Development a Minimum Data Set of the Health Information Exchange for Computerized HIV Reporting in Iran

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Summary
Background: The number of people living with HIV has increased in Iran. Creating standard templates for reporting HIV in Iran that can fulfill the needs of all beneficiaries is a basic necessity for the foundation of integrates health information systems. Objective: The aim of this study was to determine the Minimum Data Set (MDS) that is needed in the HIV/AIDS information exchange.

Materials and methods: This descriptive and cross-sectional study was performed in 2016. Data were collected from internet resources by using a checklist. The necessary data elements for designing HIV MDS were identified. In order to make a consensus about the data elements, the decision Delphi technique was applied using a questionnaire. The content validity and reliability of questionnaire were assessed by expert’s opinions and test-retest method, respectively.

Results: An MDS of HIV was developed. The proposed MDS was divided into three data categories includes nonclinical, clinical and supportive with 10, six and three Data classes and 73, 63 and 24 data elements respectively.

Discussion: The primary challenge of HIV/AIDS care systems in Iran is insufficient attention to support and consulting programmes as well as the lack of adequate information for accurate and efficient policy and decision-making. Therefore, the existing MDS has been designed to meet the needs of all groups of care providers, Health politicians, healthcare managers, administrativestaff, researchers, public health practitioners and support groups (rehabilitation). Finally, it is suggested to use messaging protocols for HIV/AIDS information exchange.

Key words: Minimum Data Set, HIV/AIDS, Public health, Information Exchange

1. Introduction

AIDS is a medical social phenomenon that is widespread in terms of social, cultural and economical dimensions, so much so that the United Nations has reported AIDS as not only a public health problem but also an obstacle in the way of human progress.(1) Centre for Disease Control and Prevention (CDC) has suggested to use integrated information systems to tackle AIDS epidemic.(2) In this regard, creating coordinated templates for reporting information on the disease in the form of a standard MDS is an essential prerequisite for the integrated systems of information exchange on AIDS. (2, 3)

Many experts has achieved a consensus about the necessity of creation of the MDS to manage and monitor treatment programs for AIDS in developing countries.(4) The MDS is a standard method to gather, store and distribute key and standard data elements,(5) designing systematic MDS is one of the first and most basic steps in foundation of national information systems and improving the communication between individuals and organizations that involved in the care programs(directly or indirectly).(6) The MDS is not only limited to particular clinical and care affairs of AIDS but is also used to facilitate managerial decisions and policy-making aspects, epidemiology and public health affairs, research programs, administrative and financial applications and etc.(4)

The prevalence of AIDS in Iran is high(1,7,8) and the effective control and management process for this disease is facing many challenges.(1, 9) One of the most important challenges is the lack of appropriate technical infrastructure.(7) Establishment of reporting systems associated with AIDS in Iran is known to be one of the major prerequisites for controlling the disease.(9) The third strategic national AIDS program in Iran emphasized the importance of using MDS.(10) Creating MDS is one of the three essential parts of the Iranian national system of registration and monitoring of AIDS.(10)

Iran lacks a comprehensive, integrated, and customized AIDS reporting system. (1) The high prevalence of this disease and the complexity of its nature(1,7) has increased the need for inter-organizational interoperability.(7) Therefore, this research aims to design a standard MDS format for the exchange of HIV/AIDS information in PHIE infrastructure.
2. Materials and Methods

This descriptive and cross-sectional study was performed in 2016. A literature review was performed to retrieve relevant resources. The resources included articles, reports and forms available on the internet.

To find materials relevant to the subject, Google scholar search engine and web of Science, Science direct, Scopus and PubMed data bases were explored. Studies were identified by keywords including “Minimum Data Set”, “Core Data Set”, “Minimum Data Element”, “Core Data Element”, “Essential Data Set” and “Essential Data Element” in English languages.

We mainly confined our search to materials published from 2000 to 2016. Sampling was not performed in this stage and all the relevant literature were retrieved and evaluated based on inclusion and exclusion criteria’s.

This research includes all full-text articles extracted from reliable sources in English between the years 2000 and 2016. Short articles, letters to the editor, accepted papers in conferences and reports extracted from blogs were not included in this study.

