Development of a unified web-based national HIV/AIDS information system in China

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Background In the past, many data collection systems were in operation for different HIV/AIDS projects in China. We describe the creation of a unified, web-based national HIV/AIDS information system designed to streamline data collection and facilitate data use.

Methods Integration of separate HIV/AIDS data systems was carried out in three phases. Phase 1, from January 2006 to December 2007, involved creating a set of unified data collection forms that took into account existing program needs and the reporting requirements of various international organizations. Phase 2, from January to October 2007, involved creating a web-based platform to host the integrated HIV/AIDS data collection system. Phase 3, from November to December 2007, involved pilot testing the new, integrated system prior to nationwide application.

Results Eight web-based data collection subsystems based on one platform began operation on 1 January 2008. These eight subsystems cover: (i) HIV/AIDS case reporting; (ii) HIV testing and counselling; (iii) antiretroviral treatment (ART) for adults; (iv) ART for children; (v) behavioural interventions for high-risk groups; (vi) methadone maintenance treatment; (vii) sentinel and behavioural surveillance; and (viii) local county background information. The system provides real-time data to monitor HIV testing, prevention and treatment programs across the country.

Conclusion China’s new unified, web-based HIV/AIDS information system has improved the efficiency of data collection, reporting, analysis and use, as well as data quality and security. It is a powerful tool to support policy making, program evaluation and implementation of the national HIV/AIDS program and, thus, may serve a model for other countries.

Keywords HIV/AIDS, information system, web-based, surveillance, monitoring and evaluation, unified, China
Introduction

Effective responses to infectious disease epidemics depend on timely information. Data collection, data management, data analysis and data use all play crucial roles in public health responses to infectious diseases. Information systems configured to provide timely data can provide essential support for disease detection, management and control efforts.1

One major challenge facing national HIV programs is the need to coordinate and harmonize data collection efforts. In the case of complex conditions, such as HIV/AIDS, the demand for data is enormous. Government agencies need data to assess the magnitude of disease, to guide policy decisions, and to shape disease prevention, treatment and control efforts. External donors need data specific to the programs that they support. Numerous other stakeholders also need data, including non-governmental organizations (NGOs) and academic researchers. In many countries, this plurality of data needs has given rise to multiple data collection systems for disease surveillance and program monitoring and evaluation (M&E). These multiple systems most often generate data that are not standardized, making comparisons over time, across geographic areas or between programmatic areas difficult or impossible.

In China, numerous HIV/AIDS data collection systems arose to meet different data collection needs, including those of Chinese government programs and donor-funded AIDS programs and research projects. Eight national routine reporting subsystems emerged, covering:

(i) HIV/AIDS case reporting;
(ii) HIV testing and counselling;
(iii) HIV sentinel surveillance;
(iv) HIV behavioural surveillance surveys (BSSs);
(v) antiretroviral treatment (ART) for adults;
(vi) ART for children;
(vii) behavioural interventions for high-risk groups; and
(viii) methadone maintenance treatment (MMT).

These subsystems were managed by different technical divisions within the National Centre for AIDS/STD Control and Prevention (NCAIDS) at Chinese Centers for Disease Control and Prevention (China CDC).

Besides these national subsystems with coverage cross the country, other major AIDS projects, such as China CARES, the Global Fund China AIDS Project, China–UK AIDS Project and the World Bank 9th Health Loan Project, also collect and manage their projects’ information, which created project-based AIDS information subsystems that also overlapped with the above eight subsystems.

While these subsystems provided a wealth of data across the spectrum of HIV/AIDS programs and focus areas, the diversity of data collection sources and methodologies created many problems. With regard to data collection, duplicative requests from different subsystems generated a heavy workload for public health field staff. Inconsistent data collection methods within and across subsystems led to problems in comparing data.2 In addition, substantial amounts of data were collected but seldom analysed and rarely shared.

Over time, China’s need for an integrated information system for HIV/AIDS surveillance and response became clear, and the creation of a unified, web-based, national HIV/AIDS information system was identified as a top priority.

