Betting on e-collaboration

Interview with Dr Alex Jadad

➜ by Anna Wagstaff

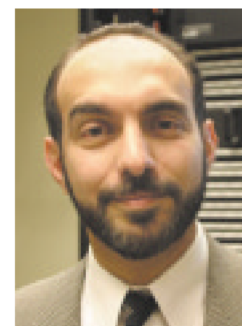
All over the world, communities are grappling in isolation with universal questions of how to prevent cancer and improve the lives of patients. But is there any reason, in this Internet age, why we should not share ideas and adapt effective strategies to local conditions. **Alex Jadad**, Director of the Centre for Global eHealth Innovation, believes there is not. And he is trying to prove it.

Global collaboration is an elusive goals pursued by many people for many different ends. What makes you so convinced it can work in the case of cancer?

ALEX JADAD I'm not convinced it will work, but it's worth a try and I'm giving it my best shot. We are all very good at believing that we are dealing with unique issues in every country, so we keep competing with one another to reinvent the wheel. Now with the Internet, we have a tool that has the potential to give communities everywhere the same access to vast quantities of vital knowledge and information and the means to communicate with one another. The problem is that the digital divide is actually widening, and most of the world still has no Internet access, nor the ability to use the information it provides. So I am trying to bring people located in strategic areas of the world together, and see whether we can make a real difference.

There are all manner of urgent health issues facing communities around the world. Why focus on cancer?

ALEX JADAD The Centre for Global eHealth Innovation, in Toronto, does not only deal with cancer, but cancer is a central interest. One reason for this is that I am a specialist in supportive case and work mainly with cancer patients. A few years ago the International Union Against Cancer [UICC] asked me to co-chair a think tank promoting global ways of working, which means I have a huge international cancer organisation interested and supporting this work. Another reason is that cancer presents unique opportunities for widespread collaboration, because it is a universal problem that crosses age groups, income levels and countries and it covers the whole spectrum of health services, from prevention to bereavement. The fact that cancer is so expensive to treat also means that governments are prepared to invest large sums in prevention.



If we can pool our ideas on ways to tackle tobacco cessation, this could have an impact, for instance, on the one and a half billion strong population of China, where tobacco use is nearing the levels we once had in Western Europe and North America.

LIBA TAYLOR / CORBIS / CONTRASTO

Centre like this one Hargeysa, Somalia, are bringing Inernet access to many parts of rural Africa

In what fields are you trying to promote collaboration?

ALEX JADAD We are concentrating initially on tobacco cessation and pain management as these are the two main issues that are widely seen as universal and transcend every boundary.

Tobacco is a huge problem everywhere, and the reasons for smoking are the same the world over. However, in some places we have had more success reducing tobacco consumption than in others. So rather than leaving each individual country, or community to work out, from scratch, ways of tackling the industry and educating young people about the dangers of smoking, we want to use the Internet to gather success stories from all over the world.

The UICC has already established a huge international network – Global Link – that connects people interested in tobacco cessation. We are now concentrating our efforts on creating what we call 'e-tool kits' to help make strategies that worked in one country equally effective in other cultural environments.

The other focus is pain management. In many countries morphine is managed as an illegal drug, and it is still very difficult to prescribe. But some countries, such as Colombia where I come from, have managed to solve the problem of how to prescribe morphine. So there is an opportunity to work with advocacy groups, to make them aware of the sort of regulations that have been successfully introduced in other parts of the world.

There are also many myths and cultural barriers that deter patients from taking effective pain relief,

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and these are surprisingly similar the world over. Some people fear pain relief might make them die sooner or turn them into zombies. Others see pain as an inevitable part of cancer, or may not wish to be seen as wimps or distract their doctors from treating the disease. So here is an important issue that affects the quality of life of 75% of cancer patients and which we can improve simply by getting the message across that pain can be stopped effectively. Research has shown that it takes around 10–15 years for an innovation that has been proved successful in one environment to be taken up and used effectively elsewhere. We can't afford this time lag in cancer, so we hope that by making these e-tool kits available we will be able to speed up the learning and adaptation process.

So instead of everyone starting from scratch and making the same mistakes, each community can benefit from the expertise and success of others

What is being done to bring Internet technology to low-tech communities with poor infrastructures?

