



Research Paper

Development a national minimum data set (MDS) of the information management system for disability in Iran

Maryam Ahmadi ^a, Talat Madani ^b, Jahanpour Alipour ^{c, d, *}^a Health Information Management Department, School of Management and Medical Information Sciences, Iran University of Medical Sciences, Tehran, IR, Iran^b Health Information Technology, School of Management and Medical Information Sciences, Iran University of Medical Sciences, Tehran, IR, Iran^c Health Promotion Research Center, Zahedan University of Medical Sciences, Zahedan, Iran^d Health Information Management, Health Information Technology Department, Paramedical School, Zahedan University of Medical Sciences, Zahedan, Iran

ARTICLE INFO

Article history:

Received 15 September 2018

Received in revised form

12 May 2019

Accepted 20 May 2019

Keywords:

Minimum data set

Disability

Information management system

ABSTRACT

Background: Disability management and policymaking require complete and valid data on disability. **Objective:** Development of a minimum data set (MDS) of the information management system for disability in Iran.

Methods: This descriptive, cross-sectional study was performed in 2017. Data were collected from the documents of persons with disabilities data bank of the State Welfare Organization of Iran available at "payment.behzisti.net", and data elements of the Ministry of Health and Medical Education (MOHME) resources, in addition to the Internet and library. A checklist was used for data collection. The Delphi technique was applied to reach a consensus about the data elements using a questionnaire. The content validity and reliability of the questionnaire were assessed by experts' opinions and the test-retest method, respectively.

Results: An MDS of disability was developed including administrative and clinical categories with 130 and 345 data elements, respectively. Two hundred and thirty eight data elements were mandatory elements (administrative: 60, clinical: 178) and the rest were optional elements.

Conclusions: An MDS can be a starting point for standardizing the disability data. A minimum data set has the potential to standardize the data and overcome the problem of low-quality disability data in Iran through providing consistent, complete and uniform data elements. Thus, the use of this MDS is useful in determination of the level of disability and its benefits, and in policy-making and effective planning for providing persons with disabilities with more efficient and cost-effective services.

© 2019 Elsevier Inc. All rights reserved.

Disability is an inevitable part of human life and almost everyone, whether temporarily or permanently, may experience it in their life.¹ About 15% of the people in the world have experienced disability and about 3% of them have severe disabilities.² Women, poor, unemployed, and older people are more susceptible to disability.² On the other hand, disability may lead to serious consequences such as unemployment, lack of income, restrictions in social relationships, and psychological disorders.³ Mitra et al. found that in developing countries, people with disabilities are significantly are characterized by higher multidimensional poverty, lower

educational achievement, and older age range.⁴

Although Soltani et al. reported a decreasing trend of disability in Iran from about 4% in 1997 to 1.3% in 2011, the general trend of disability is increasing in the whole world including Iran which can be explained by such factors as population aging, modifications in the definition of disability, the heterogeneity of the data collection methods, increased rate of chronic diseases and injuries due to accidents, natural disasters and substance abuse.^{5,6} The World Health Organization (WHO) has defined disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations".⁷

* Corresponding author. School of Paramedical Sciences, Zahedan University of Medical Sciences, Khalij Fars Ave., Zahedan, Iran.

E-mail addresses: m_ahmadi24@yahoo.com (M. Ahmadi), madani_hit@yahoo.com (T. Madani), jahanpour.alipour@gmail.com (J. Alipour).

According to a WHO estimate, Iran will face an increase in the aging population in the next decades in such a way that the elderly will comprise about 25% of the population in 2050.⁸ Therefore, it is very important to pay attention to aging and disability in Iran.^{5,9} People with disabilities need high quality data, respectable communication, and new information technologies for their empowerment.² However, limited information is available about disabilities in low-income and middle-income countries.¹⁰ Furthermore, less information is usually collected about low-level disabilities compared to severe disabilities.¹ Planning, policy-making, development, and provision of services for people with disabilities,^{5,9} and determining an individual's eligibility and its benefits for disability benefits payers² require the collection of accurate, complete and consistent data using standard tools that allow data analysis and comparison in this area at various national and international levels.⁵

A minimum data set (MDS) provides a standardized set of data elements that should be collected to enable data audit and benchmarking.¹¹ In other words, an MDS is a standard data collection tool that can cover data elements required by health information systems.¹² Development and application of an MDS are considered the forefront of disease information management programs in health care facilities, which can improve the quality of health care services. An MDS, by providing a structured method of data organization, enables effective care plans.¹³ An MDS identifies the required data elements for each patient and provides a consistent definition for common terms and data elements¹⁴ to standardize the data elements.

The main purpose of an MDS is to standardize the data to ensure data comparability and compatibility at national and international levels.¹⁵ The WHO¹⁶ as well as Kowal et al.,¹⁷ Ajami et al.,¹⁸ and Alipour et al.¹⁹ have emphasized the development of a cross-country MDS based on domestic experts' opinions and national objectives, rules, requirements, and standards. Lack of consistent definitions and measures for disability data is considered a major challenge in producing reliable and comparable statistics on disability in national and international levels.²⁰ In each arena, an MDS contains many data elements about demographic characteristics, health status, treatments, financial data, and discharge status.²¹

Hawes et al.²² reported that an MDS has the potential to improve the accuracy and comprehensiveness of the data, care plans, care quality, and life quality. Developing an MDS is the front line of data standardization, data use in different decision making processes, and data comparability at national and international levels.²³ Therefore, an MDS is an essential tool for data management in any health information system such as Electronic Disability Records (EDRs). The EDR is an electronic health care system that "contains the medical, occupational, financial, health support, and accommodation data necessary for disability payers to make a fair decision about an individual's eligibility to receive health and benefit services, as well as the extent of those services".²⁴

Disabilities impose huge social costs on societies.²⁵ Social costs of disability consist of tangible and intangible ones. The former includes financial dependence due to unemployment and sick time, time spent on seeking and waiting for treatment, and supportive care services. The latter comprises the costs of disability effects such as pain, sadness and depression, stigma and misconception, mental and physical limitations, and social limitations such as marriage and friendship.²⁶ EDRs provide access to accurate, precise, and complete data about people with disabilities, benefit payers, and care providers. Therefore, EDRs can present adequate and timely medical evidence for the disability determination process and decision-making concerning disability benefits, which in turn reduces delays causing high societal costs.²⁵ To the best of our

knowledge, there is no established national minimum data set (MDS) for disability, which is an obstacle to developing a national EDR for Iran in order to collect comprehensive and uniform data on disability for various purposes.