In order to extract data elements required for HIV reporting from related articles, a data extraction checklist was used, which included the following categories: titles of articles, the authors’ names, years of publication, article sources, the method of the study and data elements. The questionnaire was constructed using the data elements of the mentioned checklist in three data categories, include: 1. Nonclinical (Management, administrative and policy-making), 2. Clinical (Medical, clinical, evaluation and measurements), and 3. Supporting (consultation and subsidiary service’s) purposes. The questionnaire was composed of three columns with “yes” (including required and optional) and “no” in front of each data element. At the end of each section, an empty box was provided to write the data elements that were necessary to register according to experts’ opinion.

The content validity of the questionnaire was evaluated using the comments from Faculty Members in the field of health information management and medical informatics (a total of six persons, consisting of three experts in each field). To ensure the reliability of the questionnaire, it was completed by four of the aforementioned experts; they were requested to complete the questionnaire for the second time (with a seven-day interval). The collected data were analyzed with SPSS 16, Spearman’s rank correlation coefficient was used to evaluate the reliability of the questionnaire, which showed a coefficient of 85%. (Demographic characteristics of the samples are described in Table 1).

The final data elements were chosen by the 30 samples of public health specialist, epidemiologist and general practitioners working in the Iran's health ministry and National Center for AIDS Prevention. (Demographic characteristics of the samples are described in Table 1).

Through decision Delphi technique in two rounds, deciding on included data elements were based on the agreement level. In this way, data elements with less than 50% agreement were excluded in the first round and those with more than 75% agreement, were included in the primary round. Those with 50% to 75% agreement were surveyed in the second round and if there was 75% consensus over a subject, it was regarded as a final data element.

3. Results

To determine the final data elements of the MDS of the HIV reporting, data elements were chosen by 30 samples of attending experts through the Decision Delphi technique in two rounds. (Table 1, shows the attending expert’s demographic characteristics).

Table 1: Demographic Characteristics of the Samples

<table>
<thead>
<tr>
<th>The content validity and reliability assessors</th>
<th>Delphi analyzers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Samples</strong></td>
<td><strong>Frequency</strong></td>
</tr>
<tr>
<td>Academic field</td>
<td></td>
</tr>
<tr>
<td>Health Information Management</td>
<td>4</td>
</tr>
<tr>
<td>Medical Informatics</td>
<td>2</td>
</tr>
<tr>
<td>PhD</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>BSc</td>
<td>0</td>
</tr>
<tr>
<td>MSc</td>
<td>0</td>
</tr>
<tr>
<td>Physician (Non PHD)</td>
<td>0</td>
</tr>
<tr>
<td>PhD</td>
<td>6</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
</tr>
<tr>
<td>&lt; 5</td>
<td>1</td>
</tr>
<tr>
<td>5-10</td>
<td>1</td>
</tr>
<tr>
<td>10-15</td>
<td>3</td>
</tr>
<tr>
<td>15 &lt;</td>
<td>1</td>
</tr>
<tr>
<td>Total number: 6</td>
<td></td>
</tr>
</tbody>
</table>

The proposed MDS was divided into three data categories includes nonclinical, clinical and supportive (Table 2-4). Each of the categories Contain 11, six and three data classes respectively.
The nonclinical data category include Demographic, Contact, Identification, Socio-Economic, High risk/ at risk groups, Transmission category (contaminated), Patient disposition, Legal, Financial/reimbursement and documents information classes (table 2).

Clinical data category consist of Diagnostic, Prescription / medication, Laboratory investigations, History, Comorbidities/ warning diseases and Survival status information classes (table 3).

Finally, supportive data category are Consulting programs, Support programs and Subsidiary service classes (table 4).

The total number of data elements for nonclinical, clinical and supportive data categories was 95, 75 and 30 respectively. After the second round of Delphi (Table 2-4), the number of data elements were excluded.Therefore the final data elements for nonclinical, clinical and supportive categories were 73, 63 and 24 respectively.

3.1 Excluded data elements after the second round of Delphi:

1- Non-clinical data category: father’s name (Demographic data class), fax number and email address (Contact data class), admission/ visit ID, family ID, specimen ID and referral/transfer ID (Identification data class), social participation rate (Socio-Economic data class), tattoos (Transmission category data class), disease stage at referral and treatment plan (Patient disposition data class), consent for the research, consent for the transfer/referral, drug allergies and adverse effects of drugs (Legal data class), payename, insurance credit and membership status (Financial data class), document author, document goal and document description (Document data class). (22 data elements were excluded) (Table 2).

