

Proposal to
**Enhance Clinical Nursing Capacity to Diagnose and Treat HIV/AIDS through Increased
Access to Medical and Public Health Information Resources**
from
The AED-SATELLIFE Center for Health Information and Technology

Proposal Summary

The inability to access medical and health information hobbles healthcare providers in the world's poorest countries. Due to poor communications infrastructure and prohibitively high cost, doctors, nurses, and public health workers in Africa, Asia, and Latin America do not have recourse to the fundamental health information required for good practice and sound decision-making. Beyond the issue of financial exclusion, much medical information heretofore developed is irrelevant in the world's poorest regions, which lack facilities and funds for widespread laboratory testing and up-to-the-minute treatment.

The AED-SATELLIFE Center for Health Information and Technology proposes to build the capacity of clinical nurses in resource-poor urban healthcare settings to care for HIV-infected and AIDS patients by providing them with locally relevant, reliable, and accurate information at the point of care. A recently completed "AIDS PDA" pilot project funded by the John M. Lloyd Foundation field-tested a handheld computer pre-loaded with essential information for treating HIV-infected and AIDS patients in South Africa and demonstrated the efficacy of this approach.

The AED-SATELLIFE Center for Health Information and Technology is seeking support to fund the development of additional information resources, their conversion to electronic format, and the expansion of the use of the AIDS PDA to the Port Elizabeth Health Complex in the Eastern Cape province of South Africa. AED-SATELLIFE is seeking support to roll-out AIDS PDA distribution to all clinical nurses throughout the health complex.

Background and Problem Statement

The HIV/AIDS epidemic has had far reaching consequences for all social sectors and for development itself. In many regions, HIV/AIDS has decimated the workforce, created large numbers of orphans, intensified poverty and inequality, and put tremendous pressure on health and social services in countries already suffering from extreme privation. HIV/AIDS has caused a measurable fall in annual per capita growth in the hardest-hit countries of Sub-Saharan Africa and threatens to reverse the development achievements of the last 50 years in many others around the world.

The difficulties resource-poor countries have in providing adequate healthcare to populations living with HIV/AIDS and chronic diseases such as tuberculosis and malaria are exacerbated by the concomitant mass emigration of skilled health professionals in search of higher pay, career advancement, and better working conditions in Europe and North America. In addition to the loss of public educational investment and intellectual capital, the developing nations suffer from a reduced range of available services, chronic understaffing of health facilities, and ever diminishing healthcare services. Increasingly, the burden of providing care to the world's poorest populations

falls on nurses rather than doctors. Enhancing these nurses' access to HIV/AIDS information, and increasing the timeliness and accuracy of this information are elements vital to improving health service delivery.

The inability to access timely, accurate, reliable, and locally relevant information hobbles physicians, nurses, researchers, and policy makers in the world's poorest countries who are faced with some of humanity's greatest health crises, yet do not have recourse to the fundamental information and data required for good practice and sound decision-making. The communities they service, comprising millions of people around the world, suffer as a result. Access to lifesaving information is extremely limited due to poor telecommunications infrastructure and the high cost of Internet access, telephone lines, and medical journal subscriptions.

The use of small mobile computing devices and wireless communications tools is ubiquitous in the European and North American medical communities. Extensive resources, including HIV/AIDS specific content, are commercially available in PDA and Internet formats from medical information publishers. However, beyond the problem posed by the cost of this material, much of the HIV/AIDS information heretofore developed is irrelevant in low-resource environments which lack facilities and funding for widespread laboratory testing and up-to-the-minute treatment.

Project Goals

Our long-term goal is to contribute to the improvement of healthcare in resource-poor countries by introducing an effective system for the dissemination of current, relevant HIV/AIDS data and information. Having gained useful and actionable information through the pilot testing of the AIDS PDA as a tool for providing locally relevant HIV/AIDS data and information at the point of care, the next step in the evolution of this tool is to implement the changes indicated to increase the tool's effectiveness and to enhance its efficacy as an information resource for clinical nurses in urban healthcare settings.