Objective

This study was conducted to develop a national MDS for disability to facilitate the development of a national EDR for Iran.

Methods

The disability MDS was developed in five steps. In the first step, data were collected from the people with disabilities data bank of the State Welfare Organization of Iran available at "payment.behzisti.net" and the data elements of the Iranian Ministry of Health and Medical Education (MOHME) sources such as the national electronic health records system (abbreviated as SEPAS in Persian) and the integrated health system (abbreviated as SIB in Persian). The sources were continuously reviewed at this step until data saturation was achieved, and no more new data elements emerged from the sources.

In this step, all relevant documents to disability were reviewed and a checklist was used to extract the data elements from the sources listed above. The checklist included two columns. The first column was for either administrative or clinical categories and the second column was for the data elements associated with each category in the reviewed sources. The data elements extracted from these sources, and the data elements extracted from the literature review, were used to determine the data elements of the Delphi questionnaire.

In the second step, a systematized review was conducted to retrieve the relevant data sources of disability. The same checklist was also used to record the extracted data elements. All publications up until March 2017 were searched in the Persian databases of MagIran, Scientific Information Database (SID), and Irandoc and English databases of Scopus, PubMed, and Web of Science as well as the Google search engine. Applied search terms were minimum data set form, MDS, minimum data set, disability registry form, disability, and disability record. Our inclusion criteria were full-text articles in either English or Persian languages related to the disability domain with a clearly stated purpose published up until March 2017. The exclusion criteria were articles published in languages other than English and Persian, the articles whose full-text were impossible to access, reports and forms retrieved from personal weblogs, and letters to editors.

A total of 1442 papers were identified. Of these, 236 papers were duplicates and were therefore excluded. Of the 1206 remaining papers, 1144 were excluded after reviewing their titles and abstracts. The remaining 62 papers were scrutinized for eligibility, of which 34 met the inclusion criteria.

In this stage, sampling was not done; all of the studies were evaluated based on the inclusion and exclusion criteria and their data elements were entered into the checklist. The collected data were divided into clinical and administrative categories using the checklist. Then, the extracted data elements from the two previous stages were combined and a final checklist was constructed. Generally, 488 data elements were extracted from the data bank and information systems related to disability in Iran and the literature review. The data elements were then recorded in the final checklists.

In the third step, a questionnaire was constructed using the data elements of the final checklist. The questionnaire consisted of eight and ten sections for administrative and clinical categories, respectively. The questionnaire was composed of three columns with

“yes” (consisting of two parts: mandatory or optional) and “no” in front of each data element. The experts were asked to specify whether they agreed on including the data elements in the MDS by checking “yes” or “no”. In addition, if they agreed, they were also requested to determine whether it was mandatory or optional. At the end of each section, a blank row was considered for adding necessary data elements by experts.

The content validity of the questionnaire was evaluated by five experts with knowledge and experience related to the field of disability, including two health information management experts, a PhD in medical informatics, and two experts from the State Welfare Organization. Test-retest (at a 10-day interval) was done to determine the reliability of the questionnaire. The collected data were analyzed using SPSS 16, and the questionnaire had a Cronbach's alpha of 0.86.

The final data elements of the MDS were obtained in two rounds of the decision Delphi technique. Purposive sampling was used to select 24 experts for Delphi. The criterion for the selection of experts was knowledge and experience in the field of disability or recording of disability. The criterion for acceptance of data elements in the final MDS was the agreement level of experts. Thus, data elements with less than 50% agreement were excluded in the first round, data elements with 50–75% agreement entered the second round, and elements with more than 75% agreement were accepted in the first round of the Delphi technique. In the second round, an agreement level of 75% was considered for each data element. In the end, the final data elements of the MDS were obtained in two rounds.

In the fourth step, the first round of the Delphi was applied using the questionnaire to make a consensus about the data elements of the MDS of the information management system for disability. In this step, the experts agreed on 119 data elements of the administrative category and disagreed on two data elements (patient's bank account number and bank name). They also agreed on 319 clinical data elements.

In the fifth step, the second round of Delphi was conducted to survey all 12 administrative data elements with 50–75% agreement in the first round, of which 11 items were agreed upon by experts and one item with less than 50% agreement was excluded (national ID of the patient's father). Moreover, of 36 surveyed clinical data elements with 50–75% agreement in the first round, 26 items were agreed upon by experts and 10 items with less than 50% agreement were excluded (patient's appearance, date of drug prescription, drug consumption plan, obesity of patient, prosthesis serial number, severity of comorbidities and complications, differential diagnoses, and physician orders group).

Results

The MDS of disability was divided into an administrative

category with eight sections and a clinical category with 10 sections. The total number of data elements for administrative and clinical categories were 133 and 355, respectively. After applying two rounds of the decision Delphi technique, the final data elements for administrative and clinical categories were 130 and 345, respectively (Tables 1 and 2), of which 238 were mandatory (administrative: 60 and clinical: 178) and the rest were optional. The agreement of the experts was used to determine whether the data element was mandatory or optional in the final MDS.