The first major step in this direction occurred in 2005, when the China CDC instituted a web-based case-reporting system across a number of different disease areas, including HIV/AIDS.3 This system allows end users to enter case report data directly into an online system using automated forms, and it allows authorities to examine case report data in real time. In addition, the system allows users to generate automated reports that make it easier for public health staff and officials at every level to make use of data within their area of jurisdiction.

The second major step in this direction began in 2006, when the NCAIDS launched an initiative to develop a comprehensive, national, web-based HIV/AIDS information system. This system aimed to streamline data collection, data management, data analysis and data use by standardizing data collection methodologies, automating data management functions, and generating standardized statistical reports that can be readily used to guide public health efforts. The new system was launched in 2008, and has been in operation for >2 years. Here, we describe China’s new HIV/AIDS Comprehensive Response Information Management System (CRIMS) and provide a preliminary assessment of the new system.

Methods

System integration

The data unification initiative was launched in early 2006 and completed in three phases. The purpose of each phase and the steps involved are summarized in Table 1.

Phase 1

From January to December, 2006, a team comprised of technical officers from the NCAIDS/China CDC, the UNAIDS China Office, the WHO China Office and the US CDC Global AIDS Program in China, worked to create a set of uniform data collection questionnaires and forms. All questionnaires and forms from the eight existing national routine reporting systems were reviewed, along with questionnaires and forms from all major bilateral and international HIV/AIDS
programs, including the China Integrated Program for Research on AIDS (CIPRA) funded by the US National Institutes of Health (NIH), and China’s Global Fund HIV/AIDS projects. In addition, UNGASS indicators, indicators from China’s national framework for HIV/AIDS M&E, and key indicators from the WHO HIV/AIDS Strategic Information Framework were reviewed to ensure that appropriate data would be collected to meet reporting requirements.4

After key questionnaires, forms and indicators were reviewed, data fields were selected for inclusion in the draft forms for the web-based system. Criteria for data field selection included usefulness and feasibility of data collection. Redundant information from different systems was removed. Relevant identifier fields were included in all forms. Many variables or questions that did not meet criteria for data selection were dropped during the review process to ensure a reasonable data collection workload for public health staff.

The new questionnaires and forms were pilot tested in several provinces with a significant HIV/AIDS burden, including Yunnan, Henan and Anhui. The questionnaires and forms were assessed for user-friendliness, accuracy of information provided, feasibility of operation and appropriate formatting. Several levels of review were involved, including reviews by local health workers; by CDC staff at the county, provincial and national levels; and by officials from the Ministry of Health.

The reviewed, pilot tested questionnaires and forms were then compiled into a guidance document, Information Management for Comprehensive HIV/AIDS Prevention and Control. Contents included all relevant questionnaires and forms, definitions of variables and key terms, reporting frequencies and reporting organizations for each questionnaire and form.

A standardized monthly HIV/AIDS implementation report was also designed to summarize data collected from the subsystems.

Phase 2
From January to October, 2007, NCAIDS staff worked with a sub-contractor, Sinosoft, Inc., to create a web-based platform to host CRIMS. This unified, web-based platform combined the eight existing subsystems, along with one new subsystem covering contextual information for each county (including demographic data); information on infrastructure development; and information on the estimated size of high-risk groups and the number of entertainment establishments. Sentinel and behavioural surveillance were combined into one single subsystem. Seven of the eight new subsystems include two main modules: original data management and summary statistics. The original data management module has different levels of authorization; users have access to the data for levels under their jurisdiction. Summary statistics consist of real-time statistics and regular (periodic) statistics. The eighth subsystem, sentinel and behavioural surveillance, includes only the original data management module.

