

Mental Health Minimum Dataset: A systematic review and search

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Abstract

Aim and Background: Mental health is one of the most important issues of human life, but the mental disorder rate increases every day. The proper management and care taking decision-makings in this area require a minimum dataset. This study aimed to create a mental health minimum dataset.

Materials and Methods: This was a systematic review and search. Using databases including OVID, Science Direct, Scopus, WOS, and PubMed and Google Scholar search engine, the terms which were related to mental health minimum data were searched. Applying inclusion and exclusion criteria, the resources were selected and examined. Finally, the mental health minimum data elements were determined based on results of literature review.

Results: In total, 29 studies which were conducted in 2000-2016 were included. Most of them were conducted in Australia, America, Canada, England, Malaysia, and New Zealand from 2010 onwards. The data elements which were extracted from sources were classified into two general categories: management data and clinical data. The management data including identifying information admission (22 data elements), demographics / history (19 data elements), and discharge information (12 data elements) and clinical data including SERVICE EVENT DATA (46 data elements) and patient assessment (8 data elements) had the highest and lowest number of data elements, respectively. Finally, the unnecessary data elements which were named Supporting data elements (12 data elements) were added. Among

the management data elements, the Unique Identifier Number in identifying information admission section and Gender and Date of Birth in demographic data section had the highest frequency among resources.

Conclusion: The mental health minimum dataset which is essential to collect and record is a critical prerequisite to create and use electronic health records, registration systems, and information systems. It also provides the same perception for concepts and data elements and covers all mental health information to be used for clinical and managerial decision-making at macro and organization levels. Due to lack of its comprehensive form, this study conducted a literature review to design a mental health minimum dataset.

Key words: Mental Health, Minimum Dataset, Systematic Review, Search

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Introduction

The health of the population is the most important issue in all countries and should be considered from physical, mental, and social dimensions. The mental disorders are serious and common health problems which constitute nearly 20 percent of visitors of public health centers in the world. The lack of understanding of mental illnesses, lack of timely treatment, and inadequate knowledge of prevention methods have led to increased rate of mental illnesses (1, 2).

Today, mental health is important due to its direct relationship with body, individual and social performance, and psycho-social damage. Mental health is essential for living a healthy life. According to World Health Organization, 33% of total diseases (years lived with disability) are nervous-mental diseases. It is predicted that by 2020, mental illnesses will have quickly increased. The evidence shows a projected 15 percent increase in these diseases. However, up to 90 percent of patients in developing countries do not receive proper treatment (3, 4).

The access to right and high quality information, correct and timely diagnosis and identifying people with mental illness may prevent its progress and decrease the social and economic effects of mental health problems and the high costs of diagnosis and treatment. So, it is crucial to have information for management and care-taking decision-making. The scattered information may lead to wrong decision-making in this field (3, 5).

Mental health care is provided by doctors and experts at health centers. The doctors and other health care service providers may record data elements and compare, combine, and interpret them (4, 5).

The quality of a case study in terms of research, scientific information, and statistical information depends on quality of its content which is recorded by documentarians. Therefore, the consistent and uniform documentation of health records is an important, legal, and professional requirement for all experts in the healthcare system, because the proper documentation with consistent data elements and variables facilitates the exchange of patient information for all team members and guarantees all care provided to patients (4-10).

However, the information which is collected from various sources and channels in various forms may be conflicting or incomparable. As a result, this scattered information may impact negatively on current and future care of patients and thus impose more costs to the health system (11-13). In this regard, the uniform collection of data and existence of a suitable and efficient system and tool are necessary to provide accurate and timely information and statistics for decision-making and policy-making of managers and users (8, 14). The minimum dataset (MDS) is a standard tool for collecting key data, understanding it, and comparing it; it also meets the government requirements,

internal needs of each institution, and the needs of the medical community. This dataset provides the variables of individuals' health status including demographic data, administrative data, clinical data, and patient care plan, allows proper communication between care providers, and facilitates timely decision making for managers (5, 15).