2- Clinical data category: the method of test/diagnosis, body mass index, HIV diagnosis date, visit date and history of appearance of the first sign (Diagnostic / problems data class), medication type, consumption dose, drug forms and drug’s target tissue (Prescription/ medication data class), the normal range/reference of test and frequency of testing (Laboratory investigations data class), pneumonia (Comorbidities/ warning diseases data class). (12 data elements were excluded) (Table 3).

3- Supportive data category: religious consultation (Consulting Programs data class), charities services, transportation assistance, social care services and Treatment/ care supporters (Support programs data class), antenatal care (Subsidiary Services data class). (six data elements were excluded) (Table 4).
Financial/reimbursement

Data elements of the payment source include patient self-pay, high risk/at risk groups, uninsured/multiple sex, unsafe sex and transsexuals' orientations. More exposed occupations include healthcare workers (especially LAB technicians, Surgeons, nurses and nurses aids and dentists), hairdressers, immigrant and prostitution (sex workers). Types of marital status are single, married, separated, widowed and unspecified marital status.

<table>
<thead>
<tr>
<th>Data Classes</th>
<th>Demographic</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification</td>
<td>Identification number: Patient, Medical record, Treatment/ Antiretroviral Therapy (ART), Medical specialist, Provider institute, Payment, Social security.</td>
<td></td>
</tr>
</tbody>
</table>

| Socio-Economic          | Occupational, Literacy rate, Health/welfare state, Type of residence, Religion, Income, Marital status, Social circumstances, Family status and Living situation. |
| High risk/ at risk groups | 1- Incorrect sexual orientation, Receiving blood and blood products, Organ transplantation, Intravenous injection, Alcohol and drug addiction, Occupational hazards, Travel/immigration, Mental disease and Other risks.  
2- Exposure cause, Exposure place, Duration of exposure, Exposed date and Activity during exposure. |

| Transmission category (contaminated) | Injectable drug use, Sexual relationship, Mother to child transmission, Reception of blood and blood products, Organ transplant, Intravenous injection and Other factors. |

| Patient disposition | Referral / transfer source, Referral / transfer date, Referral / transfer type, Referral / transfer reason, Admission info (date, type, reason), Discharge info (date, type, reason), Follow-up info, Discharge recommendations. |

| Legal                  | 1- Privacy Code  
2- Consent for the following purposes: Treatment/diagnostic, Study and evaluation, Financial and refunds, Discharge by personal desire, Disclosure of information.  
3- Medical/prescription errors. |

| Financial/reimbursement | Payment source, policy / coverage type, Insurance name, Insurance company, Payer name. |

Data elements of the payment source include patient self-pay, financial intermediaries, charities and other payment methods. Main types of insurance coverage are public and private coverage's. Unpopular sexual orientations include gay, unbridled/multiple sex, unsafe sex and transsexuals' orientations. More exposed occupations include healthcare workers (especially LAB technicians, Surgeons, nurses and nurses aids and dentists), hairdressers, immigrant and prostitution (sex workers). Types of marital status are single, married, separated, widowed and unspecified marital status.

Table 5: The final non-clinical data elements for a minimum data set for HIV/AIDS reporting

<table>
<thead>
<tr>
<th>Data Classes</th>
<th>Data elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>Name, Surname, Partner/spouse name, Age, Sex, Race/ethnicity, Nationality, Date of birth, Place of birth</td>
</tr>
<tr>
<td>Contact</td>
<td>Address, Contact number, Postcode/ Zip code</td>
</tr>
<tr>
<td>Identification</td>
<td>Identification number: Patient, Medical record, Treatment/ Antiretroviral Therapy (ART), Medical specialist, Provider institute, Payment, Social security.</td>
</tr>
<tr>
<td>Socio-Economic</td>
<td>Occupational, Literacy rate, Health/welfare state, Type of residence, Religion, Income, Marital status, Social circumstances, Family status and Living situation.</td>
</tr>
</tbody>
</table>
| High risk/ at risk groups | 1- Incorrect sexual orientation, Receiving blood and blood products, Organ transplantation, Intravenous injection, Alcohol and drug addiction, Occupational hazards, Travel/immigration, Mental disease and Other risks.  
2- Exposure cause, Exposure place, Duration of exposure, Exposed date and Activity during exposure. |
| Transmission category (contaminated) | Injectable drug use, Sexual relationship, Mother to child transmission, Reception of blood and blood products, Organ transplant, Intravenous injection and Other factors. |
| Patient disposition   | Referral / transfer source, Referral / transfer date, Referral / transfer type, Referral / transfer reason, Admission info (date, type, reason), Discharge info (date, type, reason), Follow-up info, Discharge recommendations. |
| Legal                 | 1- Privacy Code  
2- Consent for the following purposes: Treatment/diagnostic, Study and evaluation, Financial and refunds, Discharge by personal desire, Disclosure of information.  
3- Medical/prescription errors. |
| Financial/reimbursement | Payment source, policy / coverage type, Insurance name, Insurance company, Payer name. |

Document

Data elements of the Document include document name, document title, document creation date, profile of the authorized transmitter/receiver.

