



DEVELOPING A PAN-AFRICAN RESOURCE NETWORK BY ADAPTING ICTS TO MEET SITE-SPECIFIC NEEDS

2005 COMPUTERWORLD HONORS CASE STUDY

SCIENCE

THE INTERNATIONAL AIDS VACCINE INITIATIVE (IAVI) IMPLEMENTS RELIABLE IT INFRASTRUCTURE TO TRANSMIT CLINICAL AND LABORATORY DATA FROM MULTIPLE REMOTE SITES, MAINLY IN AFRICA, TO DATABASES ABROAD. COST-EFFECTIVE, RELIABLE INTERNET TECHNOLOGIES ASSURE THAT INFORMATION IS READY AVAILABLE TO SCIENTISTS, FACILITATING CRITICAL AND TIMELY DECISION MAKING. [20055279]

A Search for New Horizons



SUMMARY

IAVI implements reliable IT infrastructure to transmit clinical and laboratory data from multiple remote sites, mainly in Africa, to centralized databases. Data is transferred through cost-effective Internet technologies to assure that valuable and accurate information is ready available to scientists, allowing them to make critical decisions in a timely fashion.

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APPLICATION

A vaccine is one of the best hopes to end the spread of the HIV/AIDS epidemic, now infecting 14,000 people—thousands in Africa—every day. A preventive vaccine would be given to people uninfected with HIV, to prevent them from becoming infected or developing AIDS.

Developing an AIDS vaccine is no easy task and requires global participation among researchers, community groups, political leaders and others to succeed. IAVI, a non-profit organization founded in 1996, operates as a hub for AIDS vaccine research and development in addition to facilitating and implementing vaccine clinical trials in developing countries across the globe.

In Sub-Saharan Africa, where nearly two-thirds of new infections occur, IAVI has been building continent-wide partnerships to link geographically dispersed health centers to core laboratories and data centers, thus creating a truly global collaboration in vaccine development. Historically vaccine development in developing countries, and particularly in Sub-Saharan Africa, has been subject to scrutiny by regulatory authorities for failing to meet timelines and abide by regulations. IAVI's challenge was to create a network that enables clinical and laboratory data of trial participants and respective Case Report Forms (CRFs) to be accessed on a daily and/or real-time basis to fulfill regulatory obligations and accelerate vaccine development.

IAVI's approach underscores the specific needs of each site and location, paying close attention to issues of sustainability, cost effectiveness, reliability and patient confidentiality. To this effect, IAVI conducted rigorous in-country site assessments to enhance the appropriateness of each implementation. In collaboration with our local partners, solutions to various problems ranging from poor communications infrastructure to user accessibility issues were addressed by leveraging technologies readily available in addition to introducing new technologies, where needed.

In clinical trial operations Information and Communication Technologies (ICTs) are used to speed up data acquisition, data transfer and data management. As IAVI implements clinical trials mostly in developing countries and in resource-constrained settings, several barriers and difficulties had to be overcome in order to implement a site-specific IT infrastructure, due to the lack of local resources and reliable telecommunication networks. For these reasons, IAVI has created a Pan-African Resource Network, which is comprised of over ten sites in Sub-Saharan Africa in five different countries (Kenya, Rwanda, South Africa, Uganda and Zambia).

IT infrastructure built at each site allows for swift data acquisition and reliable data transfer to the respective databases; it allows scientists to access clinical data faster; it prevents blood samples and CRFs from having to be physically transported from rural areas to the main cities for data entry; it allows the core laboratory to process lab exams quickly and confirm blood sample identities; it gives local professionals an opportunity to exchange information quickly and to be up-to-date on research studies and news related to the vaccine field; and it also increases the local capacity of the sites.

Pioneering the use of hybrid network systems in the search for an AIDS vaccine, has enabled IAVI to successfully bring a record number of sites online in Africa, in addition to setting an important precedent in vaccine development. Continued use of ICT and new innovations will help maintain our ambitious pace and help deliver a preventive AIDS vaccine to the world.

BENEFITS

This project has been designed to support the mission-critical search for an AIDS vaccine, particularly a preventive vaccine that would elicit immune responses to prevent people who are not infected with HIV from becoming infected or developing AIDS. Ultimately, the beneficiaries are the general population, and particularly people from developing countries, which comprise 95% of the total people living with HIV/AIDS in the world.

Past vaccine development efforts in Africa required shipping actual blood specimens to distant facilities to be analyzed, a long, costly, and ethically questionable process. The data from these specimens then had to be sent to a central database, which was predominately done via slow mail services or expensive facsimile transmissions. These former techniques resulted in vaccine development at a snail's pace—unsuitable for an epidemic that is newly infecting five million people each year.

By designing a specific and/or enhancing an existing ICT infrastructure at each site, blood specimens can now be analyzed within the communities from which they originated, while dramatically decreasing the time needed for data to be inputted into the central database. As a result, data is typically available on either a real-time or daily basis. This increase in data acquisition speed not only accelerates vaccine development, but is crucial in enabling doctors and scientists to possess the requisite data necessary to make critical decisions, especially those related to serious adverse events.