The latest statement of the Union Council of Europe emphasized on collecting and recording high quality data of mental health and actively sharing it among the members of the commission. It also noted that the information should be developed on problems, needs, and mental health services. Currently, about one-third of countries do not have an approved and standard tool and registry system for reporting mental health data and about half of the countries have no facilities to collect information on services and epidemiological data at national level. Therefore, it is an inevitable necessity to create an integrated tool for recording disease data such as that regarding mental illness (4, 11). The recording of office and computer files of all mental health cases for a defined population is the primary objective of a mental health minimum dataset; it records the individual characteristics of patients with mental health problems, features of provided care, and clinical characteristics. These data are collected continuously from different sources. Then, these data are interpreted and analyzed and retained in a center of mental health records to provide information about incidence of mental illness and time and geographical distribution of information. This information is considered as a primary source in epidemiological research to provide etiology hypotheses, treatment, control, and prevention evaluation, determining potential risk factors for mental disorders, and determining the effect of diseases. The record of mental health plays a main role in control and prevention of mental illness (5, 16-18).

In this regard, different countries such as the United States (1975) established a complex mental health statistical reporting system at national level. Consequently, a special advisory group, which consisted of federal and state employees, took the responsibility of establishing the first infrastructure of dataset (19). In New Zealand, also, the health care data of psychiatric patients who are admitted to hospital are considered as a part of national minimum dataset (20). In England, the mental health minimum dataset was published in 1999 and was considered as a framework for national service of mental health (21). In Malaysia, there is a national mental health registry system to collect, analyze, and distribute clinical and public health data, including mental health data (22). Also in Australia and Canada, some variables are considered as a mental health minimum dataset at national level (23, 24). However, there is no systematic review in this field. In this regard, this study aimed to determine the mental health minimum dataset.

Materials and Methods

This systematic search and review was undertaken in accordance with typology of reviews: an analysis of 14 review types and associated methodologies (2009 Health Libraries Group. Health Information and Libraries Journal, 26, pp.91-108) (25). It was conducted at four stages: identifying research questions, locating relevant studies, study selection, and charting the data and collating.

In the first stage, the determination of mental health minimum data was considered as the research objective and question.

In the second stage, using Google Scholar search engine, the sources were identified and restored using search terms which were related to mental health minimum data in databases including OVID, Science Direct, Scopus, WOS, and Pub Med. The inclusion criteria were: the articles should be related to objective of study and had been conducted between 2000 -2016. The exclusion criteria were: articles which were conducted in other years, language other than English, and lack of full- text.

Table 1: The Search Strategy of the Research

Search Engines and Databases: PubMed, ISI web of science, Scopus, Science Direct, Ovid, Google Scholar
Limits: Language (only resources with at least an abstract in English) Time (2000 to present)
Date: up to 2016,May, 20
Strategy: #1 AND #2 AND #3AND #4
#1 (Mental OR Psycho*). [TI].
#2 ("information system" OR "information systems" OR "data system" OR "data systems" OR "health system" OR "health systems" OR "Support System" OR "Support Systems" OR DSS OR regist*). [TI].
#3 data OR datum
#4 set OR element*

In the third stage, a total of 263 sources were selected and entered into resource management software (Mendely). The duplicates were eliminated and 145 articles were obtained. The study titles were investigated by two researchers and 117 titles which were related to the objectives of the study were selected. After investigating abstracts, 84 articles were selected. After examining full-text access, 69 sources were selected. Finally, examining content and text, 29 articles were selected for study.

Next, the selected resources were analyzed and interpreted. The main contents which were related to the research objective were classified as mental health minimum data elements. Then, the sections were classified into two general categories: management data and clinical data; these are used in valid sources for categorizing of health data (26).