Use of healthcare services and health insurance claims are major types of administrative data in healthcare facilities, which are used to determine the level of received healthcare services and related costs. Furthermore, monitoring health care processes and outcomes for different patient groups and providing patient-centered care rely on both patient administrative and clinical data. The administrative data category included the patient's demographic data (first and last name, age, sex, etc.), provider's identification data (practitioner's role, specialty, etc.), socioeconomic data (nationality, occupation, income), patient encounter (admission date, referring facility, etc.), facility identification data (name of facility, type of facility, etc.), data registrar (such as name, role, specialty, etc.), financial data (such as costs paid by the insurance company), and data of supportive services such as type of supportive services, date of commencement and termination of services, etc. Table 3 shows full list of administrative data elements.

The clinical data category included the patient's chief complaint (CC) data (CC, code of CC based on ICD-10, etc.), personal history data (history of diseases, drugs, substance abuse, nutritional habits, etc.), family medical history data (history of disability in the family, congenital and genetic diseases in the family, drug abuse during pregnancy in the family, etc.), data of the review of systems (patient's appearance, review of head and neck, nervous system, etc.), environmental factors data (food products, pharmaceuticals and technology, attitude and culture, support and social relationships, etc.).

This data category also included the diagnosis and disability determination data (type of disability, code of disability based on ICF, underlying cause of disability, etc.) diagnostic and therapeutic procedures data (physician's orders, nursing interventions, rehabilitation procedures, etc.), follow up data (type of order for follow up, patient's problems at follow-up, date of next follow-up, etc.), discharge condition data (outcome of care, patient status on discharge, etc.). As the last item in the clinical category, death data included the underlying and direct cause of death, autopsy results, and date and time of death (Table 4).

Discussion

According to a WHO report in 2018, over a billion people in the world suffer from at least one form of disability and this rate is

Table 1
Administrative data category for minimum data set for disability.

Data sections	Number of data elements	First round of Delphi			second round of Delphi			Final number of data elements
		<50%	50–75%	>75%	<50%	50–75%	>75%	
Demographic	18	0	0	18	0	0	0	18
Provider ID	6	0	2	4	0	0	2	6
Socioeconomic	45	0	3	42	0	0	3	45
Patient encounter	16	0	2	14	1	0	1	15
Facility identifier	14	0	3	11	0	0	3	14
Data registrar	7	0	0	7	0	0	0	7
Financial	17	0	1	16	0	0	1	17
Supportive services	10	2	1	7	0	0	1	8
Total	133	2	12	119	1	0	11	130

Table 2
Clinical data category for minimum data set for disability.

Data sections	Number of data elements	First round of Delphi			second round of Delphi			Final number of data elements
		<50%	50–75%	>75%	<50%	50–75%	>75%	
Patient CC	14	0	3	11	0	0	3	14
Personal medical history	51	0	2	49	0	0	2	51
Family history	8	0	0	8	0	0	0	8
Review of system	118	0	5	113	2	0	3	116
Environmental factors	15	0	4	11	0	0	4	15
Diagnosis and disability determination	45	0	6	39	3	0	3	42
Procedures	79	0	10	69	5	0	5	74
Follow up	8	0	0	8	0	0	0	8
Discharge condition	7	0	2	5	0	0	2	7
Death	10	0	4	6	0	0	4	10
Total	355	0	36	319	10	0	26	345

Table 3
Administrative data elements for a minimum data set for disability.

Section name	Data elements
Demographic	<p>Mandatory Patient medical record number- National identity number- Patient name- Patient surname- Sex- Date of birth- Father name- Family languages- Family Second Language- Name of the representative or guardian of the disabled person- Last name of representative or guardian</p> <p>Optional Admission serial number- Pseudonym- Patient ID number- ID Issue Place- Patient blood type- National identity number of the representative or guardian- Patient middle name</p>
Socioeconomic	<p>Mandatory Patient ethnicity- Patient nationality- Source of patient income- Average monthly income of the patient's family- Patient job- Householder job- Family supporting agencies- Living status (alone, ...)- Family Householder - Marital status- Number of children (if applicable)- Type of residence (urban, rural, ...)- Type of ownership of housing- Current Residence address- Residence Telephone-Religion- Educational degree- Code/record number in the support institution</p> <p>Optional Country of birth- Province of birth- City of birth- Language preference- Employment status (yes, no)- Starting date to work- Organization or company of work place- Work place address- Career (retired, working)- Patient role in the family- Number of family member- Spouse name- National identity number of children- Number of brother and sister- National identity number of brother and sister- Province Residence Address- City Residence Address- City name- District or metropolitan area- village name- Geographic coordinates of the place of residence- Date of residence- Cell phone- e-mail- Residence zip code- Educational status- Spouse national identity number</p>
Patient encounter	<p>Mandatory Date of admission or referral to the facility- Time of admission or referral to the facility- Previous medical record number- Name of institution or referral center- Name of referrer person/physician- Surname of referring person/physician- specialty of referring person- Informed consent</p> <p>Optional Previous referral history- Type of institution or referral center- Identification code of the referral institution or center- Identification code of the referring person- Address of referring person- Phone number of referring person or institution- Reason for referral or admission- Physical status at the time of admission</p>
Provider ID	<p>Mandatory Name of the service provider person- Family name of the service provider person- Identifier code of the service provider person</p> <p>Optional Family physician identification code- Specialty of the service provider- Role of the service provider</p>
Facility identifier	<p>Mandatory Facility Name- Identification code of the facility- Full facility address- Telephone of facility</p> <p>Optional Establishment identifier- Facility type (hospital, rehabilitation center ...)- Ownership of facility (public, private)- Institute's academic affiliation- Provincial facility location- City of facility location- Fax of facility- Facility zip code- Facility website- Geographical coordinates of the facility</p>
Data registrar	<p>Mandatory The name of the person who registered the data- Role of the person who registered the data- Identification code of the person who registered the data</p> <p>Optional The surname of the person who registered the data- Specialty of the person who registered the data- Registration date- Registration time</p>
Financial data	<p>Mandatory Primary insurer company- Insurance number- Primary insurance credit date- Supplemental insurance- Supplemental insurance credit date- Service code- Service cost- The patient sharing at the cost of health care services</p> <p>Optional Type of primary insurance- The source of payment of primary insurance premium- The identity of the payer- Service description- Service number- The primary insurance company sharing at the cost of health care services- The supplemental insurance sharing at the cost of health care services province of insurance issuance- The identity of the payer for supplemental insurance</p>
Supportive services	<p>Mandatory Individual eligibility for receive support services- Included in receiving welfare services- Type of supportive service- Amount of pension received from welfare- The identity of the other supporting facilities</p> <p>Optional Start date of support services- End date of support services- Pensioner of the Welfare Organization (Yes, No)- Code of supportive service- Other supporting organizations (Yes, No)</p>