The proposed project will investigate whether access to relevant HIV/AIDS information has an impact on nursing practice. The primary goal of the project is to gain greater understanding of how clinical nurses use information available on the AIDS PDA, and if and how access to HIV/AIDS information results in changes to their behavior in patient care. To achieve this goal, AED-SATELLIFE has set the following objectives:

1. to build the capacity of clinical nurses to use PDAs to access HIV/AIDS information;
2. to build the capacity of clinical nurses to use health information resources in caring for HIV/AIDS patients;
3. to determine if clinical care of patients changes as a result of nurses' access to HIV/AIDS information.
4. to build the capacity of local partners to incorporate information technology in their healthcare initiatives.

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Project Description

Supported by a generous grant from the John M. Lloyd Foundation, AED-SATELLIFE developed a prototype “AIDS PDA” to meet the urgent need for current, reliable, and locally relevant information and diagnostic tools at the point of care. This portable, relatively inexpensive device provides users with immediate access to medical references, national and international drug databases, treatment guidelines, diagnostic tools, and customized software to facilitate patient care and case management. Collaborating with South African medical practitioners, AED-SATELLIFE identified and adapted appropriate existing content and tools for the PDA.

The AIDS PDA was field tested in clinical and public health settings in KwaZulu Natal, South Africa in collaboration with The Valley Trust, McCord’s Hospital, and HealthNet South Africa. Analysis of data collected during and after the study period indicates that clinical nurses in urban settings found the tool to be extremely useful in performing their daily tasks and the information provided beneficial to the delivery of care and treatment to HIV-infected and AIDS patients. These participants exhibited high levels of appreciation and enthusiasm for the access to information and to technology which the program provided. The post-pilot data collected also highlighted areas for improvement to increase the efficiency of implementation and the effectiveness of the tool. The proposed project will incorporate the lessons learned during the pilot study.

The problem to be addressed by the proposed intervention is poor access among clinical nurses to up-to-date HIV/AIDS and related healthcare information and the inability to consult at the point of care the relevant medical texts, guidelines, and tools which can improve the quality of treatment. AED-SATELLIFE will apply the lessons learned in the AIDS PDA pilot study to improve project implementation and will enhance the tool to specifically address the needs of clinical nurses working in resource-constrained urban healthcare settings. Project activities will include:

Identifying and Engaging In-country Partners

Working with South Africa Partners and the Cambridge Health Alliance, we have identified the Port Elizabeth Health Complex (PEHC) as partner for the proposed AIDS PDA project expansion. PEHC encompasses three hospitals and five ARV clinics. It employs approximately 1,000 nurses serving a city of over 1.4 million people located in the Eastern Cape province of South Africa. The CEO of Port Elizabeth Health Complex, Dr. Lulamile JamJam, is the acting director of the district health service and contributed to the formulation of the South African National Antiretroviral Treatment Guidelines. He has named information technology as a top priority and has indicated his strong support for this project. We believe that PEHC has a vested interest in the outcome of the project and will provide support with all phases of the project, including on-site coordination, content selection, training, monitoring and evaluation, and recurrent feedback.

Identifying Local Needs

The proposed intervention will commence with a thorough needs assessment among clinical nurses at the health complex to ascertain existing and emerging medical information requirements. We will use this assessment data as our guide to identify additional HIV/AIDS information resources for dissemination to AIDS PDA users that will enable clinical nurses to improve standards of health care and acquire new skills.