Results

In total, 29 studies which were conducted between 2000-2016 were included. Most of them were conducted in Australia, America, Canada, England, Malaysia, and New Zealand from 2010 onwards. The data elements which were extracted from sources were classified into two general categories: management data and clinical data. The management data had 56 data elements including identifying information admission (22 data elements), demographics / history (19 data elements), and discharge information (12 data elements). Among the data elements, the Unique Identifier Number in section of Identifying information Admission (11 frequency), and Gender (15 frequency) and Date of Birth (17 frequency) in section of demographic data had the highest frequency. The elements including Residential Arrangement at Admission, Year of Arrival, Health district, Province or Territory of Registration, patient electoral ward, local patient identifier, data source, provider city, and the provider code in section of Identifying information Admission had one frequency. Also, the data elements including Occupation, Registration Inactive Status Reason, Health Service of Residency, history of mental illness, Family mental health history, and Current family relationship in section of Demographics / history had the lowest frequency. In the section of discharge information, the data elements including Referral to further care, Total psychiatric care days, Medications to Avoid, and Payment source had the lowest frequency.

The clinical data including SERVICE EVENT DATA (46 data elements) and patient assessment (8 data elements) had the highest and lowest number of data elements, respectively. Among the management data elements, the Unique Identifier Number in identifying information admission section and Gender and Date of Birth in demographic data section had the highest frequency among resources.

Finally, the unnecessary data elements which were named Supporting data elements (12 data elements) were added.

(See Figure 2 - page 368 onwards)

Discussion

As discussed, mental health is important due to its direct relationship with body, individual and social performance, and psycho-social damage. However, the mental health diseases are more prevalent than any other diseases in the world and it is predicted that this rate will increase. The review of studies showed that in most countries, there is no standard, comprehensive, and consistent registration system and tool for registration and management of mental health data in different centers, better and more accurate understanding of people with mental illness, and better management and care decision-making and planning for patients at central, national, and international levels (25). According to this study, only the countries such as Britain, Australia, Canada, and parts of America have designed and determined a mental health minimum data set