increasing because of population aging and rises in chronic health conditions.²⁷ According to the United Nations reports in 2015, the prevalence of disability in the Iranian population is estimated at 1.5% (1.9% in males versus 1.1% in females), and physical disorders (48.3%), mental disorders (25.8%), voice and speech disorders (10.1%), blindness (7.9%), and deafness (7.9%) are the most common types of disability in the Iranian population.²⁸ Furthermore, Moradi et al.²⁹ reported that 1.4% of the Iranian people have at least one type of disability.

Lack of disability data, especially in developing countries, is the most common obstacle to policymaking and development of programs for disability management based on evidence-based, accurate, and reliable data,^{30,31} while high quality data of the people

with disabilities has a crucial role in policymaking and providing comprehensive health care services.^{5,9} Quality data plays a key role in decision-making and planning in health information systems and poor data increase medical errors and decrease the efficiency of health care services. Similar to previous studies^{13–15,32–36} the MDS of disability was divided into administrative and clinical categories with eight and ten sections, respectively.

Administrative data include patient demographics as well as healthcare provider and insurance data. Thus, this category of data could be used to determine healthcare costs, disability benefits and insurance claims. Collecting quality clinical data for health care institutions is crucial to evaluating the quality of care, improving its associated standards, and making correct diagnosis

Table 4

Clinical data elements for a minimum data set for disability.

Section name	Data elements
Patient CC	<p>Mandatory The source of clinical information -Chief Complaint of patient/referral -The patient's chief complaint code based on ICD-Starting date of chief complaints-Disability from the current condition/disease-Comorbidities and complications</p> <p>Optional Current condition/disease sign-Cause of current condition/disease sign- Current condition/disease progress-History of current condition/disease recurrence- Response to treatment of current condition/disease -The site or sites involved in the current condition/disease- The severity of the disability resulting from the current condition/disease- Effect of Comorbidities and complications on the current condition/disease</p>
Personal medical history	<p>Mandatory Alcohol consumption/addiction- Opium abuse/addiction- Type of opium- Cigarette consumption/addiction- Daily cigarette consumption- The name of the medications used- Name of the allergic substance or drug- Description of specific nutritional habits- Perinatal period disease history- Childhood disease history- Infectious and parasitic disease history- Cancer history- Metabolic disease history- Endocrine disease history- Mental disease history- Suicide history- Eye disease history- Ear disease history- Nervous system disease history- Circulatory system disease history- Respiratory system disease history- Congenital abnormalities history- Kidney disease history Blood and blood forming tissue disease history- Musculoskeletal disease history- Description of accidents and poisonings - Description of history of therapeutic procedure- Organ transplantation history- - Description of rehabilitation procedure history- Home care history- Surgical procedure history</p> <p>Optional The code of the medications used- The dosage of the medications used- Allergy (yes, no)- Special food habits (yes, no)- The age of the first menstruation begins- Contraceptive method- Previous gravida number - Number of previous pregnancies- Number of previous deliveries- Number of previous abortions - Sterilization - Age of menopause- Accidents and poisoning history (yes, no)- History of therapeutic procedure (yes, no)- Hospitalization history - Rehabilitation procedure history (yes, no)- The length of the rehabilitation course- Prosthesis and technical orthopedic services history- The type of surgical procedure performed- The organ or site of the surgery</p>
Family history	<p>Mandatory Family history of disability description- Family history of congenital or genetically diseases- Family history of progressive neurodegenerative disorders- Family history of mental disease</p> <p>Optional History of drug use and maternal addiction during pregnancy- History of disease and maternal injury during pregnancy- Family history of other diseases- Type of disability in family</p>
Review of systems (ROS)	<p>Mandatory Height and weight- BMI- Type of disability of individual- Description of the reviewed mental function (consciousness, orientation, intellectual, sleep, ...)- Description of the reviewed sensory and pain function (seeing, hearing, pain, ...)- Description of the reviewed voice and speech function (voice, speech, articulation, ...)- Description of the reviewed cardiovascular system function (function of heart, blood vessel, blood pressure, ...)- Description of the reviewed cardiovascular system function (function of heart, blood vessel, blood pressure, ...)- Description of the reviewed hematological and immunological system function (hematological, immunological, ...)- Description of the reviewed respiratory system function (respiration, respiratory muscle, ...)- Description of the reviewed digestive system function (ingestion, digestive, defecation, ...)- Description of the reviewed metabolic and endocrine systems function (general metabolism, water, mineral and electrolyte balance, endocrine gland, ...)- Description of the reviewed genitourinary system function (urinary excretory, urination, sensation related to urinary, ...)- Description of the reviewed reproductive system function (sexual, menstruation, procreation, ...)- Description of the reviewed neuro musculoskeletal and movement-related function (muscle, movement, ...)- Description of the reviewed skin and related structure function (skin, hair and nail, ...)- Description of the examined structure of the nervous system (brain, spinal cord, meninges, ...)- Description of the examined structure of eye and related adnexa (eye socket, eyeball, ...)- Description of the examined structure of ear and adnexa (inner ear, middle ear, ...)- Description of the examined structures involved in voice and speech (nose, mouth, pharynx, larynx, ...)- Description of the examined structures of the cardiovascular system (heart, arteries, veins, ...)- Description of the examined structures of the immunological system (lymphatic vessel, spleen, thymus, bone marrow ...)- Description of the examined respiratory system structure (nose, mouth, pharynx, larynx, ...)- Description of the examined structures of the digestive, metabolic and endocrine systems (salivary gland, esophagus, intestine, pancreas, liver, endocrine glands ...)- Description of the examined structures of the genitourinary system (kidney, ureters, urethra, urinary bladder gland, esophagus, intestine, pancreas, liver, endocrine glands ...)- Description of the examined structures of the reproductive system (ovaries, uterus, nipple, vagina, scrotum, penis, ...)- Description of the examined structures related to movement (head and neck, shoulder, pelvic, trunk, upper and lower extremity, ...)- Description of the examined structures related to skin and related tissue (skin, skin glands, nail, hair, ...)- Description of the learning and applying knowledge (including: reading, writing, thinking ...)- Description of the mobility status (including: Changing basic body position, maintaining a body position, transferring oneself, walking, moving around in different locations, and using transportation)- Description of the individual self-care level (including: Washing oneself, toileting, dressing, eating, and drinking, ...)- Description of the individual self-care level (including: Washing oneself, toileting, dressing, eating, and drinking)- Description of the domestic life status (including: Acquisition of goods and services; shopping, preparing meals, doing housework, and Washing and drying clothes and garments, ...) Description of the interpersonal interactions and relationships status (including: general interpersonal interactions, particular interpersonal interactions, ...)- Description of the major life areas (including: education, basic economics transactions, and so on)</p> <p>Optional The dominant hand of patient- Assessment of mental functions status review (yes, no)- The test or method used to assess mental function- The test result of the mental assessment- Corresponding ICF- Assessment of sensory function and pain status review (yes, no)- The test or method used to assess sensory and pain function The test result of sensory and pain assessment- Corresponding ICF code- Assessment of voice and speech function (yes, no)- The test or method used to assess voice and speech function- The test result of the voice and speech assessment- Corresponding ICF code- Assessment of functions of the cardiovascular, hematological, immunological and respiratory system (yes, no)- The test or method used to assess cardiovascular system function- The test result of the cardiovascular system function assessment- Corresponding ICF code- The test or method used to assess hematological and immunological system function- The test result of hematological and immunological system function assessment- Corresponding ICF code- The test or method used to assess respiratory system function- The test result of the respiratory system function assessment- Corresponding ICF code- Assessment of functions of the digestive systems (yes, no)- The test or method used to assess digestive system function- The test result of the digestive system function assessment- Corresponding ICF code- Assessment of functions of the metabolic and endocrine systems (yes, no)- The test or method used to assess metabolic and endocrine system function- The test result of the metabolic and endocrine system function assessment- Corresponding ICF code- Assessment of genitourinary functions (yes, no)- The test or method used to assess genitourinary system function- The test result of the genitourinary system function assessment- Corresponding ICF code- Assessment of reproductive functions (yes, no)- The test or method used to assess reproductive system function- The test result of reproductive system function assessment- Corresponding ICF code- Assessment of neuro</p>