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Providing Locally Relevant Healthcare Information

The project will provide a rich knowledge-base of healthcare information which can be readily updated and will facilitate the delivery of appropriate and timely continuing provider development (CPD) materials associated with the prevention, diagnosis, treatment, and care of HIV-infected and AIDS patients. While much HIV/AIDS content has already been developed during the AIDS PDA pilot study, for the proposed intervention AED-SATELLIFE will generate additional locally-relevant, PDA-formatted HIV/AIDS information to meet the needs of PEHC nurses including information on Extremely Drug Resistant Tuberculosis (XDR-TB) and other opportunistic diseases which effect HIV-infected and AIDS patients. These resources may include medical applications, algorithms, and calculators; drug databases; and textbooks. Collaborating with PEHC, the Eastern Cape Department of Health, and other stakeholders, we will identify appropriate medical content focusing on information generated in South Africa, in Africa, and in other developing countries for inclusion on the AIDS PDA. In addition, AED-SATELLIFE has long-standing relationships with major medical and public health journals around the world, which provide us access to excellent content related to health problems of low-resource countries at low or no cost. AED-SATELLIFE will leverage these relationships to ensure that a full and complete library of HIV/AIDS materials is available on the device.

Developing an Electronic Knowledge-base

To ensure that the AIDS PDA contains the maximum amount of useful information, adequate resources will be allocated for the conversion of selected HIV/AIDS print content into user-friendly PDA applications and of medical algorithms into sophisticated tools that match symptoms with diagnosis and identify appropriate course of treatment. For example, the South African medical formulary is currently only available in printed format. We believe this information asset would be extremely useful as a PDA-based reference accessible at the point of care. If funded, the project partners will pursue obtaining the necessary legal permissions, convert the formulary to electronic format, and make this tool widely available both to project participants and to other South African healthcare providers.

Deploying Information-loaded AIDS PDAs

We will deploy new handheld computers featuring extended battery life and non-volatile memory to each clinical nurse at PEHC participating in the proposed project. Past experience has indicated that while it is possible for health workers to share devices, participants become more comfortable with the PDA and incorporate its use into daily work more quickly when they have the device at hand 24-hours-a-day. Individual PDAs also offer equipment maintenance and security advantages.

Training Healthcare Providers to Use Technology

The pilot study indicated that extensive training in the use of the resources available on the AIDS PDA is required to ensure users fully understand the tools and how to apply them. Our approach for the proposed intervention will stress initial and ongoing in-service training on both the functionality of the PDA and the application of the information it holds to everyday healthcare delivery tasks at PEHC. Each of the three PEHC hospitals will have a fully trained project staff member on site to provide user training and support for both equipment and the medical tools provided. Throughout the project, PEHC will identify nurses from the cohort of those trained to

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receive additional instruction which will prepare them to lead future nurse training sessions and to provide peer-support and guidance. These nurses will be rewarded for their additional efforts through a stipend, an increase in grade, and/or certification for the training they have received.

Keeping Participants Engaged

To ensure that the AIDS PDA is meeting the needs of the intended users and to encourage users' long-term engagement with the information tool, on-site staff will play a proactive role through outreach to clinical nurses and by scheduling periodic training sessions to refresh users' understanding of the breadth of PDA functionality and to introduce new or updated information. The on-site technical support leader will supervise and mentor the nurses chosen to be trainers and peer-support providers. They will play a key role in monitoring and evaluation of the project, conducting both formal and informal surveys of user perceptions and satisfaction. The in-country Project Manager will also visit participants at the study sites at regularly scheduled intervals to solve content and technology problems, to supervise training and support activities, and to analyze monitoring and evaluation data.

Keeping Participants Up-to-Date

The information on the AIDS PDAs will be updatable using the "hot synch" functionality which allows for wireless data transfer between the PDA and other infrared equipped computing devices. Each of the three on-site project staff members will be provided with a laptop computer and Internet connectivity. They will download updated content as it becomes available and will have access to AED-SATELLIFE's HealthNet News suite of health information newsletters. Through their outreach efforts to nurses, the on-site project staff will ensure that updated information is regularly transferred to the AIDS PDAs from the project laptop.

Building Local Capacity

The proposed intervention will provide the AIDS PDA to all clinical nurses working within PEHC facilities. To accomplish this we plan to build the capacity of health complex-affiliated nurses, administrators, and information technology staff to provide training, administrative support, and technical support for the planned future expansion of the AIDS PDA project at PEHC. By the end of the first year, all training sessions will be led by trained PEHC nurses in conjunction with the on-site technical support staff member. Trained nurses will also provide peer-support for end-users with content and/or technical issues. By the end of the three-year project, PEHC information technology staff will be able to maintain and upgrade equipment and manage AIDS PDA program operations.