Figure 1: PRISMA Flow Diagram for the scoping review process

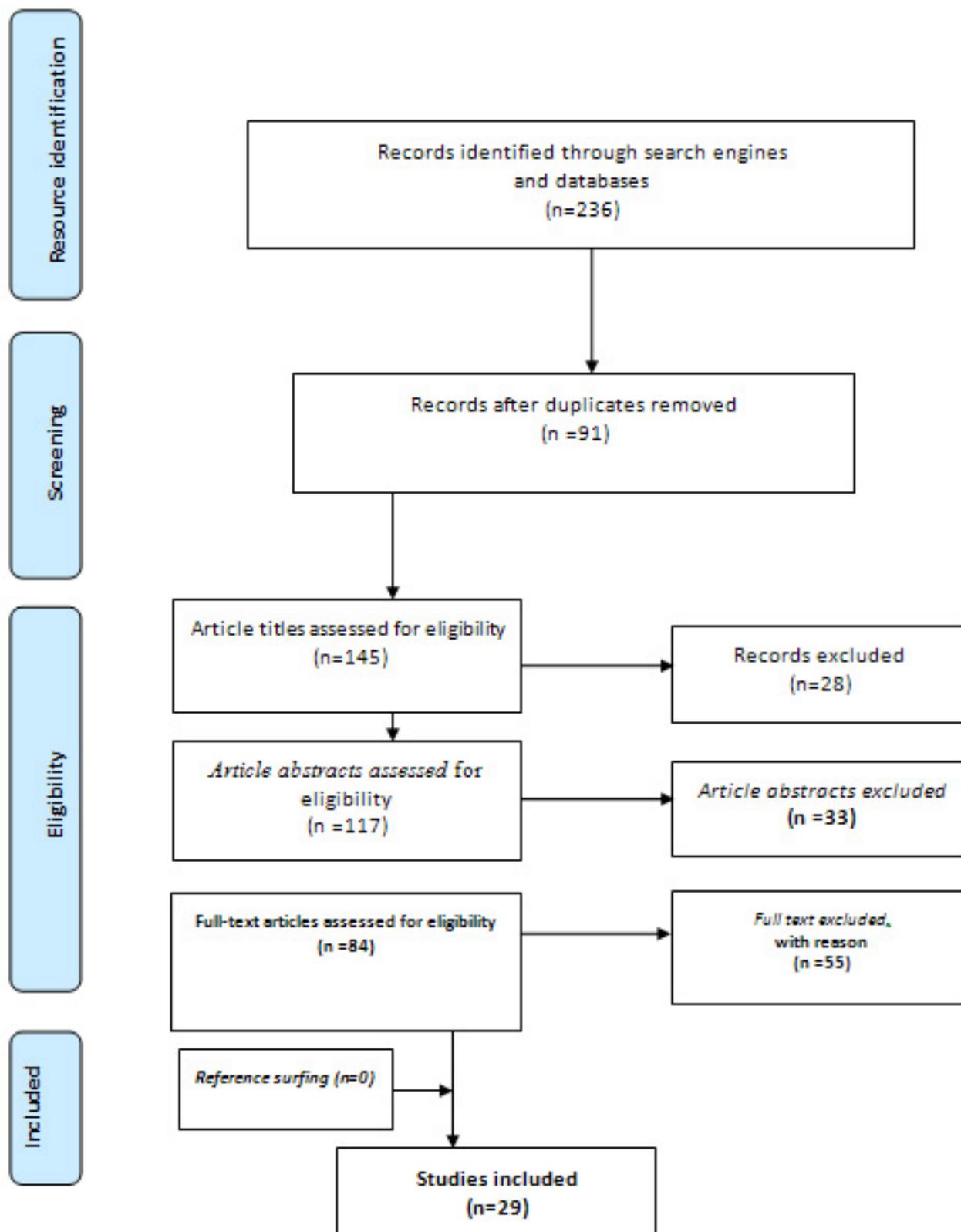


Table 2: Results of systematic review of scientific databases to determine minimum dataset (MDS)

Category	Section	Data element	Description	Reference No.	
Management data	Identifying information admission	Unique Identifier Number		(27-37)	
		Admission date		(29-32)	
		Admission method		(35, 37)	
		Residential Arrangement At Admission		(27, 28)	
		Address		(29, 35)	
		Telephone		(29, 33)	
		Health district		(29)	
		Care Episode Agency		(31)	
		Country of Birth	Country of birth of the client coded to National Standards	(27, 28, 30)	
		Year of Arrival	Year of Arrival to this country	(28)	
		Postcode	Postcode of residence	(27, 28, 38, 39)	
		Province or Territory of Registration		(28)	
		Suburb	Suburb of residence	(27, 40)	
		Area of usual residence		(27, 41)	
		Local patient identifier	This is usually a number that the local providers use against a patient or service user's record	(42, 43)	
		patient electoral ward		(39)	
		local patient identifier		(39)	
		organization code	Primary care Group	(39, 44)	
		provider code		(41)	
		provider city		(41)	
	Ethnic Group		(44, 45)		
	Source of data	Source of the mental health data	(27, 28, 45, 46)		
			Gender	Sex of client	(27-31, 47, 48)
			Name and last name		(44, 48-52)
			Date of Birth	Date of Birth of client: Birth month and year Year of birth	(27-33, 39, 47-51)
			Religion	Religious affiliation at admission	(29-46)
			Education Status	Level of education achieved at time of admission	(29, 38, 44, 49-51)
			Occupation	Occupation at time of admission (for example: Architect/Draftsmen/Surveyors/Professional Engineers')	(27)
			Employment status	Employment status at time of admission (for example: Student, 'Employed' 'Full Time Employment' 'Part Time Employment' 'Supporting Parent Pension' 'Unemployment Benefit')	(27, 30, 38, 44, 46, 49)
			Indigenous Status	Self-report measure as to whether a person identifies themselves as Aboriginal and/or Torres	(27, 30, 46)