(continued on next page)

Table 4 (continued)

Section name	Data elements
	<p>musculoskeletal and movement-related functions (yes, no)- The test or method used to assess reviewed neuro musculoskeletal and movement-related function- he test result of neuro musculoskeletal and movement-related function assessment- Corresponding ICF code- Assessment of skin and related structure functions (yes, no)- The test or method used to assess skin and related structure function- The test result of skin and related structure function assessment- Corresponding ICF code- Review of structure of the nervous system (yes, no)- Corresponding ICF code- Assessment of the eye, ear and related structure (yes, no)- Corresponding ICF code- Corresponding ICF code for structure of the eye- Assessment of structures involved in voice and speech (yes, no)- Corresponding ICF code- cardiovascular, hematological, immunological and respiratory system (yes, no)- Corresponding ICF code for cardiovascular system- Corresponding ICF code for hematological and immunological system- Corresponding ICF code for respiratory system- Assessment structure related to the digestive, metabolic and endocrine systems (yes, no)- Corresponding ICF code- Assessment of structures related to the genitourinary and reproductive systems (yes, no)- Corresponding ICF code for genitourinary system- Corresponding ICF code for reproductive system- Structure related to movement assessment (yes, no)- Corresponding ICF code - Skin and related structure assessment (yes, no)- Corresponding ICF code- Review of learning and applying knowledge status- Corresponding ICF code- Review of mobility status (yes, no)- Corresponding ICF code- Review of self-care level (yes, no)- Corresponding ICF code- Review of self-care level (yes, no)- Corresponding ICF code- Review of domestic life status (yes, no)- Corresponding ICF code- Review of interpersonal interactions and relationships status (yes, no)- Corresponding ICF code</p> <p>Review of major life areas status (yes, no)- Corresponding ICF code</p>
Environmental factors	<p>Mandatory Description of product or technology facilitator and barrier (including products and technology for daily living, education, communication, ...)- changes to environment facilitator and barrier (including physical geography, climate, natural events, light, sound, ...)- description of the support and relationship facilitator or barrier (including immediate and extended family, friends, peers, subordinators, health professions, ...)- description of facilitator or barrier attitudes that influence individual action (including attitudes of immediate and extended family, friends, peers, subordinators, health professions, social norms, ...)- description of services, systems, and policies facilitator or barrier (including the production consumer goods, housing, utilities, communication, transportation, civil protection, and ... services, systems and policies).</p> <p>Optional Review of products and technology facilitators or barriers (yes, no)- ICF code for products and technology facilitators and barriers- Review of natural environment and human-made changes to environment facilitators and barriers (yes, no)- ICF code for natural and human-made environmental changes facilitators and barriers- Review of support and relationships (yes, no)- ICF code for support and relationship facilitators and barriers- Review of attitudes (yes, no)- ICF code for attitude facilitators and barriers- Review of services, systems, and policies (yes, no)- ICF code for services, systems, and policies facilitators and barriers</p>
Diagnosis and disability determination	<p>Mandatory Mental disability description- Mental disability code by ICD-10- Underlying cause of mental disability</p> <p>Disability severity- Body Functions code by ICF- Body Structures code by ICF- Activity and Participation code by ICF- Visual disability description- Underlying cause of visual disability- Underlying cause of visual disability code based on ICD-10- Visual disability severity based on visual acuity- Visual disability severity based on visual field- Body Functions code by ICF- Body Structures code by ICF- Activity and Participation code by ICF- Underlying cause of voice, speech and language disability - Underlying cause of voice, speech and language disability code based on ICD-10- Voice, speech and language disability severity- Body Functions code by ICF- Body Structures code by ICF- Activity and Participation code by ICF- functional and motion disability description- Underlying cause of functional and motion disability- Underlying cause of functional and motion disability code based on ICD-10-functional and motion disability severity- Body Functions code by ICF- Body Structures code by ICF- Activity and Participation code by ICF- Other disability (yes, no)- Description of other disability- ICD-10 codes for other disability- ICF codes for other disability- Description of diagnosis</p> <p>Diagnosis code based on ICD-10-Environmental facilitators for person with disability (including: product and technology; natural and human-made environments; support and relationships; attitudes; services, systems, and policies)-ICF code/codes for environmental facilitators- Environmental barriers for person with disability- ICF code/codes for environmental barriers- Extent of environmental barrier or facilitator</p> <p>Optional Mental disability (yes, no)- Visual disability (yes, no)- Voice, speech and language disability (yes, no) functional and motion disability (yes, no)- Type of diagnosis (admission, interim, principle, and other),</p>