Monitoring and Evaluation

The pilot study yielded extremely useful information on how the AIDS PDA was used and how to improve it. We will conduct ongoing monitoring and periodic evaluations of the intervention to ensure that the information provided best meets the users' needs. The on-site technical support leader will play a key role in monitoring and evaluation of the project, conducting both formal and informal surveys of user perceptions and satisfaction. The in-country Project Manager will be responsible for gathering, compiling, and analyzing data and will report quarterly to the Project Director.

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An independent local consultant will administer a survey designed to ascertain the impact of the AIDS PDA on nurses' clinical decision making including whether the information provided changed some aspect of HIV/AIDS patient care such as diagnosis, choice of drugs or other treatment, or the advice given to the patient. The survey will also track nurses' perceptions of changes in behaviours and their satisfaction with the tool. The local consultant will compile the results and submit her findings to the Project Director. The Project Director will write a review of activities, including an analysis of the user survey, and will highlight successes, lessons learned, and indicated program adjustments.

Key questions to be examined over the course of the intervention and in the final evaluation will be:

- Are clinical nurses at PEHC successfully integrating the AIDS PDA into their work processes?
- Are clinical nurses at PEHC accessing HIV/AIDS information at the point of care?
- Are clinical nurses at PEHC utilizing the provided diagnostic tools, medical algorithms, and medical calculators in their care and treatment of HIV/AIDS patients?
- Has the ability to access HIV/AIDS information at the point of care effected self-perceived patient treatment?
- Have the AIDS PDA and the availability of medical information at the point of care effected self-perceived confidence to provide high quality medical care?
- What common problems are surfacing and how can they be addressed?
- What issues must be considered in planning for more widespread use of this technology among clinical nurses in urban healthcare settings?

Technology, Training, and Support

Handheld Computers

Handheld computers are small, lightweight computers designed to fit in a person's hand. They are powerful devices that make it possible to store, access, and organize large volumes of information quickly and easily. They can function as a date book, calculator, or address book; some versions also work as alarm clocks, telephone, or camera. PDAs can be used to send and receive email or to exchange information electronically with other digital devices.

Portable, durable even in harsh conditions, and very powerful for their size, PDAs can perform many of the same tasks as a desktop or laptop computer at a fraction of the cost. While not a substitute for a conventional computer, a PDA costing less than \$200 is a workable and cost-effective alternative, especially in under resourced environments.

Project partners will procure and distribute handheld computing devices to clinical nurses working with HIV/AIDS patients at PEHC, each of whom will be trained to use it for work related purposes. Each user will be responsible for the upkeep and security of the unit and will be

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encouraged to customize her/his unit to meet individual needs and tastes. However, when the person leaves the health center s/he will turn in the handheld computer for use by another health worker at that site.

AED-SATELLIFE will leverage its worldwide technology partnerships to obtain handheld computers at significantly reduced prices for use in the project and will be responsible for developing the specifications, procuring the units, and shipping the equipment and accessories to PEHC.

Training

Past experience indicates that high quality end-user training is critical for the effective utilization of technology. AED-SATELLIFE, PEHC, and the Eastern Cape health authorities will collaborate to develop appropriate training materials. Training sessions are expected to last approximately 2 days and will be scheduled at the convenience of PEHC.

Technical Support

AED-SATELLIFE and the in-country Project Manager will initially be responsible for supporting end-users on technical and content use issues. As the number of nurses participating in the project increases, one on-site technical support staff member will be placed at each of the three PEHC hospitals to provide training, troubleshoot technical problems, and provide ongoing technical and content support to end-users. This staff member will also supervise and mentor the nurse/trainers and peer-support providers, and will play a key role in project monitoring and evaluation.

Project Management

The AED-SATELLIFE Center for Health and Information Technology will be the lead implementer for the proposed AIDS PDA intervention.

