WHO guidance on electronic systems to manage data for tuberculosis care and control

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ABSTRACT

The World Health Organization (WHO) actively promotes eHealth, which includes electronic health information systems, as means to generate better data on tuberculosis and on interventions to control tuberculosis. However, introducing electronic data management needs long-term investment in both staff and infrastructure and has profound social and organizational impacts. It is easy to make costly mistakes and to lose potential benefit due to poor organizational, technical, or financial planning and unrealistic expectations. The Stop TB Department of WHO in collaboration with technical partners have just released guidance on planning, developing, and managing such systems. The document provides practical advice to decision makers and others involved in tuberculosis control on planning revisions to information systems, whether they are creating new systems or enhancing existing ones. The guide uses examples from eHealth projects recently implemented in Brazil, China, Pakistan and other settings to illustrate how projects in diverse settings have overcome different challenges.

In recent years, the World Health Assembly has urged Member States to promote eHealth[i] services and requested the World Health Organization (WHO) to support Member States by disseminating best practices and guidelines.[1 2] In 2007 and 2009, other World Health Assembly resolutions promoted the strengthening of health information systems through both country and WHO action as a means to gather evidence about the global response to tuberculosis (TB) and drug-resistant TB.[3 4]

In 2011, the Stop TB Department of WHO, in cooperation with international experts and end-users at country level, developed new and important guidance on electronic recording and reporting for TB care and control. The aim of the guide, published in early 2012 (http://www.who.int/tb/publications/electronic_recording_reporting/), is to assist countries in the design and implementation of electronic systems to handle TB data according to best practice standards.

In this paper we describe the background to the development of the guide and highlight the main topics on which guidance is provided. While the guidance document focuses on TB, much of its content is also applicable to the development of information systems for other infectious diseases and health problems.

[i]eHealth is defined by WHO as 'the use of information and communication technologies (ICT) for health.' Examples include treating patients, conducting research, educating the health workforce, tracking diseases, and monitoring public health. (Source: http://www.who.int/topics/ehealth/en/; January 30, 2012).

A STRONG TRADITION IN RECORDING AND REPORTING FOR TB CARE AND CONTROL

TB is an important public health concern and the proper notification of cases to public health authorities and the careful monitoring of patients while on treatment are crucial. Recording and reporting have therefore been central cornerstones of WHO's framework for effective TB control for many years. The Stop TB Strategy, which WHO adopted in 2006, reiterated this emphasis on monitoring, evaluation, and impact measurement.[5] As a result, there is a fairly consistent understanding among staff in national TB programmes and other experts about case definitions and key indicators for TB surveillance. By 2008, >99% of TB cases were reported by countries that had adopted WHO-recommended recording and reporting standards.[6] This wide implementation has made TB data comparable across many thousands of treatment facilities worldwide and over several years. The Stop TB Department reports on the global status of TB control every year by using information from countries that provide WHO with standard datasets via a web-based tool.[7]

WHY ELECTRONIC SYSTEMS?

These achievements notwithstanding, many TB programme managers and others dealing with TB data still face formidable challenges. Much of the recording and reporting of TB information is still done on paper, which means that checking the quality of data, aggregating reports, updating missing information, assigning outcomes of treatment correctly, and analyzing and disseminating information are inefficient, labor-intensive, and time consuming. Opportunities for timely action when stock-outs of anti-TB drugs or laboratory consumables are imminent or in the early stages of an outbreak may be missed because the system is not reactive enough. Another major challenge is the diversity and geographical spread of public and private units which deal with TB patient data, including treatment facilities in the public and private sector, be it hospitals or ambulatory centers, laboratories, and pharmacies. This heterogeneity may also be reflected in the way reporting systems are employed, as well as in the quality and comparability of the data. The recent drive to scale up the care of patients with drug-resistant TB is expected to exacerbate these challenges, since the

data requirements for these patients are far heavier than for patients with drug-susceptible TB.

Electronic systems can help to address these challenges. Potential benefits include improvements to data quality (eg, via in-built checks for implausible or inconsistent values), reduced workload (as some tasks can be automated), wider and quicker access to data (especially in web-based systems in which data can become available at all levels in real-time), and enhanced flexibility (eg, modifying digital forms and reports compared to printing and distributing new paper forms and taking older versions out of circulation). It also becomes easier to analyze data because datasets can be directly imported into statistical packages, and analyses become much more powerful if electronic datasets with records for individual cases or patients are available. Reporting of results can also be improved via the generation of automated reports. In turn, these benefits can considerably enhance the three broad functions of recording and reporting: clinical care of individual patients, management of programme resources, and public health surveillance.