Procedures	<p>Mandatory Physician order group- Physician order description- Nursing observation and assessment- Controlling and verifying orders by the nurse- Nursing intervention and procedures- Consultation type- Consult ordering physician- Consult referring physician- Comments, diagnosis and advice of referring physician- Rehabilitation service name- Instructions for exercises at home- Short-term rehabilitation services goal-Long-term rehabilitation services goals - Patient response to rehabilitation treatment- Patient response to educational rehabilitation- Prosthesis name- Prosthesis code or serial number- Anatomical site of prosthesis- Prescribed drug names- Drug code or Serial number- Drug formulations (tablet, syrup, ...)- Drug dosage- Starting date of drug consumption- Ending date of drug consumption- Adverse drug reaction (If applicable)- Requested laboratory test/tests- Type of test request (emergency or elective)</p> <p>Laboratory test results- Pathology reports- Limb' name for medical imaging- Medical imaging technique-Type of request (emergency or elective)- Radiologist diagnosis report- Type of anesthesia (local, ...)- Anesthesia risk level- Date and time of anesthesia- Start of anesthesia- End of anesthesia- Description of operational procedure- Operational procedure code by ICD-9- CM- Start of operation- End of operation- Diagnosis after operational procedure</p> <p>Optional Type of order (admission, consultation, therapeutic, ...)- Physician/ordering identification code- Order time- Order date- Checking and applying physician orders by nurses (yes, no)- Description of intervention and procedure type- Date of Nursing intervention and procedures- Time of Nursing intervention and procedures- Rehabilitation service group- Rehabilitation services code- Schedule of rehabilitation treatment plan- Functional level of the patient before rehabilitation- The reason for changing the therapeutic goals (if necessary)- Prosthesis number- Prosthesis request date- Drug prescription date- Drug consumption plan- Date and time of request of tests- Test code or serial number-Date of medical imaging- Radiologist authentication- Date of medical imaging - Time of medical imaging- Medical imaging code- Special care during anesthesia- Patient status at the beginning of anesthesia- Patient vital sign during anesthesia- Patient vital sign at the end of anesthesia- Date of operation- Time of operation- Operational team authentication</p>
Discharge condition	<p>Mandatory Discharge date- Discharge time- Discharge status (Home, other facility, Rehabilitation services, Expired, Left against medical advices, ...)- Medication and educational instructions at discharge</p> <p>Optional Length of stay in hospital or other facility -Post discharge advice-Places to visit follow up</p>
Follow up	<p>Mandatory Type of Rehabilitation- Requested Rehabilitation- Type of follow-up order (therapeutic, rehabilitation, ...)- Follow up outcome</p> <p>Optional Number of rehabilitation sessions- Description of the follow up order- Follow up date- Facility or center for follow up</p>
Death	<p>Mandatory Date of death- Time of death- Place of death (facility, ...)- Direct cause of death- Code of direct cause of death by ICD-10- Intermediate cause of death- Underlying cause of death - Code of underlying cause of death by ICD-10- Autopsy (yes, no)</p> <p>Optional Code of intermediate cause of death by ICD-10</p>

and treatment decisions. The patient's chief complaint data identify the necessity and level of patient's needs for diagnostic and therapeutic services. Appropriate and effective clinical decision-making depends on the availability of the patient's medical history. Follow-up data, as a category of clinical data, are necessary for determining the effectiveness of the therapeutic and operational procedure outcomes. Death data enable death reporting at national and international levels. The MDS realizes these factors through data standardization and improvement of complete and consistent data collection.

By relying on the definition of the WHO for disability,⁷ we tried to address the components of disability (body functions and structures, activities, participation, and environmental factors) in the designed MDS. Thus, the designed MDS can help to clarify and harmonize the concept of disability and to collect accurate and comprehensive data of the persons with disabilities for use in planning, policy-making and provision of health care services to these people. Although the MDS allows disability data comparisons at different levels through standardizing data and improving data quality (completeness, consistency and accuracy), the designed MDS may not cover all specific needs of all centers related to disability given the nature of the MDS, which is a minimum data set of essential data in a specific field.