		Registration Inactive Status Reason		(28)
		Age On Contact	Age of individual on date of contact	(28, 44, 52)
		Marital Status	Marital status at time of admission	(27, 30, 35, 38, 39, 44, 48, 51, 53)
		Health Service of Residency	Health Service of residency	(28)
		Living arrangements	such as owner, tenant, homeless	(29-31, 36, 38, 46, 53)
		Year of first mental health treatment		(28, 35, 39)
		History of mental illness	History of admission, family history of mental patient, history of substance abuse, a history of physical and sexual abuse	(38)
		Non-psychiatric disease history		(38)
		Family mental health history		(38)
		Legal History		(29, 31, 38, 39, 48, 51)
		Current family relationship.		(38)
	discharge information	Date of discharge Or Episode End Date	End date of episode also called discharge date	(29, 39, 43, 53)
		Discharge Type	1=Discharged – treatment complete 2=Discharged – against medical advice 3=Death 4=Transfer 5=Conditional LOA 9=Other	(29, 38)
		Referral to further care (psychiatric patients)		(30)
		Name of the professional responsible for discharge		(53)
		Total psychiatric care days		(30)
		Length of Stay (days)		(29, 30, 46)
		Continuity of care details(Pt Discharged for F/up to)	=PHC 03=01=Comm. MH Clinic 02Pte Sector Care 04=Life care 99=Other Please provide FULL contact details of where patient has been discharged to: Contact person: _____ _____ Organization Name: _____	(29, 30)

			_____ Address: Phone: _____ _____ Fax: _	
		Discharge Diagnosis (DSM-IV)		(29, 34)
		Medications to Avoid (e.g., Allergies, side-effects, failed treatments)		(29)
		Drug		(29, 34)
		Dose		(29, 34)
		Payment source		(29)
Clinical data	Patient assessment	Current symptom	Depressed mood, inability to enjoy the activities, reduced or increased sexual desire, inability to concentrate, insomnia or hypersomnia, attacks, anxiety, inability to concentrate, increase. High-risk behaviors, loss of appetite, feelings of guilt, increased irritability and hallucinations	(38, 53)
		evaluation of psychological states	The origin of disease, patient Talking, the impact of disease, thought process, thought content, intelligence and senses, Risk of harm to self, risk of harm to others, Legal conflict and violence experienced records, Hallucinations, delusions, obsessions and fears	(38, 54, 55)
		suicide risk assessment	Having thoughts of suicide, history of suicide or intentional self-injury, how self-injury, Last place that patient Has attempted to commit suicide, The reason for the suicide, patient factors that control this behavior	(38, 42)
		behavioral/emotional conditions	Anxiety states, depressive states, Disability / disappointment, guilty feel, worry, Concern for the body, Having a sense of hostility, Having a sense of mistrust, Social participation, Good mood, Concentrating, joy states, hyperactivity, Speech disorder, magnification modes, unusual ideas, States of hallucination moods.	(38, 55)
		drug abuse assessment	History of substance abuse treatment, diet therapy for drug abuse, review and evaluate the patient after the drug treatment program.	(38, 42)

	family safety/violence assessment	A sense of security in life, physical or sexual harm to other people, reason for the stress in life, The patient's emotional state, Activity in times of stress.	(38)
	Evaluation of the physical states	Nutrition, gastrointestinal evaluation, evaluation of the urinary system, Evaluation of the nervous system, skin assessment, evaluation of rest and sleep, blood pressure, body temperature and walking / active motion	(38, 42)
	Ability to function and daily activity	Rest and sleep, entertainment, the ability to self-care and communication skills	(38)
SERVICE EVENT DATA	Date Of First Contact	Date of contact with ambulatory service	(27, 51)
	The first year in which the patient is known to have received care from any specialist in mental health service		(31)
	Referral source		(29, 49, 51)
	Data of referral Or Episode Start Date	Start date of episode also called referral date	(27, 31, 51, 53)
	Referral Target		(51, 53)
	Date of first appointment		(31)
	Main Service Provided		(37)
	Main Specialty Code		(48)
	Mental Health Care Cluster		(48)
	Diagnosis related group		(30, 45)
	Major diagnostic category		(30, 46)
	Details of where the referral came from	(For example GP, etc).	(31)
	Types of ward the person stayed in		(31)
	Types of team the person has been in contact with	(for example, a community mental health team, crisis team or learning disability team)	(31, 39, 48, 53)
	Diagnoses	(for example, psychosis or depression)	(31, 33, 39)
	Periods of seclusion or restraint		(31)
	Use of the Mental Health Act	(Including leave and absence without leave).	(31)
	Clinical intervention		(30, 46)
	Clinical review		(30, 46)
	Elective surgery		(30, 46)
Hospital boarder		(30, 46)	
Hospital-in-the-home care		(30, 46)	
Intensive care unit		(30)	

