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 fulfil 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 MDSwere 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 andthree Data classes and 73, 63 and24 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, theexisting 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, storage 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 andetc.(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 appropriatetechnical 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 theIranian 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.

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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, ScopusandPubMeddata 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 exclusioncriteria'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 checklistin three data categories, include: 1. Nonclinical (Management, administrative and policymaking), 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 datawere analyzed with SPSS 16, Spearman's rank correlation coefficient was used to evaluate the reliability of the questionnaire, which showed a coefficient of 85%.(Demographiccharacteristics of the samples are described in Table 1). The final data elementswerechosen by the 30 samples of public health specialist, epidemiologist and general practitionersworking in the Iran's health ministry and National Center for AIDS Prevention. (Demographiccharacteristics of the samples are described in Table 1).

Through decision Delphi technique in tworounds, deciding on included data elements were basedon the agreement level. In this way, data elements withless than 50% agreement were excluded in the first roundand those with more than 75% agreement, were included in the primaryround. Those with 50% to 75% agreement were surveyed in the second round and if there was 75% consensus overa 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)

The content validity and reliability assessors		Delphi analyzers			
Samples	frequenc y	Samples	frequenc y		
Academi	c field	Academic fie	ld		
Health Information Management	4	Public Health/ Environmental Health	21		
Medical	2	Epidemiology	5		
Informatics	2	GP	4		
Educat	tion	Education			
BS	0	BS	17		
MSc	0	MSc	7		
Physician (Non PHD)	0	Physician (Non PHD)	4		
PhD	6	PhD	2		
Sex		Sex			
Male	4	Male	19		
Female	2	Female	11		
Age group	(years)	Age group (years)			
20-30	0	20-30	12		
30-40	4	30-40	9		
40-50	1	40-50	7		
50 <	1	50 <	2		
Work experience (years)		Work experience (years)			
< 5	1	< 5	13		
5-10	1	5-10	8		
10-15	3	10-15	5		
15 <	1	15 < 4			
Total number: 6		Total number: 30			

Table 1: Demographic Characteristics of the Samples

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.

140	ic 2. Non Chinear Data				пр кср	onting		
Data Classes	Total Number of	First	Round of D	Delphi	Second Round of Delphi			Final
	DataElements	< 50%	50-75%	75% <	< 50%	50-75%	75% <	Finai
Demographic	10	1	2	7	0	0	2	9
Contact	5	1	1	3	1	0	0	3
Identification	11	2	3	6	2	0	1	7
Socio-Economic	11	1	0	10	0	0	0	10
High risk/ at risk groups	13	0	2	11	0	0	2	13
Transmission category	8	0	1	7	1	0	0	7
Patient disposition	10	1	1	8	1	0	0	8
Legal	11	3	2	6	1	0	1	7
Financial/reimbursement	9	3	2	4	1	0	1	5
Documents	7	2	2	3	1	0	1	4

Table 2: Non Clinical Data Classes for a Minimum Data Set for AIDS Reporting

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).

Table 3: Clinical Data Classes for a Minimum Data Set for AIDS Reporting

Data Classes	Total Number of	First	Round of D	elphi	Second Round of Delphi			Final
Data Classes	DataElements	< 50%	50-75%	75% <	< 50%	50-75%	75% <	rmai
Diagnostic /problems	19	3	5	11	2	0	3	14
Prescription/ medication	21	2	4	15	2	0	2	17
Laboratory investigation	16	1	2	13	1	0	1	14
History	7	0	2	5	0	0	2	7
Comorbidities/warning diseases	7	1	2	4	0	0	2	6
Survival status	5	0	1	4	0	0	1	5

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

Table 4: Supportive Data Classes for a Minimum Data Set for AIDS Reporting	ng
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Data Classes	Total Number of	First	Round of D	elphi	Round of	Final		
Data Classes	Data Elements	< 50%	50-75%	75% <	< 50%	50-75%	75% <	Fillai
Consulting Programs	12	1	3	8	0	0	3	11
Support programs	9	2	4	3	2	0	2	5
Subsidiary Services	9	0	2	6	1	0	1	8