So far, several minimum data sets have been developed in Iran in the fields of burn injuries,¹³ orthopedic injuries,³² traffic accidents,³⁷ breast cancer,³⁸ thalassemia,³⁹ schizophrenia,⁴⁰ multiple sclerosis,^{41,42} speech therapy,⁴³ and diabetes mellitus.⁴⁴ Some of these data sets share some general data elements with the disability MDS and most of them are similar in categorizing data elements into administrative and clinical data. Because of the primary users of the disability information systems (disability benefit payers) and its application (determination of disability and benefits), these systems need to have comprehensive data elements in the fields not covered by previous data sets.

Although the developed MDS for disability is rather similar to most previous minimum data sets in some sections such as demographic, provider ID, financial, discharge, and death data elements, it contains specific data elements that could provide comprehensive data elements required by disability information systems and can be useful in meeting the needs of the disability data users. Lack of involving of patients with disability as one the main beneficiaries of the MDS was a limitation of the present study, as considering the opinions of people with disability in the MDS could further improve the MDS comprehensiveness and quality.

Conclusions

This study showed lack of comprehensive and uniform data elements of disability in Iran. Therefore, a MDS was developed for disability in Iran as a starting point for standardizing the disability data and developing an EDR. A minimum data set has the potential to standardize the data and overcome the problem of low-quality disability data in Iran through providing consistent, complete and uniform data elements. Thus, this MDS is useful in determining of disability and benefits and in policy-making and effective planning for providing persons with disability with more efficient and cost-effective services.

Funding

This study was supported by Grant No. IUMS/SHMIS_1395/9311304009 from Vice Chancellor for Research and Technology of Iran University of Medical Sciences.

Competing interests

The authors declare that they have no competing interests.

Acknowledgments

The authors wish to thank the Vice Chancellor for Research and Technology of Iran University of Medical Sciences for supporting the project.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2019.05.008>.

References

- World Health Organization, World Bank Group. *World Report on Disability*. Malta: WHO Press; 2011.
- WHO & World Bank. *World Report on Disability*. World Health Organization and The World Bank; 2011.
- Noorbala AA, Faghihzadeh S, Kamali K, et al. Mental health survey of the Iranian adult population in 2015. *Arch Iran Med*. 2017;20(3):128–134. doi: 0172003/AIM.003.
- Mitra S, Posarac A, Vick B. Disability and poverty in developing countries: a multidimensional study. *World Dev*. 2013;41:1–18. <https://doi.org/10.1016/j.worlddev.2012.05.024>.
- Soltani S, Hafshejani AM, Salehiniya H. Trend of disability prevalence in Iran: an evidence to improve disability data. *J Res Med Sci*. 2015;20(5):531–532.
- Soltani S, Khosravi B, Salehiniya H. Prevalence of disability in Iran. *Iran J Public Health*. 2015;44(10):1436–1437.
- World Health Organization (WHO). Disabilities [internet] [cited 2019 Jan 30]. Available from: <https://www.who.int/topics/disabilities/en/>; 2019.
- Alipour J, Zarei A, Saravani-aval S, Mehdipour Y. Health information technology acceptance factors by caregivers in nursing home facilities in Iran. *Int J Adv Biotechnol Res*. 2017;8(Special Issue 1):75–81.
- Halbesleben JR, Whitman MV. Evaluating survey quality in health services research: a decision framework for assessing nonresponse bias. *Health Serv Res*. 2013;48(3):913–930. <https://doi.org/10.1111/1475-6773.12002>.
- Bachani AM, Galiwango E, Kadobera D, et al. A new screening instrument for disability in low-income and middle-income settings: application at the Iganga-Mayuge Demographic Surveillance System (IM-DSS), Uganda. *BMJ open*. 2014;4(12), e005795. <https://doi.org/10.1136/bmjopen-2014-005795>.
- Davey CJ, Slade SV, Shickle D. A proposed minimum data set for international primary care optometry: a modified Delphi study. *Ophthalmic Physiol Optic*. 2017;37(4):428–439. <https://doi.org/10.1111/opo.12372>.
- Ajami S, Maghsodlora AA. National cerebral palsy minimum data set. *J Res Med Sci*. 2015;20(4):321–322.
- Ahmadi M, Alipour J, Mohammadi A, Khorami F. Development a minimum data set of the information management system for burns. *Burns*. 2015;41(5): 1092–1099. <https://doi.org/10.1016/j.burns.2014.12.009>.
- Wager KA, Lee FW, Glaser JP. *Health Care Information Systems: A Practical Approach for Health Care Management*. third ed. USA: John Wiley & Sons; 2013.
- Abdelhak M, Grostick S, Hanken MA. *Health Information: Management of a Strategic Resource*. fourth ed. Saunders WB Co; 2012.
- World Health Organization. *Human Resources for Health Information System: Minimum Data Set for Health Workforce Registry*. Geneva, Switzerland: WHO; 2015.
- Kowal PR, Wolfson LJ, Dowd JE. Creating a minimum data set on ageing in sub-Saharan Africa. *southern African journal of Gerontology*. 2000;9(2):18–23. <https://doi.org/10.21504/sajg.v9i2.203>.
- Ajami S, Lamoochi P. Comparative study on national burn registry in America, england, Australia and Iran. *J Educ Health Promot*. 2014;3:106–111. <https://doi.org/10.4103/2277-9531.145892>. November.
- Alipour J, Ahmadi M, Mohammadi A. The need for development a national minimum data set of the information management system for burns in Iran. *Burns*. 2016;42(3):710. <https://doi.org/10.1016/j.burns.2015.03.018>.
- Cappa C, Petrowski N, Njelesani J. Navigating the landscape of child disability measurement: a review of available data collection instruments. *ALTER, European Journal of Disability Research*. 2015;9(4):317–330. <https://doi.org/10.1016/j.alter.2015.08.001>.
- Cai S, Mukamel DB, Veazie P, Temkin-Greener H. Validation of the minimum data set in identifying hospitalization events and payment source. *J Am Med Dir Assoc*. 2011 Jan;12(1):38–43. <https://doi.org/10.1016/j.jamda.2010.02.001>. Epub 2010 Aug 7.
- Hawes CH, Morris JN, Phillips CD, Fries BE, Murphy K, Mor V. Development of the nursing home resident assessment instrument in the USA. *Age Ageing*. 1997;26(suppl 2):19–25. https://doi.org/10.1093/ageing/26.suppl_2.19.
- Bauer JM, Sieber CC. Significance and diagnosis of malnutrition in the elderly. *Z Arztl Fortbild Qualitatssich*. 2007;101(9):605–609. PMID: 18269051 [PubMed]

