



Research article

Developing a minimum data set required to create a registry system for patients with vitiligo

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HIGHLIGHTS

- Minimum data sets (MDSs) can be useful in establishing a patient registry, planning, policy-making, and improving the quality of patient care.
- The goal of the vitiligo MDS is to improve data comparability and compatibility by using standard data items that share the same definitions.
- Defining an MDS for a vitiligo registry system is an effective step towards improving information management for this disease.

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ABSTRACT

Background: Vitiligo can be psychologically devastating and stigmatizing, with significant impacts on patients. As such, the early treatment and understanding of the profound psychosocial impact of this skin disease cannot be overstated. A standardized method of data collection with consistent definitions is a prerequisite for vitiligo management. Against this background, this study aimed to develop a minimum data set (MDS) for the vitiligo registry system.

Materials and methods: The study was conducted in four steps in 2020 in Iran. After a comprehensive literature review to find relevant resources in English, medical records of patients with vitiligo were examined to assess the status quo of the country. Then, a model was developed from the data obtained in the previous step and through interviews. To reach a consensus on the data items, the Delphi technique was applied using a questionnaire, and the mean of expert judgments on each data item was calculated.

Results: A total of 127 data elements were developed through two rounds of the Delphi technique. The MDS was divided into an administrative part with three sections and 18 data items, and a clinical part with seven sections and 109 data items.

Conclusion: This study is the first step towards establishing a registry system for patients with vitiligo. Accurate identification of data items, such as MDSs, can be useful in establishing a vitiligo registry, planning, and improving the quality of patient care.

1. Introduction

Vitiligo is an acquired pigmentary disorder of unknown origin. The condition can be psychologically problematic, especially in people with dark skin [1]. The cause of the disease has not been precisely determined,

but autoimmune and genetic factors are known as the main etiological factors in vitiligo. Many other factors such as stress, infections, nerve abnormalities, misplaced melanocyte function, and genetic sensitivity also play a role in it [2]. The prevalence of segmental vitiligo ranges from 5 to 30% in the reports published worldwide. However, its prevalence

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and incidence are not precisely known [3]. It occurs in all races and can severely impact the quality of life of the affected individuals [4].

Minimum data sets (MDSs) provide an organized method for healthcare organizations to create effective care plans and allow researchers and policy-makers to decide which data items should be collected. They also ensure that common terminology and data items are standardized and consistent [5]. The goal of all MDSs, such as core health data elements, is to improve data comparability and compatibility by using standard data items that share the same definitions [6].

A patient registry is an organized system for collecting uniform data that uses observational methods to evaluate specific outcomes for a population defined by a particular disease and serves one or more specified scientific, clinical, or policy purposes [7]. Patient registries are of great importance in dermatology. Dermatologists are expected to recognize more than 3000 dermatological conditions. Many skin diseases are rare and are seldom diagnosed in the clinic, so rare disease research relies on patient populations and data obtained through rare disease registries. Registries for diseases such as psoriasis have helped evaluate long-term safety data for immunosuppressive medications, promoted long-term data surveillance for skin cancer, and provided data on the incidence and prevalence of these diseases [8].

Several dermatologic disease registries provide information on the long-term effects and safety of systemic therapies [9, 10]. They also enable the collection of comprehensive data elements required to provide evidence on existing therapies and monitor the presentation of new therapies at a given time [11]. Patient registries are databases that often use an MDS to facilitate accurate analysis [12].

Despite mounting evidence on the treatment of vitiligo in Iran, research findings do not provide sufficient information on this disease [13, 14]. Since the psychosocial effects of vitiligo are important and recognized, disease information management is essential to improving the quality of health care. To the best of our knowledge, no registry for vitiligo has been developed in Iran, and no research has been conducted to identify an MDS for a vitiligo registry in this country. This paper represents our attempt to identify an MDS and data elements for vitiligo as a means to establish a vitiligo registry.

2. Materials and methods

This descriptive and cross-sectional study was conducted in 2020 in Iran. The vitiligo MDS was developed in the following four steps:

- Step I Comprehensive literature review
- Step II Evaluation of the medical records of patients with vitiligo
- Step III Design of a proposed model of the data elements
- Step IV Validation of the data elements using the Delphi technique

Step I: Comprehensive literature review

Sources from Scopus, ProQuest, Embase, PubMed, Web of Science, and ScienceDirect databases were used for the literature review. Since the above databases index only articles, and other texts such as reports, standards, and guidelines on vitiligo should also be used, the World Health Organization (WHO) website and the Google Scholar search engine were also searched. A keyword search of these databases was performed using words associated with the concept of MDS (e.g., MDS, core data set, data elements, core data elements, essential data set, necessary data set, minimum data set, core factor, necessary factor, necessary element, and core set), words associated with registries (e.g., registry, population register, population registers, register population, registers population, hospital registration, clinical registry, institutional registry, patient registries, and disease registries), and words associated with vitiligo (vitiligo). The inclusion criteria were all articles, reports, forms, and dissertations in English published without a time limit aiming to establish vitiligo registries and develop a vitiligo MDS. Articles without an abstract and a full text, letters to the editor, short communications,

and seminar abstracts that did not specifically relate to the vitiligo registry and MDS were excluded.

After reviewing the full text of the papers, any disagreement regarding the inclusion of papers that were potentially relevant to the study was resolved by discussions among the research team members. The data extraction form, designed in Microsoft Word, was the tool used at this stage. This form included data such as country, registry name, purpose, MDS, type of registry, and data registration method, which were obtained by reviewing the texts. Its content validity was confirmed by two health information management experts, two health informatics experts, and two dermatologists. The selected databases were searched by the formulated strategy. After applying the inclusion criteria, only one paper designing the Dallas Vitiligo Registry was included in the study.