Staff at clinical sites also benefit from access to the latest research information on the Internet, email communication and real-time study data. This helps to reduce the isolation of researchers and professionals working in Africa by enabling them to be in constant contact with other professionals and exchange information and results faster, thereby making the search for an AIDS vaccine more efficient.

Finally, investing in Africa's ICT infrastructure has important externalities that benefit local communities and economies by increasing the demand for ICT-related services, facilitating the training of individuals in computers and networking, as well as increasing Africa's ICT capacity for use in other development initiatives.

IMPORTANCE

It usually takes around 20 years to research, test, approve, and make any vaccine available in the market. IAVI's mission is to accelerate this process and reduce the time needed to have an effective AIDS vaccine available for the world, and particularly for developing countries. Information Technology (IT) is a critical tool to accelerate the search of an AIDS vaccine by providing real-time mechanisms to transmit and process data.

Aside from enabling IAVI to conduct clinical trials at multiple locations from several parts of world, IT has done much to help mobilize people in different regions. For instance, Internet newsletters, websites and email help inform health professionals and donors of vaccine developments. Also, informative and user-friendly websites are increasingly aiding our initiatives in volunteer and trial participant recruitment.

ORIGINALITY

IAVI's Pan-African Resource Network has pioneered the use of hybrid network systems to increase the cost efficiency and reliability of long-distance data transmissions needed to conduct clinical trials in Africa. Data is transmitted in different ways, depending on the bandwidth and technology available in each country, as well as service reliability. For instance, trials in Rwanda utilize a Radio Link internet connection to connect to the central database whereas in Uganda a more robust and fast satellite connection is used. Bandwidth solutions are shared with partner organizations using radio link and/or fiber optic connections, whenever possible.

Online and offline solutions are used depending on the type of application and bandwidth needed, as well as cost and service reliability. Additionally, security mechanisms are used due to the sensitive nature of the data and to ensure confidentiality of trial participants.

SUCCESS

The judicious implementation of ICT across eleven disparate sites in Africa in five countries has surpassed our goals for reliable and efficient data communication.

While well-organized data management is a requisite for meeting stringent regulatory guidelines, the desire to accelerate the search for an AIDS vaccine comes from within IAVI and its partner organizations.

Furthermore, securing donor confidence and funding for larger efficacy trials, has been contingent on IAVI's ability to demonstrate that regulation-grade vaccine trials are possible in remote locations in Africa, and that reliable data can be produced. As a result of the success of early trials, IAVI is now provisioning for the first time ever, a multi-center, multi-country efficacy HIV vaccine trial, which will involve over 6,000 participants, will require over 400,000 Case Report Forms (CRFs) to be transmitted and 200,000 laboratory tests. A suitable and extended IT infrastructure is being designed to support this trial and provide real-time safety data.

DIFFICULTY

Many countries in Sub-Saharan Africa present a unique set of difficulties and barriers to effective ICT implementation. Perhaps the foremost obstacle is the lack of a sufficient and reliable telecommunication infrastructure. This often forces applications that require consistent connectivity to incur high fees to bypass in-country networks. IAVI has successfully implemented satellite and mid-range radio links to circumvent local telecom connections that fail frequently because of inadequate maintenance and mismanagement.

Other problems arise from government monopolies and excessive regulation, as in Kenya, where radio frequency and satellite licensing formalities can delay solution implementations by months or years. Kenya and other African countries currently route out-of-country Internet traffic through a central government monopoly, which slows down transmissions considerably. Government bureaucracy in general is often slow and new technologies are constantly prevented from adoption because local authorities fail to "approve" new technologies in a timely manner. Thanks to diligent work with the local communications commission, IAVI has finally gotten an uplink license in Kenya to by-pass the government Internet provider.

Vital to finding solutions for disparate sites are detailed assessments that take into account both the needs of the prospective site and the local and national climate for ICT. For instance, it would be ill-advised to install a system that could not be supported by local talent. This is often successfully countered by providing additional training and support to otherwise capable IT consultants and, if necessary, assistance may be provided from abroad. Additional difficulties often relate to unreliable electrical infrastructure that may render a site without electrical power five or more hours everyday. IAVI has implemented generators or power supplies at the sites to assure that power will be available for the IT equipment as well as for the freezers that store the blood samples.

Finally, conducting clinical trials in Sub-Saharan Africa and in resource-constrained settings almost always presents challenges of getting appropriate technology to remote sites quickly, accelerating slow medical panels in granting regulatory approval and assuring proper steps are taken to protect patient privacy and site security. These technologies, while sometimes challenging and difficult to implement, are central to IAVI's ability to co-ordinate its world-wide efforts to help accelerate the development of an AIDS vaccine.

IAVI believes that a world without AIDS is possible and that ICT will help to accomplish this mission more efficiently. We will continue to implement cost-effective technologies as they are an integral tool in the fight against AIDS.