Table 6: The final clinical data elements for a minimum data set for HIV/AIDS reporting

<table>
<thead>
<tr>
<th>Data Classes</th>
<th>Data elements</th>
</tr>
</thead>
</table>
| Diagnosis / problems info | Diagnosis finding (related or unrelated to AIDS), Primary and final diagnosis, HIV status,Chief Complaint, Signs and Symptoms, Physical Examination, Assessment & plan, HIV staging (WHO classes), HIV subtype (type one or two), Vital signs, Medical procedures (related or unrelated to AIDS), First sign/symptom onset date, Age of patient at the time of diagnosis, The duration between being infected and the diagnosis.  

Prescription/ medication

| ART/ARV summary | Current ART/ARV regimen, ART/ARV eligibility (date, reason), ART/ARV initiation (date, reason), ART/ARV end (date, reason), ART/ARV discontinuation/ intermittent (date, reason), ART/ARV alternative /changing (date, reason), ART/ARV dispense (date, reason), Time between diagnosis and the ART initiation, HIV stage/ Cluster of Differentiation4 (CD4) levels when starting the ART, Compliance/adherence assessments.  

Laboratory / evaluation investigation

| HIV test name | HIV test type, Reason for the test, First HIV test date, Related (sub) tests, Specimen data, HIV test interpretation and result, Date of the first HIV test, HIV test interpretation date, HIV test result, Date of the first positive HIV test, Date of the last negative HIV test, HIV/AIDS diagnosis date, Radiographic information.  

History

| Diseases/condition history | Medication history, Procedure/ treatment history, High-risk sexual relationship history, Pregnancy/delivery history, Mental history, Social history.  

Comorbidities/ warning diseases

| Tuberculosis, Pneumonia, Hepatitis, Sexually transmitted infections, Cancer, Opportunistic infections and etc.  

Survival status

| The current state of life, Underlying cause of death, Date of death, The time between diagnosis and death, The time between initiation of the ART until death.  

Elements related to the type of AIDS consist of one, two and unknown types. Data element representations of the status of AIDS include active, inactive and unknown statuses. Data elements of AIDS-specific tests consist of the HIV antibody / antigen detection, CD4 counts, Cluster of Differentiation8 (CD8) counts and viral load test. The three main HIV related tests (sub-tests) are the, 1- Complete Blood Count (CBC), 2- Venereal Disease Research Laboratory (VDRL) and 3- Purified Protein Derivative (PDD) tests. AIDS-related drug administration data consist of ART [treatment], ARV [prevention] and Co-trimoxazole [prevention].

The HIV disease is segregated into four phases- I, II, III, and IV. The patient's referral or transfer data (healthcare utilizations) include those from hospital, emergency, specialized clinics, medical offices, counselling/support, outpatient services and public health organizations.

Historical data class consists of two main categories, 1- historical data elements with the primary objective (medical, clinical and treatment history) and historical data elements with the secondary objective (social history). In laboratory data class, sample data comprise elements such as type of sample, place/institution of taking sample, sample quality, date of sample receipt and delivering to the laboratory, date of interpretation, date of result delivery and identifying information.
Consulting programs consist of two main categories, 1- consultation with primary objectives (medical, psychological, nutrition and diet therapy, rehab, prevention, medication consumption, pregnancy) and 2- consultation with secondary objectives (religious, marital, sexual behaviors, occupational and socioeconomic).

4. Discussion

The high prevalence of AIDS in Iran (1, 7) has persuaded authorities to pay special attention to managing and controlling this disease at the national level. (1) The successful management of AIDS requires the active participation of patients in many healthcare programs. (11)

To improve the care experiences and outcomes, all health care providers, policy makers, public health specialists, administrative staff, researchers and etc. should use information technology infrastructure in order to optimize information exchange. (11) In this regard, the use of MDS is necessary for improving systematic reporting. (4, 6, 12)

Primarily, the results of this study show that the HIV/AIDS data were not collected in a systematic and standard way in Iran and development of MDS was required for HIV/AIDS information exchange.