- indexed for MEDLINE].
24. Tulu B, Horan TA. The electronic disability record: purpose, parameters, and model use case. *J Am Med Inform Assoc*. 2009;16(1):7–13. <https://doi.org/10.1197/jamia.M2405>.
 25. Feldman SS, Horan TA, Al-Buhairan F, Lytle-Kosola N, Tulu B. Information systems for disability determination: a multi-stakeholder assessment of electronic medical evidence needs and processes. *Commun Assoc Inf Syst*. 2011;29:325–344. <https://doi.org/10.17705/1CAIS.02918>.
 26. Soltani S. Hidden cost of disability: what policy makers usually forget. *J Res Med Sci*. 2018;20(23):15. https://doi.org/10.4103/jrms.JRMS_760_17.
 27. World Health Organization. Disability and health [internet] [updated 2018 January 16 cited 2018 June 13]. Available from: <http://www.who.int/news-room/fact-sheets/detail/disability-and-health>; 2018.
 28. United Nations. Disability at a glance 2015: strengthening employment prospects for persons with disabilities. In: *Asia and the Pacific. Bangkok, Thailand: Economic and Social Commission for Asia and the Pacific. ESCAP*; 2016, 186 pp.
 29. Moradi G, Mostafavi F, Hajizadeh M, et al. Socioeconomic inequalities in different types of disabilities in Iran. *Iran J Public Health*. 2018;47(3):427–434.
 30. Nidhi S, Rabaa M. *Disability Data for Effective Policy Design: Reflections from the TEACH Project in Pakistan* [Internet]. Washington Group on Disability Statistics; 2018 [updated 2018 February 26; cited 2018 June 13]. Available from: <http://www.washingtongroup-disability.com/disability-data-effective-policy-design-reflections-teach-project-pakistan/>.
 31. United Nations. Improvement of disability data and statistics: objectives and challenges. In: *Conference of States Parties to the Convention on the Rights of Persons with Disabilities*. 2015:1–8. June 9–11 New York 2015.
 32. Ahmadi M, Mohammadi A, Chraghbaigi R, Fathi T, Baghini MS. Developing a minimum data set of the information management system for orthopedic injuries in Iran. *Iran Red Crescent Med J*. 2014;16(7), e17020. <https://doi.org/10.5812/ircmj.17020>.
 33. Davis NA, LaCour M. *Foundations of Health Information Management-E-Book*. Elsevier Health Sciences; 2016.
 34. Carter J, Evans J, Tuttle M, et al. *Making the "Minimum Data Set" Compliant with Health Information Technology Standards*. Executive Summary US Department of Health and Human Services; 2006.
 35. Sadoughi F, Safdari R, Meraji M, Ramzan Ghorbani N, Ghazisaeedi M. Designing a minimum data set for national cancer registry in Iran. *Journal of Urmia Nursing And Midwifery Faculty*. 2013;11(8):622–629 ([In persian]).
 36. Ahmadi M, Rafii F, Habibi Koolaee M, Mirkarimi A. A comparison of data elements of nursing minimum data set. *Iran J Nat Resour*. 2012;7(24):45–52 ([In Persian]).
 37. Mohammadi A, Ahmadi M, Gharagozlu A. Developing a minimum data set for an information management system to study traffic accidents in Iran. *Iran Red Crescent Med J*. 2016;18(3):e23677. <https://doi.org/10.5812/ircmj.23677>.
 38. Ghaneie M, Rezaie A, Ghorbani N, Heidari R, Arjomandi M, Zare M. Designing a minimum data set for breast cancer: a starting point for breast cancer registration in Iran. *Iran J Public Health*. 2013;42(Supple1):66–73.
 39. Moeil Tabaghdehi K, Ghazisaeedi M, Shahmoradi L, Karami H, Bashiri A. Designing a minimum data set for major thalassemia patients: towards electronic personal health record. *Journal of Community Health Research*. 2018;7(1): 24–31.
 40. Khodae MR. Minimum data set for electronic health card of schizophrenia. *Ann Med Health Sci Res*. 2015;13(2):67–71 ([in persian]).
 41. Golchehreh A. *Development of Minimum Data Set of Multiple Sclerosis Department of Medical Record* [MSc Thesis]. Isfahan: Isfahan university of medical sciences; 2013 ([in persian]).
 42. Ahmadi G, Ajami S, Saghaeian-Nejad Isfahani S, Etemadifar M. Multiple sclerosis minimum data set. *Acta HealthMedica*. 2017;2(2):183. <https://doi.org/10.19082/ah183>.
 43. Damanabi S, Abdolnejad S, Karimi G. Suggested minimum data set for speech therapy centers affiliated to tabriz university of medical Sciences. *Acta Inf Med*. 2015;23(4):243–247. <https://doi.org/10.5455/aim.2015.23.243-247>.
 44. Hosseini A, Moghaddasi H, Jahanbakhsh M. Designing minimum data sets of diabetes mellitus: basis of effectiveness indicators of diabetes management. *Health Inf Manag*. 2010;7(3):330–340 ([In Persian]).