issues can be hugely important as well.

### **What's ahead in terms of HIFA's work in 2017 and beyond?**

Our main focus is continuing to build the community and to do more thematic discussions in collaboration with our 280 supporting organisations. Together with WHO we want to expand HIFA into new languages. At the moment we have English, French and Portuguese, and this year we plan to introduce HIFA in Spanish. We aim to eventually include other UN official languages such as Arabic, Russian and Chinese.

We are currently running eight projects, including one called the Prescribers and Users of Medicines Working Group & Project, which is looking at ways to increase the availability and use of reliable information for prescribers and users of medicines. We now have two members of the WHO Essential Medicines and Products Department on that working group and a former Editor of the British National Formulary, which despite being produced mainly for the UK, is popular in English speaking countries – you will often see old second hand copies of it lying around in LMICs. We are looking at ways of increasing the availability of information for prescribers. We're currently doing a global literature review and a survey of information needs among prescribers in Kenya, and we're looking at the possibility of holding a roundtable conference in 2017 to highlight and address this issue.

It's becoming urgent that we promote more responsible use of antibiotics in particular, as overprescribing is one of the biggest drivers of antimicrobial resistance, a growing threat to the human race. Over the next 10-20 years we could revert to a situation where most infections are simply not treatable, which would take us back to Victorian times. One of the many factors that contribute to this is that many prescribers and users of antibiotics do not have ready access to reliable information on the medicines that they are prescribing. It's not just the information on the individual medicines that's important, it also information on how

to assess the individual patient and select the appropriate medicine for that patient among the options available.

We also need to be doing more analysis and advocacy around information needs and how to meet them. With support from *The Lancet* we have developed the [HIFA Voices database](#), a specialised resource to provide the evidence we need for our advocacy, and the evidence our members need to increase the impact of their health information activities. We now have a dedicated project on Evaluating Impact, which includes key staff from WHO Geneva, and is looking at ways to help WHO measure and promote the impact of their publications from 2017.

The continued growth and development of HIFA reflect a real need not provided elsewhere. As we grow we have reached a point where there is so much more we could be doing but are unable to do through lack of capacity. We have only one full-time staff (me) and 200 volunteers. We welcome offers of technical and financial support to help us grow further and accelerate progress towards our shared vision: a world where every person and every health worker has access to the information they need to protect their own health and the health of others.

### **How can people get involved with HIFA?**

We would like to invite anybody and everybody who is interested in improving the quality of healthcare and, in particular, improving the availability and use of health information for health workers, policy makers and citizens, to [join the growing HIFA](#) community (free), which has more than 16,000 members from 175 countries interacting in English, French and Portuguese.

For more information contact [news@eHealthNews.co.za](mailto:news@eHealthNews.co.za), like us on [Facebook](#) or tweet us [@eHealthNewsZA](#).