Lai showed that the AIDS MDS improved health through interoperable information exchange and was capable of changing the traditional interactions of caregivers. (13) According to Liu, the use of MDS for the electronic reporting of conditions related to public health, plays a significant role in improving the interoperability. (14) Therefore, designing the standard and integrated templates for reporting, is the most important activity in the establishment of PHIE. (15)

The main objective of MDS is to facilitate inter-organizational reporting. (5) This is the most essential prerequisite for public health and rapid and timely detection of bioterrorism and critical decisions. (16)

Darabi et al. designed the MDS for Iranian Children's Health Records in the context of public health in two clinical and demographical areas. (17) The designed MDS in the present study considers the HIV reporting system in three main groups of non-clinical, clinical and supportive and in addition, many of the requirements for public health reporting have been anticipated.

Nematollahi et al. has introduced the MDS as one of the major prerequisites for national information management system for AIDS in Iran. (18)

The results obtained by Sadoughi showed that the present inability of the Iranian health information management system to meet national and international requirements is due to the lack of comprehensive MDS in various fields. (19) Therefore, MDS creation with clinical and nonclinical objectives in the context of AIDS can play a fundamental role in the improvement of the management of this disease. (4)

One of the most important features of a comprehensive system of reporting of AIDS is considering the needs of various stakeholders. (20) The designed MDS in the current study for the reporting of HIV has considered the numerous stakeholder information needs.

Castilla et al emphasized the importance of demographical, socioeconomically and clinical or health status information for designing MDS of AIDS. (21) Freezer et al. focused on the importance of administrative, managerial, support, and clinical information. (22) The WHO report relied on the primary (medical and clinical) and secondary (administrative and management) needs (23), while another report emphasized the importance of demographic, clinical and behavioral information for designing MDS of AIDS. (24)

Putkemerd and colleagues also focused on the demographic, identification and clinical information on this subject. (25) Tierney et al. considered clinical (history, diagnostic test, Prescription, physical examination, procedures, patient disposition) and non-clinical (registration, scheduling, and practice management) needs to design the MDS of AIDS. (4)

Ahmadian and colleagues in three separate studies, suggested the use of MDS of information management system in the orthopaedic, radiology, and burn in Iran in two areas—management (secondary purposes) and clinical (primary purposes). (5, 6, 26)

According to Hamidi study, information classes for designing the electronic health card of schizophreniawas included demographic and clinical classes. (27) Tierney et...
al designed MDS was included the two main information categories and 36 data elements.(4)

In this study, MDS contains three main categories, 19 informational classes and 160 data elements for the clinical, nonclinical and supportive purposes. In addition to the application of data elements for the improvement of healthcare primary objectives (medical and clinical), the secondary needs (administrative, management, and policy-making) and supportive applications (consulting, rehabilitation, support and the provision of ancillary services) have also been considered. Therefore, one of the strengths of the proposed MDS is its comprehensiveness.

In two studies conducted by Patra et al., on the creation of Clinical Document Architecture (CDA) for AIDS, data elements was structured in two parts, CDA title (meta information about the document) and CDA body (clinical and nonclinical narrative reports).(28,29) Gordon et al., presented data elements for HIV reporting in the form of a personal profile for patients.(30) A study by Magnus and colleagues suggested data elements for AIDS in order to improve PHIE.(31)

Due to the complex nature of AIDS (32), there is a great need for multidisciplinary teams with better interoperability and information-sharing among them. (28,29) Therefore, this study, by presenting MDS in the three main categories of non-clinical data classes (demographical, socioeconomically, contact and identification information) for CDA title and clinical and support data classes for CDA body, has become a necessary prerequisite for PHIE.

Recently, healthcare providers, managers, policy makers, researchers and etc. have emphasized the importance of maintaining continuity of care for patients—not only in primary healthcare sectors, but also in professional and other sectors, like support, consultation, and even non-clinical sectors.(12,27) Recent studies demonstrate that the use of comprehensive and standard reporting templates in the form of MDS plays an important role in creating a case (coordinate) management atmosphere for AIDS care and treatment and removes problems in making critical decisions due to information shortage.(2)

5. Conclusion

In this study, most areas related to the treatment and care of AIDS are covered through the design of the MDS of AIDS, which consists of three main data categories, 19 data classes and 160 data elements.

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References