Phase 3
In November and December, 2007, the new platform was pilot tested and modified based on findings from pilot testing. A user-friendly interface was optimized to make data entry and uploading fast and convenient. Automated checks were designed to ensure logical relationships between questions and variables.
including automated skip patterns and connections between subsystems. For example, if an individual receives an HIV screening test, the test result first must be recorded in the client register within the HIV testing and counselling subsystem. If the HIV test result is positive, the health-care worker is automatically directed to input data required for case reporting. If the HIV test result is negative, the health-care worker is automatically directed to input whether or not the individual was provided with post-test counselling. During Phase 3, contents of the automated statistical reports were also verified using statistical software (SPSS and SAS) to ensure the accuracy of programming.

Other major AIDS projects stop to collect their own data that have the same contents with the eight new subsystems. Project officers can directly use information from the eight new subsystems for their AIDS projects.

**Preliminary system assessment**

After the system had been in operation for >2 years, we conducted an informal review of the new, integrated system based on US CDC guidelines for the evaluation of surveillance systems and included additional assessment criteria, such as data security.\(^5,6\)
Results

System integration

China’s new national HIV/AIDS CRIMS began operation on 1 January 2008. This system covers all levels of the public health system, from the local level up through the central level (Figure 1).

CRIMS is composed of eight subsystems (Figure 2). These include the existing seven subsystems plus an additional subsystem that houses county level contextual information. In 2008 alone, 45,572 new HIV case cards, over 260,000 case follow-up questionnaires, 15,021 new adult ART cards and 307 paediatric ART cards, 81,130 new MMT patient cards and more than 1.7 million voluntary counselling and testing (VCT) visits were entered into the new platform.

A summary of changes to each of the eight subsystems over the course of integration is presented in Table 2.

The processes of data entry, data management, data analysis and data use were all transformed as a result of integration. Data entry was streamlined by harmonizing data collection forms, thereby reducing the number of forms staff at the local level are required to complete. Identifying information (site codes, individual unique identifiers) is now automatically entered on all data collection forms, thereby reducing errors and eliminating the need for staff to spend time manually completing forms. Because internet outages remain a challenge in some areas, the system was designed to allow for offline data entry. Certain subsystems, including the VCT, MMT and ART subsystems, have client software used to collect data offline. Data are then uploaded to the web-based subsystem whenever the terminal users are online.

Data management was simplified through integration. Paper forms no longer need to be sent by post from the local level up to higher levels within the reporting system; rather, all data are entered directly into the web-based system and may be accessed. Variables, variable definitions, variable formats and variable codes are now standardized nationwide, facilitating data analysis and data use. It is also easy for system users to access and download datasets.

Data analysis, primarily in the form of descriptive statistics, was automated through the web-based systems integration process (Figure 3). Users at all levels of the system can generate automated reports relevant to their area of jurisdiction. This allows users at all levels of the system to generate descriptive statistical reports, regardless of computing ability. Data can also be searched or analysed across subsystems.

Preliminary system assessment

After CRIMS had been in operation for >2 years, we conducted an informal system assessment. The results of this assessment are presented in Table 3.

Discussion

The creation of a unified HIV/AIDS web-based management system has significantly improved HIV/AIDS data collection, data management, data analysis and data use. The new integrated system has provided support for policymakers as well as those designing and implementing HIV surveillance, prevention, testing and treatment programs.

The new system has also had an impact on HIV/AIDS programs. First, it has provided tools to improve program implementation. For example, one challenge in China’s national MMT program was finding a way to allow MMT patients to access services at different MMT clinics instead of being required to attend a specific clinic. With the new information system in place, it is now straightforward for MMT clinic staff
Table 2 An overview of the eight subsystems before and after the data integration initiative