Patient—previous specialized treatment, code N		(30)
Episode of acute care		(30)
Person—labor force status, acute hospital and private psychiatric hospital admission code N		(30)
Person—labour force status, public psychiatric hospital admission code N		(30)
Residential mental health care service		(30)
Primary Diagnosis Code	Last known primary diagnosis code for episode as at contact date	(27, 39, 48, 53)
Additional diagnosis		(30, 39, 53)
Principal diagnosis		(30, 39, 53)
Time of Contact	Time of day contact began (eg. 18:30:00)	(27)
Duration of Contact	Length of time for service event	(27)
Stream Type	Mental Health services grouped into Child & Adolescent, Adult, Seniors	(27)
Contact Type	Type of contact	(27)
Venue of Contact	Location where the contact occurred	(27)
Patient Present at Contact	Was the client present at the contact?	(27)
Medium of Contact	Medium in which the contact was delivered such as 1='FACE TO FACE' 2='BY PHONE' 3='BY VIDEOLINK' 4='NOT APPLICABLE'	(27)
Referral To	Referral to X at discharge	(27)
Referral From	Referral from X at admission	(27)
Mental health legal status		(30)
Mode of separation		(30)
Source of referral to public psychiatric hospital		(30)
Service contact date		(30)
Treatment type/plan	Drug therapy, psychotherapy with medication, electroconvulsive therapy, medical staff and in-depth psychotherapy.	(30, 38, 39, 45, 49, 55)
Treatment Outcome	Treatment completed, The average recovery, Brief improvement and Not treated., referred to another service, client did not attend, etc.	(27, 38)

Supporting data elements		
Supporting data elements	Acute care episode for admitted patients	(30)
	Episode of residential care end	(30)
	Episode of residential care	(30)
	Establishment number	(30)
	Establishment sector	(30)
	Region code	(30)
	Resident	(30)
	Residential mental health care service	(30)
	Specialized mental health care service	(30)
	State/Territory identifier	(30)
	Establishment number	(30)
	Establishment sector	(30)

(19, 21, 23, 24). Some other countries such as Malaysia have designed tools for recording the data of a specific disease and mental problems such as schizophrenia or depression (23); they also have collected a mental health dataset of specific groups such as drug addicts, children (47, 48), nurses (49), and nursing in homes (50). Other studies have more or less considered the design of a mental health minimum dataset with an emphasis on various topics. This indicates that there is no consistent and comprehensive design for a mental health minimum dataset which has considered all aspects and diseases of mental health in all health centers.

According to findings, most studies have focused on admission, Identifying information, Demographics / history, and discharge information. This indicates that most countries consider only admission and discharge information (management data) and less attention is paid to patient care data and patient services data. Also, less attention is paid to data elements which are related to evaluation of mood, thoughts, actions, and symptoms which are important in health care, mental health care, and patient health records to provide services and avoid duplication of tests and evaluations (38, 42, 53). These have been seen only in some studies; this may indicate that there is no comprehensive minimum data set which includes both management data and care data.

Among the studied sources, the topics which were related to data elements in the UK national system dataset were more than the topics which were found in other studies. The data elements of mental health minimum dataset in England's national registry system dataset were more comprehensive and better covered the information needs. Also, the data elements in the national minimum data set of Australia, Ontario, Canada (45), and Europe (46) were significant. Considering the outcome and systematic review of these resources, a mental health minimum data set was designed which tried to cover mental health data needs in clinical and management sections comprehensively.

Conclusion

The mental health minimum dataset which is essential to collect and record consistently the dataset is a critical prerequisite to create and use electronic health records, registration system, and information system. It also provides the same perception for concepts and data elements and covers all mental health

information to be used for clinical and managerial decision-making at macro and organization levels. Due to lack of its comprehensive form, this study conducted a literature review to design mental health minimum dataset.

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