The AED-SATELLIFE Center for Health and Information Technology was born from two organizations dedicated to connecting people and creating change. Founded in 1961, the Academy for Educational Development (www.aed.org) is an independent, nonprofit organization committed to solving critical social problems and building the capacity of individuals, communities, and institutions to become more self-sufficient. AED works in all the major areas of development with a focus on improving health, education and economic opportunities for the least advantaged in the United States and throughout the world. AED-SATELLIFE has a seventeen-year history of facilitating knowledge building and knowledge sharing throughout the developing world. AED-SATELLIFE has created a global information and communication network called HealthNet that serves an estimated 130,000 health professionals around the globe by providing access to current, reliable, and relevant sources of information on strategic health issues using affordable and appropriate technologies. HealthNet can be accessed online at <http://www.healthnet.org>.

Current Programs

To address the linked challenges of information poverty and the digital divide and to achieve its mission to lead a global partnership of healthcare institutions and practitioners fostering communication and information sharing, AED-SATELLIFE pursues three streams of activities:

Health Publications: AED-SATELLIFE produces four electronic publications: *HealthNet News*, *HealthNet News-AIDS*, *HealthNet News-Community Health*, and *HealthNet News-Nursing*, with content culled from 60 of the world's leading medical journals and available ***free of charge to residents of developing nations***.

Global Forums: AED-SATELLIFE's expertly moderated discussion groups cover topics such as HIV/AIDS, essential drugs, African health research and development, and cardiovascular health. Participation in these forums is available to ***all free of charge***.

Special Technology-based Projects: AED-SATELLIFE works with in-country local partners to build their capacity to use cost-effective technology to meet their urgent information and communication needs and to expand this capacity throughout the local health community. We have implemented technology projects in Ghana, Tanzania, Uganda, Nepal, Bangladesh, Kenya, and Ethiopia for organizations including the American Red Cross, the International Development Research Centre, and the World Health Organization. AED-SATELLIFE's technology projects improve the capacity of healthcare systems to collect and analyze vital data, to disseminate urgent, lifesaving medical information, to educate and inform healthcare workers in remote rural areas, and to participate in the global exchange of knowledge.

Constituency

AED-SATELLIFE provides its information services to an estimated 130,000 healthcare workers in 159 countries. Through their hands millions of people worldwide receive better quality, more informed care. The *HealthNet News* audience is comprised of physicians (clinical and public health), nurses, medical students, program managers, policy makers, researchers, pharmacists, and other allied health professionals. Readers use the material contained in *HealthNet News* in a variety of ways: for clinical treatment, management and care of patients, medical academic teaching, research, continuing medical education, health care delivery program design, planning and implementation, current awareness, writing proposals, and staff training. *HealthNet News* subscribers report that they constantly share the information contained in the *HealthNet News* publications with their colleagues, thereby expanding the reach of this information to a much larger audience. For some *HealthNet News* readers, especially those in isolated rural areas, *HealthNet News* is the ONLY source of current health information.

Institutional Capabilities

AED-SATELLIFE has a long history of providing medical and health information to the developing world with extensive experience working on three continents, including the establishment of locally owned and managed affiliated HealthNets in Uganda, Eritrea, Ethiopia,

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Zimbabwe, Kenya, Nepal, and South Africa, and successful technical projects in Bolivia, Uganda, Ghana, Kenya, Rwanda, and Ethiopia. AED-SATELLIFE has unique expertise as an information aggregator and is able to identify, acquire, edit, and compile the intellectual property which healthcare workers in the developing world need. AED-SATELLIFE staff has long-term, deep experience in disseminating health and medical information and in implementing ICT projects in the developing world.