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<th>Subsystem</th>
<th>Purpose</th>
<th>Before integration</th>
<th>After integration</th>
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| HIV/AIDS case reporting            | • To collect demographic and health data on individuals who have tested positive for HIV infection.  
• To record follow-up information on cases. | Before 2005, data were collected in paper and pencil format and submitted up the reporting chain by post. In 2005, China instituted a national web-based infectious disease case reporting system that improved data reporting and use. | The statistics module of the case reporting system was supplemented to ensure all relevant statistics are provided. New function modules were developed to supplement the HIV/AIDS component of the national, web-based infectious disease case reporting system. These new modules included:  
(i) the generation of case follow-up reminders to ensure local health-care workers know when to follow-up cases; and  
(ii) an outbreak alert feature flagging increased case reporting. |
| HIV sentinel surveillance          | • To monitor trends over time in HIV prevalence and key risk behaviours among key populations. | Before 2005, local HIV sentinel surveillance sites sent encrypted data in EpiInfo format to the NCAIDS via e-mail. | The HIV sentinel surveillance subsystem and BSS subsystem were integrated into one surveillance subsystem in 2008. Terminal software was developed to collect data offline and submit data online to the platform for higher level CDC downloading and analysing. |
| HIV BSS                            | • To monitor trends over time in HIV prevalence and risk behaviours among key populations. | Before 2005, local HIV sentinel surveillance sites sent encrypted data in EpiInfo format to the NCAIDS via e-mail. | An integrated questionnaire was developed to collect both counseling and testing information. All information pertaining to VCT clinics is easy to access ensuring policy makers can easily ascertain and monitor the coverage and efficiency of VCT. |
| HIV testing and counselling        | • To collect data on access to testing services.  
• To monitor service coverage and utilization. | Before 2008, VCT information was reported quarterly using a simple report form by post. Local health-care workers had to fill out one counselling questionnaire and a separate testing questionnaire for a participant, and complete a quarterly reporting form to be submitted via post or e-mail to provincial CDC. Similarly, 32 provincial aggregated forms were then submitted to the central CDC. | Each county level CDC reports data on behavioural interventions for high-risk groups to the platform directly, including the estimated size of each high-risk group, the number of contacts with each group, and the related intervention information in their area of jurisdiction. From this, the data are aggregated into prefectural, provincial and national data sets and the CDC at each level is able to review the aggregated data at their level and below. If data has not been submitted, this can be easily identified by the next administrative level of the CDC ensuring expedient information management. |
<p>| Behavioural interventions among high-risk groups | • To collect data on population size, intervention coverage, and key behavioural indicators (e.g. number of sexual contacts). | Before 2008, each county submitted behavioural intervention information via e-mail on a quarterly basis using an Excel spreadsheet. Data were aggregated at each level, with 32 aggregated provincial forms submitted to the NCAIDS. | (continued) |</p>
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<th>Subsystem</th>
<th>Purpose</th>
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| ART for adults | • To provide data on treatment needs for HIV-positive adults.  
• To provide data on the effectiveness of adult ART regimens. | In 2004, the NCAIDS established a nationwide observational cohort of adults on ART. An electronic ART database system was established, and standardized case report forms (CRFs) were completed at each patient visit and faxed to the NCAIDS via DataFax. As the population of patients receiving ART swelled with the expansion of ART programs across the country, the DataFax system at the NCAIDS was no longer able to handle the volume of CRFs being submitted. By the end of 2008, there were 1574 ART sites and 58 795 HIV-positive adults receiving ART. | A web-based ART treatment information system was implemented in 2009. Terminal software was used to collect data instead of DataFax. Data can be entered and/or uploaded at any time. |
| ART for children | • To provide data on paediatric treatment needs for HIV-positive children.  
• To provide data on paediatric ART regimens. | A subsystem to monitor ART among HIV-positive children was established in 2008. | The data collection tool was modified. |
| MMT | • To provide data on injection drug user treatment needs.  
• To provide data on MMT program operations. | Before 2008, incomplete patient information and clinic information were collected from each MMT clinic using a data collection tool developed by the NCAIDS. The data were compressed and submitted to the NCAIDS via e-mail. | The establishment of the MMT subsystem integrated all MMT clinics into one platform for sharing information for the first time. It is the most complicated of all the subsystems due to its abundance of information, including demographic information with photos, laboratory information of HIV, syphilis and hepatitis C testing results, methadone dosage levels, patient clinic transfer information, clinic information, staff information, logistic information and statistics. |
| County-level background information | • To provide an understanding of the contexts in which local HIV epidemics are unfolding. | Before 2008, there was no such subsystem. | Information from all 2893 counties was annually updated at the platform through internet. County-level background information provides an understanding of the contexts in which local HIV epidemics are unfolding. Information collected includes: demographic information; information on local infrastructure; the number and types of entertainment establishments; HIV/AIDS epidemic characteristics; high-risk population size estimates; AIDS orphan population size estimates; and the number of AIDS orphans receiving care and support. |
to access individual patient records. This practical tool has allowed for a change in policy that has helped expand program coverage to those MMT patients with more mobile treatment needs. Secondly, the new system has made the comprehensive M&E of the national HIV program possible. For example, data for China’s 2008 and 2010 UNGASS reports came primarily from CRIMS. Integrating China’s HIV/AIDS information systems has vastly improved data quality and availability, but a number of challenges remain. First, efforts to integrate HIV/AIDS data with data from other related public health information systems, such as tuberculosis and hepatitis, could help improve both disease prevention efforts and patient outcomes. Secondly, ongoing efforts to improve data quality are necessary. Thirdly, improvements can be made with regard to the visual display of information with the addition of more user-friendly graphs and graphics. Fourthly, integration with geographic information systems (GIS) could provide a more sophisticated understanding of disease patterns and program coverage that could lead to stronger HIV/AIDS program efforts.