Finally, supportivedata 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, 75and 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-clinicaldata category:father's name (Demographicdata class), fax number and email address (Contact data class), admission/ visit ID, family ID, specimen ID and referral/transfer ID (Identificationdata class), social participation rate (Socio-Economic data class), tattoos (Transmission categorydata class), disease stage at referral and treatment plan(Patient disposition data class), consent for the research, consent for the transfer/ referral, drug allergies andadverse effects of drugs(Legal data class), payername, insurance credit andmembership status (Financial data class),document author, document goal anddocument 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 anddrug's target tissue (Prescription/ medication data class),the normal range/reference of test andfrequency of testing (Laboratory investigationdata 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).

Table 5: The finalnon clinical data elements for a minimum data set for HIV/AIDS reporting

Data Classes	Data elements
Demographic	Name, Surname, Partner/spouse name, Age, Sex, Race/ethnicity, Nationality, Date of birth, Place of birth
Contact	Address, Contact number, Postcode/Zip code
Identification	Identification numberof: Patient, Medical record, Treatment/ Antiretroviral Therapy (ART), Medical specialist, Provider institute, Payment, Social security.
Socio-Economic	Occupation, Literacy rate, Health/welfare state, Type of residence, Religion, Income, Marital status, Social circumstances, Family status and Living situation.
High risk/ at risk groups	 Incorrect sexual orientation, Receiving blood and blood products, Organ transplantation, Intravascular injection, Alcohol and drug addiction, Occupational hazards, Travel/immigration, Mental disease and Other risks Exposure cause, Exposureplace, Duration of exposure, Exposuredate andActivity during exposure.
Transmission category	Injectable drug use, Sexual relationship, Mother to child transmission, Reception of blood and blood
(contaminated)	products, Organ transplant, Intravenous injection and Other factors.
Patient disposition	Referral / transfer source, Referral / transferdate, Referral / transfertype, Referral / transferreason, Admission info (date, type, reason), Discharge info(date, type, reason), Follow-up info, Discharge recommendations.
Legal	 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	Document name, Document title, Document creation date, Profile of the authorized transmitter /receiver.

Data elements of the payment source includepatient 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' nt creation date, Profile of the authorized transmitter /receiver. 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 6: The finalclinical data elements for a minimum data set for HIV/AIDS reporting

Data Classes	Data elements
Diagnostic / 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	General prescription: Prescription name, Consumption timing, Route of administration, Prescription date, Drug allergy, Drug toxicity, Drugs adverse effects. ART/ARV summary: Current ART/ARVregime, ART/ARVeligibility (date, reason), ART/ARVinitiation (date, reason), ART/ARVend (date, reason), ART/ARVdiscontinuation/ intermittent (date, reason), ART/ARValternative /changing (date, reason), ART/ARVdispense (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 andresult, Date of the first HIV test, HIV test interpretation date, HIV test result date,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 transferdata (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.

Table 7: The finalsupportdata elements for a minimum data set for HIV/AII	DS reporting
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Data classes	Data elements
Consulting programs	Consultation for the following purposes: Psychological, Family/family planning, Pregnancy / delivery, Nutrition and Diet therapy, Rehab, Occupational, Prevention, Medication/timing of consumption, Before and after the first test, Marital, Sexual behaviors.
Support programs	Education and awareness programs, Housing assistance, Isolation programs, Screening services, Advocacy groups.
Subsidiary services	Laboratory tests, Imaging procedures, Dental care, Mother/baby health, Rehabilitation activities, Immunizationservices, Preventive or prophylaxis services, Contraceptive programs.

Consulting programs consist of two main categories, 1consultation with primary objectives (medical, psychological, nutrition and diet therapy, rehab, prevention, medication consumption, pregnancy) and 2consultation 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, theresults of this study show that the HIV/AIDSdata 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 interorganizational 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 maingroups 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 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)

Putkemerand 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)

Ahmadiand 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

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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 multidisciplinary teams for 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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