- AED-SATELLIFE's information services are managed by Dr. Leela McCullough, Director of Information Services, who has for more than a decade formulated AED-SATELLIFE's global information strategy. Ongoing coordination is performed by an Information Officer supervised by Dr. McCullough.
- Mr. Berhane Gebru has eighteen years of experience developing, managing and implementing projects in the fields of health information systems, rural development, and water supply and sanitation for low-income countries. As Director of Programs, Mr. Gebru is engaged in all aspects of project design, budget development and monitoring, program and financial reporting, compliance with donor regulations, coordination and supervision of in-country project teams, strategic planning, work plan development, and project evaluation.
- Technical aspects of project implementation and ongoing support are supervised by Mr. Balazs Kosaras, AED-SATELLIFE's Technical Director. Mr. Kosaras has over six years' experience developing software applications in support of health data collection and communications systems for the exchange of public health and medical content.
- Ms. Holly Ladd, Center Director, has extensive experience in non-profit management and the law. Ms. Ladd directed the Boston AIDS Consortium, served on the planning committee for the International AIDS conference in Amsterdam, and assisted in the start-up of the FXB Center for Health and Human Rights at the Harvard School of Public Health.
- In addition to these dedicated staff, AED-SATELLIFE is able to draw upon the extensive knowledge and broad experience of resources throughout AED. Their backgrounds in global health, population, nutrition, and education is bolstered by field staff in more than 30 countries

Project Partners

South Africa Partners (SA Partners) is a non-profit organization that connects people in the United States with their counterparts in South Africa to share the skills, talent, and resources required to build the New South Africa. Focusing on health, education, and economic development, SA Partners works with community organizations, government departments, and academic institutions in each country to develop mutually beneficial partnerships that address social, political, and economic needs in a manner that strengthens communities, builds institutional capacity, and fosters local leadership.

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Improving the health and well being of South Africa's most disadvantaged communities is essential if South Africa is to meet its goal of equitable and sustainable development. To support this work, SA Partners has established its Partnerships for Healthy Communities Program to focus efforts on strengthening health care infrastructure in the Province of the Eastern Cape, the most disadvantaged of South Africa's nine provinces. Specific areas of work thus far have focused on public health sector concerns as diverse as hospital management; pharmacy system development; women's health, including domestic violence; HIV/AIDS and STD control; clinical and epidemiologic research capacity development; and NGO capacity development.

Collaborating since February 2003, the **Cambridge Health Alliance** and the **Port Elizabeth Health Complex** have signed a Memorandum of Understanding to serve as the basis for partnership activities addressing key areas of need including hospital management; clinical training; human resource development; and information technology. Cambridge Health Alliance is a nationally recognized, award winning academic public healthcare system that includes three hospitals, over 20 primary care sites, a Public Health Department, a managed Medicaid health plan, and is also a teaching affiliate of Harvard Medical School. The Port Elizabeth Health Complex was established in 2001 through the merger of three former racially segregated hospitals that together serve a population of 1.4 million people in the Port Elizabeth metropolitan area. The CEO of the Port Elizabeth Health Complex, Dr. Lulamile JamJam, is the acting director of the district health service and contributed to the formulation of the South African National Antiretroviral Treatment Guidelines. He has named IT as a top priority and has indicated his strong support for this project.

Conclusion

AED-SATELLIFE is uniquely qualified to perform the work described in this proposal. AED-SATELLIFE (and the *HealthNet* "brand") is recognized and respected around the world because of its accomplishments over the past seventeen years providing healthcare information to doctors, nurses, community health workers, and public health administrators in the developing world; its achievements in implementing ICT projects in multiple countries using multiple technologies; its long-term relationships with medical publishers, technology developers, and the international development and global health communities; and its commitment to quality healthcare as a fundamental human right.

Among the most important resources in the world today are information and knowledge. Unfortunately, even with the advent of technologies which have brought this wealth to many, vital medical and health information is not allocated equitably. Solutions such as the project highlighted in this proposal can only become reality through the generous support of individuals, corporations, and foundations. The AED-SATELLIFE Center for Health Information and Technology is seeking assistance in addressing this challenge in the developing world. We ask for your support in bringing vital medical and healthcare information to the frontline healthcare workers who daily confront the HIV/AIDS pandemic in South Africa.

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