Realizing the potential of electronic systems has become much more viable in many parts of the world with the rapid development in information technologies and electronic communication networks that has occurred in recent years. For instance, the ubiquity of cellular phones presents an important opportunity to expand electronic data management. It is estimated that there were 5.3 billion mobile phone subscriptions by the end of 2010 and this figure is expected to exceed 6 billion in 2012, reaching even the remotest corners of low-income countries[8] (G Presland, GSM Association personal communication, 2011). In many low-resource countries mobile phones have been used for secure banking transactions for several years. Riding the wave of this revolution, one group running a private health facility in an urban setting in Pakistan reported a doubling of TB case notifications in a short space of time following provision of financial incentives to family doctors and community health workers for screening patients and referring suspected cases to TB centres.[9] This group has also developed innovative methods to capture data on doses of drugs administered under observation to TB patients by community health workers using low-cost mobile phones and pioneered open source software. The evidence base for the effectiveness of these interventions is steadily increasing.

MAKING THE RIGHT CHOICES

The implementation of electronic health records is difficult and failures are common even in well-resourced environments.[10] It is not simply about adopting existing software or developing new computer programs, it is also about changing how people and organizations work. Established workflows and methods of task performance are often affected. This needs careful consideration, planning, and consultation.

Computerization is not an antidote to bad record keeping and must be preceded by groundwork to bring TB recording and reporting up to WHO-recommended standards. This ensures that the primary objectives of a new electronic system are clearly defined and agreed in consultation with the future users and beneficiaries of the system. Experience from Brazil and China, where national databases have been implemented for TB surveillance and care in recent years with important gains in completeness of information, demonstrates the feasibility of such endeavors even in very large countries.

The guide developed by WHO is designed to meet the growing demand from countries for advice on electronic recording and reporting in the context of TB control, drawing, wherever possible, on lessons learned in countries that have implemented such systems. It was developed by an expert group that first met at WHO headquarters in April 2011 and subsequently drafted, reviewed, and finalized the material between May and December of the same year. The release of the guidance document is being widely publicized among national TB programmes and the experts who are expected to make use of it.

Box 1 Key questions when considering electronic solutions for tuberculosis (TB) data management (reproduced from the original document)

Organization

1. Is there a functioning TB recording and reporting system in place?
2. Who needs to provide overall oversight and participate in decision-making related to the adoption, design and implementation of an electronic recording and reporting system for TB?

Scope

3. What are the primary objectives of building an electronic recording and reporting system for TB care and control?
4. Who are the users and beneficiaries of the system?
5. Which patients will the system cover?
6. Which locations will the system cover?
7. Will the system be a stand-alone system or will it be integrated with other electronic systems?
8. What elements of paper-based recording and reporting should be maintained?
9. Is the basic unit of recording clinical data a patient, a case or a group of cases?
10. What data items need to be captured?

Capabilities

11. Who enters data, where and when will data be entered, and how do data flow within the system?
12. What data quality assurance processes are required?
13. How is feedback provided to system users?
14. What standard outputs, reports and other analyses are required?
15. What are the data entry screen or interface requirements?
16. How will data confidentiality and security be ensured?

Resources

17. What staffing is required?
18. What user support is needed?
19. What technical support is needed?
20. What level of service availability, response times and contingency planning is required?
21. What funding is required for both start-up and routine operations?
22. How long will electronic data be retained and will they be archived?

Infrastructure

23. How is the electronic recording and reporting software made available to users?
24. What devices will users need to use the system?
25. What database software is required?
26. Where will the servers be located?
27. What communications networks are needed?
28. What are the electrical power needs?

Evaluation of the uptake of recommendations by Member States will be built into the routine data on TB collected by WHO each year.

The guide introduces national TB control managers to key concepts and processes using plain language so that they can work with system designers and procurement specialists. While the guide does not provide detailed specifications of data items, data models, or workflows, it does present policy-makers with a framework for thinking logically about the options that they have before them and about the main considerations which should inform their decisions. In addition to introducing TB managers to the general concepts involved in designing, rolling out, and maintaining digital information systems, the guide also informs systems analysts about the recording and reporting activities that are specific to TB care and control. Thus the guide will bridge the communication gap between TB managers and informatics experts so that they can work together to develop the solution best suited to a particular country's needs.

The first two chapters of the guide put forward 28 fundamental questions that need to be considered in the adoption, design, and implementation of electronic recording and reporting systems (box 1). These prompt decision-makers to work with system designers to define the scope of a system and then identify functional and non-functional system requirements. In each case, the reason why the question is important is explained, the options available are described, and recommendations based on best practice are provided.

The third chapter covers the practical aspects of how to commission an electronic system, including developing requests for proposals, drawing up agreements, and finalizing contracts. This will be useful when acquiring, developing, or customizing electronic systems.

The fourth and final chapter of the guide discusses the practical aspects of implementing the commissioned system, based on recent country experience. It highlights the cyclical and iterative nature of information systems development and addresses practical organizational lessons learned, such as considering how the implementation of electronic recording and reporting systems affects staff.

SUSTAINABILITY

Building information systems is a long-term endeavor with regular cycles of planning, development, roll-out, and maintenance. Planning for the long term rather than for a one-off project is important to avoid ending up with a 'perpetual pilot' that cannot be maintained or adapted to cope with changing circumstances and needs. The use of open source solutions, which draw upon the contributions of worldwide communities of software developers, can help by overcoming licensing and financial restrictions normally associated with commercially produced software and can help to nurture programming expertise within countries.

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