Information and Communication Technologies for Disease Prevention and Management: Beyond National Boundaries

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Introduction

The study of Information and Communication Technologies (ICTs) in healthcare (Medical Informatics) has had a slow start, but recently has been gathering speed. This is due in part to wider availability of effective technology and better computer literacy but perhaps the most important change is evidence of beneficial effects of medical informatics on the quality of patient care. Notable examples are the prevention of drug errors, reminders to ensure uniform prescribing and alerts of abnormal laboratory test results[1].

While major hospitals in the developed world can invest tens of millions of dollars on ICT in a fairly speculative manner, developing countries must be much more careful and focused. With little resources even for essential treatments, technology purchases must be clearly based on evidence of need and effectiveness[2]. Added to the many challenges of ICT implementation in the developed world (detailed below) are the problems of poor infrastructure, lack of reliable electricity, shortage of technical skills, poor network access and lack of physical security.

In implementing ICTs there are three fundamental questions to be answered:

1. What is the medical problem to be addressed?
2. Do we need an ICT approach to solve it?
3. Can we provide an effective ICT solution in the developing world and if so how?

Recent experience by our group and many others suggests that there are a number of areas where ICTs may be useful in the developing world, though each situation needs to be carefully assessed.

Potential uses of ICTs in developing countries

- Getting new medical knowledge to the point of care
- Understanding risk factors and monitoring their presence
- Monitoring the spread and prevalence of infectious diseases
- Improving diagnosis (including telemedicine)
- Creating archives of images and teaching material
- Reducing medical errors
- Improving management plans for individual patients
- Recognizing failing patients who need changes in management
- Communicating and analyzing laboratory results, including use of remote international reference laboratories.
- Supporting clinical trials

- Ensuring that critical medical supplies particularly drugs are ordered appropriately for treatment sites
- Monitoring resources to ensure that they get to the right sites and people, and avoiding theft and other losses.

There are alternative ways to manage clinical information using paper cards and charts, but for clinical trials, monitoring and analysis of population data and telemedicine, computerization of some sort is generally required. A key challenge is to create sustainable systems that are able to be used widely and can support several of the above tasks, rather than using multiple "stove pipe" applications.

Problem issues with ICTs and Electronic Medical Records

- Data collection and entry (including data completeness and quality)
- Data standards (common data models and open standards)
- Difficulties in reuse of technology and avoiding re-invention of systems
- Tensions between standard approaches and local requirements
- Safety, security and confidentiality of medical data
- Language and cultural differences
- Short term quick solutions that do not scale up, especially spreadsheets!

Since many of the problems have not been solved in the developed world we need to be cautious in advocating widespread adoption in resource-poor areas. Our group, Partners In Health in Boston, has recently confronted many of these problems in setting up a program to manage drug resistant TB in Lima, Peru, run by a sister organization Socios En Salud[3]. It was decided that an electronic medical record would be required to assist with the complex patient management and allow monitoring and analysis of patient data. In addition there was a requirement for telemedicine capabilities and a system to track drug supplies. Many of the problems discussed above were present, including limited dialup network access, poor physical security and use of many small spreadsheet and Access programs.

The PIH-EMR

The approach taken in this project was to build a web based electronic medical record (PIH-EMR) which included the facility to store digital images for telemedicine[4]. The web pages are available in English and Spanish. Implementation started in the fall of 2000, and the system now has data on over 1100 patients including 650 in active treatment. Physicians can get clinical summaries from the system as well as search for patients with a variety of characteristics. A key issue with a system such as this is how to get the clinical data to the physicians when they need it for patient care. Although Socios En Salud has 2 offices in Lima with some Internet connectivity, most clinical sites in the developing world will, at best, have intermittent connectivity to one or two machines. We have developed 3 methods to propagate information to the clinicians: paper summaries, an indexed archive of HTML summaries to use on a laptop, and the use of the Avantgo[5] browser to store HTML summaries on Personal Digital Assistants. Each approach has its benefits and problems (especially security and confidentiality). The ideal solution is probably a combination of the above, plus targeted clinical email alerts.

The PIH-EMR contains detailed and up-to-date data on all drug regimens and sputum bacteriology results (including drug sensitivity test results), allowing a variety of important analyses to be carried out in real time. Patient outcomes are monitored monthly from smear and culture results, and patterns of resistance to different anti-tuberculous drugs are tracked. Drug supply management is probably the most important application at present.

Data on individual drug regimens can be aggregated to produce accurate projections of future drug requirements for groups of patients at each treatment site (called a morbidity analysis[6]). This information is of critical importance in ensuring that supplies are available to treat patients at all times. In addition, by allowing the accurate ordering of drugs well in advance, much better prices can be obtained especially through agencies such as the International Dispensary Association. We have recently added facilities to enter drug prices and calculate costs per patient treated. These projections highlight which drugs dominate the budget and help to ensure optimum use of scarce resources.

Conclusions

The true test of success for a system such as PIH-EMR is daily use over an extended period of time once the initial enthusiasm has worn off. Better still, the system should be used by other programs treating MDR-TB. Such transfers of systems beyond the original project site are unusual in medical informatics. One example is the District-Based Health Information system in South Africa, which started in one province but has now been adopted as a national standard[7]. The leaders of that project were able to manage the delicate balance between standardization and local flexibility. We plan to apply a similar approach to developing information systems to support HIV management in the developing world in collaboration with other interested groups.

Some of the key objectives to be met in successful ICT projects include:

- a generally accepted core dataset which can be extended by individual sites
- well designed, easy to use software that has been properly evaluated
- practical systems to collect and enter accurate data (rarely done by doctors)
- sufficient local technical skills to maintain and perhaps extend the system
- a supportive managerial and legal environment
- ability to run the system in the local language (or be able to convert it)
- buy-in from healthcare workers who can see benefits from the system in their practice
- Systems that combine functions such as clinical care, research and logistics to obtain maximum benefit from the data

If we are to find an effective role for healthcare ICTs in developing countries we need to develop strategies to ensure that these systems are promoted for roles that have been shown to be effective in evaluation studies[8]. Systems should be developed with a view not only to solving local problems but also with a clear vision for how they can be expanded and re-used by other sites. Systems based on open standards and open source can usually be extended, modified and integrated with other applications[9]. Changing

language becomes a chore not an impossibility, and preferred local analysis tools can be supported be they Access, Epi Info, SAS or others. However there is a serious tension between the need for good design and implementation of ICTs, and the often urgent need to support a particular research or healthcare project. This may manifest itself in the need to wean people off large numbers of incompatible spreadsheets by providing them with a web-based database with a single shared dataset. The best results are likely to come from cooperation between institutions and countries to adopt common protocols and core datasets for monitoring and analyzing medical data, as has happened with MDR-TB and the South African project described above. Finally it is essential to build on local problem solving approaches where possible to ensure that the system solves the "real" problems[10].

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