Electronic medicine, without borders?

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Disease knows no borders and now researchers in Europe and the Mediterranean shoreline are using electronic infrastructures (e-Infrastructures) to coordinate and cooperate internationally.

Disease knows no borders. With migration, mixing populations and globalisation, genetic disorders, too, spread and blend easily. In each country where particular diseases emerge, national authorities deploy resources to track, treat and research common diseases.

This is helpful, and often very successful, but tends to duplicate efforts internationally many times over. Moreover, researchers working in one country may not be in touch with those in another, where their knowledge could be invaluable.

European and Mediterranean specialists working on the ITHANET project have increased coordination of their efforts and pooled their knowledge using e-Infrastructures, like different communication tools, databases, grids and web portals. This type of knowledge sharing is fertile ground for enriching the internet, but still remains one of the least explored and developed functions.

Blood disorder

Of course, knowledge networks of one type or another proliferate on the web, but specialised networks, gathered around one specific problem, are still comparatively rare.

ITHANET hopes to change that. By focusing their efforts on one group of blood disorders, the thalassaemias, the EU-funded project gathered experts from every country where the disorder is common - in particular among populations surrounding the Mediterranean.

As such, ITHANET provides the basis for future collaboration on inherited anaemia, more generally, and could serve as a model for international coordination and cooperation on other diseases.

”Haemoglobin disorders are common, potentially lethal, diseases posing a global health challenge," explains Carsten Lederer, a researcher with the ITHANET project.

"With global migration and intermixing of carriers, demanding flexible health planning and patient care, haemoglobinopathies may serve as a paradigm for the use of electronic infrastructure tools in the collection of data, dissemination of knowledge, harmonisation of treatment and coordination of research," he notes.

Like sickle-cell disease, thalassaemia's most common symptom is anaemia, but there are also a list of devastating secondary complications.

In its most severe form, untreated thalassaemia leads to death in the first decade of life. When managed, thalassaemia still interferes enormously with a person's quality of life, limiting their activities and requiring frequent blood transfusions and other expensive, life-long treatment.

"Even with the best of care, it still leads to a shorter life-span," says Lederer.

Mediterranean effort

ITHANET involved specialists from 26 organisations spread across 16

countries, including Egypt, Israel, Lebanon, Tunisia and Turkey, making it a truly Mediterranean effort.

"The problem is, many of these experts are still very unfamiliar with computer technology. Some researchers had no email of their own. In other cases, there is little or no electronic infrastructure, and most patient records are still on paper," declares Lederer.

But the project found that there were enormous potential benefits to be had from linking these experts up. Each had invaluable knowledge and experience, which is vital.

Thalassaemia is a complex disease which requires two out of a set of multiple genes to be defective. If only one of the genes is 'broken,' you are a carrier, if two are broken, then you have the disease. "If parents each carry the disease, then there is a one-in-four chance that the child suffers from [the disease]. And there are degrees, too, depending on the type of broken gene each carrier has," notes Lederer.

Experience sought

As a result, there is a multitude of possible phenotypes, of widely varying degrees of severity. "Chances are, one of the experts in one of the countries where this disease is common has experience with a particular combination of defects," argues Lederer. "The problem is, it is probably just written down in some notebook somewhere."

ITHANET sought to bring all that 'hidden' knowledge to light, to educate researchers about e-Infrastructures and encourage the development and deployment of appropriate tools and technology.

The potential for the internet and allied technologies to unlock undreamed-of knowledge and experience that already exists is

enormous, but the challenges are considerable, too.

"Initially, we wanted to use an excellent, open source platform for our primary network, and for videoconferencing, but it required some technical knowledge and setting up at each site [but without the right IT support] it was not practicable," recalls Lederer.

Better bandwidth

So they moved to a proprietary, more expensive, videoconferencing solution, which partially tackled the bandwidth issues. Bandwidth on the server side (at source) was fine, but bandwidth at the destination needed to be improved.

The team also set up courses and seminars using live webcasts and streaming video, where participants could pose questions in real time, during the live sessions, or via a blog after the streaming sessions. These were more successful.

The team also set up the ITHANET Portal for the central collection of data and easier communication of breaking news and events about the disease, and that remains live today. The forums, in particular, were very popular and led to many fruitful exchanges about particular, or very rare, cases of the disease.

Finally, in a continuation of the ITHANET project, a wiki and database have been set up which, over time, will integrate all the data, terminology, protocols and guidelines to identify and treat particular instances of thalassaemias.

Accelerated learning

"We really learned a lot during the project," Lederer relates. "[One time] we got all the experts together to discuss the way forward, and talk quickly went from e-Infrastructure to all sorts of different research projects they could set up."

That sort of face-to-face exchange and networking is important, suggests Lederer, but it would not have been be possible without the the virtual interaction made possible by ITHANET, stimulating the use of available and emerging e-Infrastructure technologies.

The enthusiasm of the participants demonstrated that there is a need and a real value in providing exactly the kinds of infrastructure that ITHANET developed. It underlined the value of a 'networked expertise' paradigm, where the most learned in a particular topic hold a global conversation from wherever they are located in the world.

Pioneering and ambitious

The ITHANET project was a pioneering and ambitious attempt to put that paradigm into practical use for a relatively obscure disease in very challenging circumstances, where often the fundamental infrastructure and familiarity with technology is missing.

But its success demonstrated that these types of networks have enormous potential. ITHANET's work could be applied not only to any haemoglobinopathy, but to any disease. It is even a potential early start towards cheaper, very large-scale epidemiological studies.

Epidemiological studies are invaluable, but they are enormously expensive to run and require huge cohorts to reveal real trends. Ultimately, projects like ITHANET could be the precursor to population-wide epidemiological studies using digital patient records, case notes and research.

ITHANET developed and executed a very ambitious programme and learned many of the fundamental lessons. In the process, it offered a tantalising glimpse of a very compelling future.

The ITHANET project received funding from the Sixth Framework Programme for electronic infrastructure development and is presently maintained with funding from the Research Promotion Foundation of Cyprus.

More information: www.ithanet.eu/

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