**Conclusion**

The development of a unified web-based HIV/AIDS information platform hosting eight subsystems is a milestone in Chinese HIV/AIDS information management. CRIMS has improved the efficiency of data collection, reporting, analysis and use, as well as data accuracy and security, and the usefulness of information generated from the platform. It ensures that relevant, timely and accurate data are available to national program leaders and managers at each level of the health-care system, and it ensures that the national program is able to meet the reporting requirements of donor projects and international agreements. This integration of AIDS information systems may also be a model for other countries.

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<th>China’s HIV/AIDS CRIMS</th>
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<td><strong>Simplicity</strong></td>
<td>System structure. CRIMS is simple with regard to the structure of reporting, with each reporting unit having clearly defined tasks and responsibilities. It is complex, however, with regard to the overall number of reporting units, with over 2800 counties reporting data through CRIMS, along with many hospitals and other units. At present, CRIMS remains a vertical information system, and linkages have not yet been made with other related infectious disease monitoring systems, such as tuberculosis or hepatitis. However, the case reporting segment of CRIMS is integrated with China’s larger infectious disease monitoring system, the Chinese Disease Surveillance System (CDSS). <strong>Subsystem structure.</strong> CRIMS is simple with regard to the clearly defined purposes of each subsystem, but it is complex with regard to the amount of data collected through the system. There is substantial variation between subsystems, with some subsystems collecting relatively small amounts of data (e.g. the case reporting system) and other subsystems collecting relatively complex data (e.g. BSS, MMT and ART data). <strong>System operation.</strong> Data collection under the new system is much simpler than it was before integration. Forms with site and other identifiers are generated automatically, reducing staff errors and saving time. Forms are standardized and consistent with the user interface, making data entry straightforward. Data management is easier than before, with search fields available to help retrieve data as needed. Data sharing between sites and clinics is straightforward, helping mobile patients to access services in different locations. Data reporting is also simple under the web-based system. Forms used to be mailed up through the system by post; now, data are transferred electronically. Data analysis has also been simplified, with automated descriptive statistical reports available within each subsystem.</td>
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<td><strong>Flexibility</strong></td>
<td>The system is flexible enough to accommodate changing information needs. The program management module within CRIMS allows users at the provincial level to add programs and data collection forms for specific projects. The information technology sub-contractor, Sinosoft Co. Ltd, has a contract with the NCAIDS that includes adjustments to current subsystems as necessary to adapt to changing information needs or operating conditions.</td>
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<td><strong>Data quality</strong></td>
<td>Data quality remains a major challenge in China. Completeness of data is generally good, but there are notable problems. For example, an internal study examining loss to follow-up among people living with HIV/AIDS found that by the end of 2008, 12.4% of living HIV/AIDS cases were lost to follow-up because of incomplete case reporting cards. Data validity is also generally good, though there is also room for improvement. For example, another internal study examined laboratory data quality in 12 provinces, and found that one province had 100% agreement between web-based data reporting and actual laboratory test results; five provinces had &gt;95% agreement; four provinces had between 90 and 95% agreement; and two provinces had &lt;90% agreement. On-site data quality supervision and evaluation, along with staff training on data collection and input, are needed to ensure that higher quality data can be collected and reported.</td>
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<td><strong>Acceptability</strong></td>
<td>China’s Ministry of Health and the NCAIDS require all levels of CDCs and AIDS-related clinics and hospitals to report data through CRIMS. Therefore, participation in the system is high, with all levels of CDCs and AIDS-related clinics at the county level and above contributing data to the system.</td>