ALEX JADAD A lot. The United Nations has turned parts of India into a living lab for experiments on how to widen access to the Internet, and there are now more than 2000 different projects to mobilise the community behind these efforts. One of these is an attempt to extend Internet access from towns to the surrounding rural areas by fitting antennae on local buses. The antennae provide a wireless (Wi-Fi) connection for anyone within a 300-metre radius, which means that villagers will be able to sign on for short periods, two or three times a day, as the buses drive around their village. In some rural areas in Africa there are now "telecommunity centres" with phones, Internet access, photocopiers, all under one roof. These initiatives have many different purposes: to support farming communities, encourage small businesses, promote basic health and hygiene, bring information to schools… My question is: why not use the same resources to promote cancer prevention and disseminate information on palliative care?

This is what I mean about global collaborative effort – looking at what is there and working together to achieve goals that go beyond what was originally intended. It's important to remember that we are not talking about a computer in every home. Community workers, health workers and teachers can all act as "information brokers," downloading what they need, adapting it and getting the message across in appropriate ways.

Even if these communities do get Internet access, what good will it do them? The information is almost entirely in a language they can't understand, and written in the contexts of economic, cultural and health environments that differ radically from their own.

ALEX JADAD If we collaborate, then language is not an insuperable problem. Toronto, where I work, is a good example. It is like a mini-world with 150 ethno-cultural communities. Here we have a telephone service called 211, which provides a translation service in 100 different languages, 24 hours a day, seven days a week. It is expensive, and paid for partly by the state and the phone company, and partly by charitable trusts. But it serves 3000 community groups and support agencies in the city, so there are huge economies of scale. None of the groups could provide this service alone, but through collaboration, they are able to overcome language barriers even in the most linguistically diverse city in the world.

But the problem goes well beyond language. If we are to provide information on cancer care and prevention to Africa's Swahili-speaking communities, that information will have to be relevant to the local culture and conditions. Here too, collaboration is everything. All it takes is for one local community health team to work with us to adapt existing materials for their own use. The materials can then be made available via the Internet to all Swahili speaking communities of Africa, and health care workers or teachers in these communities can then download them and use them and then introduce their own modifications on the basis of their own experience, and pass these on to others. So instead of everyone starting from scratch and making the same mistakes, each community can benefit from the expertise and success of others.

Much of what we do at the Centre therefore focuses on helping people take information developed elsewhere and adapt it for local use. This is the purpose of the "e-tool kits." They consist of the raw information, strategies for adapting the information (how to sift out what is irrelevant and make it locally pertinent), and options for getting the message across. If the material is to be posted on a website, it will need to be designed and organised in a certain way, if it is for downloading and photocopying for use in schools or clinics, then it will need presenting in a different way. Or one may want to use local television or radio to spread the message, in which case we have the facilities to achieve this in Toronto, including 400 actors and 1000 patients and their families from very diverse backgrounds who speak 52 different languages between them.

Does your work have any relevance for Europe?

ALEX JADAD The potential for using the Internet and other information technologies in health work is now a major debate in both Europe and North America. The European School of Oncology (ESO) took the important step last year of bringing together some of the key voices at the First Conference on Cancer on the Internet, held in New York last September, and I have now been invited to co-chair the Second Conference, which, among other issues, will address fostering global collaboration and promoting digital inclusion.

In Europe, the Internet may not be the main answer to improving access to information, at least not yet. In many European countries, fewer than one in three families have access to the Internet – compared to almost nine out of ten in North America. The mobile phone, however, is becoming almost universal, certainly for the younger generation, but increasingly for seniors as well. And it is an incredibly powerful way to communicate – mobile phones today can send and receive e-mails and text messages, and can be used to watch television programmes and videoclips.

We wish to help local organisations develop ways of exploiting mobile phones – perhaps in conjunction with the Internet – to disseminate information about cancer treatment and prevention. The key is finding out how people wish to receive the information. Do they want audiovisual clips? Would they prefer text – large type or small? Everything we do is subjected to "usability" tests to ensure the service will be easy to use.

At what point will you know whether e-collaboration can produce the health benefits you hope for?

ALEX JADAD We've achieved a great deal in a short period of time. Through the UICC we have access to hundreds of organisations working in the area of cancer, tobacco cessation and pain, and we have set up the infrastructure to link them together. We have ESO in Europe, we are collaborating with six regional Health Ministries in Spain, one of which wants to work with us to develop a telehealth initiative for North Africa and Latin America. India is likely to take the lead on pain management tool kits.

We need to think big, act small and deliver quickly. Let's try it – what did we learn? Make some changes – what did we learn? And hopefully after four or five cycles of doing and learning, we will have the basis for something effective that can be used by groups all over the world to make a real difference.

More information on the Centre for Global eHealth Innovation can be found at: www.ehealthinnovation.org