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<td><strong>Sensitivity with regard to case reporting</strong></td>
<td>The sensitivity of the system is relatively low in comparison with systems designed to detect acute infections, though sensitivity is improving. By the end of 2009, there were an estimated 740 000</td>
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<td>Sensitivity with regard to outbreak detection</td>
<td>refers to the ability of the system to detect outbreaks and monitor changes in the number of cases over time. The system is sensitive enough to detect outbreaks, and it can monitor changes in the number of cases over time. An outbreak alert feature was designed into the system to flag places with increased case reporting. The outbreak alert feature measures data in 10-day period of each month (i.e. Days 1–10, Days 11–20 and Days 21–31), and data can be analysed at each level, from the county level to the national level. In general, representativeness is a substantial challenge in HIV epidemiology due to the inherent challenges of identifying members of hidden or hard to reach populations—such as injecting drug users (IDUs), sex workers and men who have sex with men—and encouraging them to participate in HIV prevention and response activities. In China, there are differences in reporting between different provinces, areas or health-care providers, though steps have been taken to identify where these differences might lie. For example, IDUs may be divided into two general groups, IDUs in detention facilities and IDUs living in the community. Many reporting agencies oversample from IDUs in detention facilities because it is easy to reach this group. In the past, no distinctions were made between IDUs in detention facilities and IDUs in the community, making the interpretation of surveillance data challenging. In the new system, however, these data are clearly distinguished.</td>
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<td>Representativeness</td>
<td>refers to how well the system accurately describes the occurrence of HIV/AIDS over time and its distribution in the population by place and person.</td>
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<td>Timeliness</td>
<td>refers to the speed between steps in a surveillance system. CRIMS represents a great improvement in the timeliness of data reporting, data analysis and data use. Changes in system operation noted above have streamlined case reporting, surveillance and program monitoring, making real-time data available to system users.</td>
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<td>Stability</td>
<td>refers to the reliability (i.e. the ability to collect, manage and provide data properly without failure) and availability (the ability to be operational when it is needed) of the system. The stability of CRIMS is high, particularly given the amount of data collected through the system. Since 2005, there were only three unscheduled outages and down times for the system server and only once did the server need to be repaired. Unsuccessful attempts to access to the system occur occasionally when too many users attempt to update or download data at the same time. Currently, there is a special data backup server for downloading data at any time for further different needs. High capacity servers will be put into operation in 2011.</td>
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<td>Security</td>
<td>refers to the ability to limit system access to registered, trained users. A secure system also limits access to individual information. System security is strong. At each level, there is one single system manager authorized to provide new accounts for those authorized to access the system. Appropriate levels of access are in place for all users of the platform, enabling users to analyse data and generate statistics and reports relevant to their needs. Other relevant ministries have access to the different subsystems, with access limited to summary statistics and not individual patient information.</td>
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This overview is based on CDC guidelines for the evaluation of public health surveillance systems.\(^5\)
KEY MESSAGES

- Integration of separate HIV/AIDS data systems has harmonized information management.
- Unified, web-based HIV/AIDS information system has improved the efficiency of data collection, reporting, analysis and use, as well as data quality and security.
- The HIV/AIDS information system has become a powerful tool to support policy making, program evaluation and implementation of the national HIV/AIDS program.

References