Step II: Evaluation of the medical records of patients with vitiligo

After extracting the MDS from the relevant resources, it was compared with the status quo in Iran. To this end, the medical records of patients with vitiligo in Imam Khomeini and Razi hospitals in Tehran, Ghaem and Imam Reza hospitals in Mashhad, and Shahid Faghihi hospital in Shiraz were examined from September 22 to December 20, 2020. These hospitals were selected due to their higher number of patients with vitiligo to assess the status quo of the country. At the hospitals, the number of vitiligo medical records that were properly completed during this period was 200, so 132 vitiligo medical records were randomly selected and examined using Morgan's table [15]. A data extraction form was used to extract the data elements from the patients' medical records. This form was divided into administrative and clinical parts. The form's validity was confirmed by two health information management experts, two medical informatics experts, and two dermatologists. One of the researchers (a Ph.D. student in health information management) visited the health information management department of the selected hospitals and recorded the data items into the data extraction form until reaching data saturation. Any disagreement regarding the inclusion of the medical records' data was resolved by discussions among the research team members, and the final decision was made by consensus.

Step III: Design of a proposed model of the data elements

In this step, semi-structured interviews were conducted to obtain experts' opinions on the MDS of a vitiligo registry system. Interviewees were selected using purposive, nonrandom sampling. Interviews were conducted with five dermatologists with at least 10 years of experience in dermatology treatment centers, three health information management experts, and a medical informaticist having educational and research experience with registry systems. The interviews were conducted in person at the participants' workplace and at a time announced in advance. They lasted at least 45 min, were conducted by one of the researchers, and continued until saturation, which occurred at the 9th interview. The five-stage framework analysis method was adopted to analyze the data. In the first stage, to be familiarized with the data, the researcher listened to the audio files of the interviews and read the transcriptions several times. In the second stage, to identify a thematic framework, the repeated ideas in the familiarization process were categorized into groups consisting of similar ideas or codes. In the third stage, i.e., indexing, unit or parts of the data that were related to a specific code were identified. In the fourth stage, after indexing, the data were summarized in the form of a code table based on the thematic framework, and in the fifth stage, the data were finally combined, mapped, and interpreted to define concepts and show the relationship between concepts used to determine the nature of the phenomenon and provide explanations and suggestions [16]. No software was used for data coding and classification. The codes generated from the interviews were presented to a researcher who confirmed them. The outcome of this stage was the proposed model for the data extracted from the previous two stages and the interviews to create an MDS for a vitiligo registry system consisting of an administrative and a clinical part.

Step IV: Validation of the data elements using the Delphi technique

The Delphi technique was used in two rounds to reach a consensus on the data elements. For the first round, a questionnaire was developed with a five-point Likert scale ranging from *low importance* [1] to *high importance* [5]. At the end of each section, there was a blank space for the experts to add the required data. The research sample in the first round was selected by purposive non-random sampling, as well as the opinion of the research team (three health information management experts; three health informatics experts who had a Ph.D., were faculty members with educational, executive, and research experiences related to registries, and worked at the Department of Health Information Management and Technology of Tehran, Shiraz and Kashan Universities of Medical Sciences; and 30 dermatologists working in Shahid Faghihi, Razi, and Imam Reza hospitals in Shiraz, Tehran, and Mashhad who had educational, executive, and research experience with registries). The sample size was determined to be 36 individuals based on the research team's opinion. A researcher-made questionnaire was designed by combining closed-ended questions and an open-ended question. The Likert scale was used to weigh the responses, including *very high* [5], *high* [4], *medium* [3], *low* [2], and *very low* [1]. The questionnaire was given to the experts; the health information management and medical informaticist experts were asked to complete the administrative part, and the dermatologists were asked to complete the clinical part. The researcher-made questionnaire was distributed among the research population either by e-mail or in person upon prior coordination.

The criterion for the inclusion of data elements in the final MDS was the level of expert agreement. Data elements with an agreement level of more than 75% were accepted in the first Delphi round; elements with an agreement level of 50–75% moved to the second round; and those with an agreement level of less than 50% were eliminated in the first round.

The items that received 50–75% of the experts' approval in the first round, along with the proposed items, entered the second round for further review. In the second round, the same questionnaire as that in the first Delphi round was administered. The difference was that the line suggesting data elements had been removed, and the elements that had received 50–75% agreement in the first Delphi round and were suggested by the experts were included in the second round. Like the first round, elements that had received 75% agreement from the experts were considered for inclusion in the MDS. The remaining elements were eliminated.

The research sample in the second Delphi round was selected among the participants in the first round, which included two health information management specialists, two medical informatics specialists, and 15 dermatologists. We invited all the participants of the first round, but only some of them participated in the second round. The final data elements of the MDS were obtained in two rounds. Each Delphi round lasted six weeks. The content validity of the Delphi questionnaire was confirmed by an expert panel that included four dermatologists, one health information management specialist, and one medical informaticist specialist. The data were analyzed by descriptive statistics in SPSS 23.0.

2.1. Ethical consideration

This study was approved by the Research Ethics Committee of Shiraz University of Medical Sciences, Shiraz, Iran (approval number: IR.SUMS.REC.1399.1219). We received informed consent from all the participants and ensured them about the confidentiality of their personal and professional identities.

3. Results

3.1. Comprehensive literature review

After searching the databases, a relevant article that met our inclusion criteria had focused on the Dallas Vitiligo Registry. This registry has enrolled more than 280 patients since its inception in 2013 [17]. Data items in the Dallas Vitiligo Registry were classified into four main

Table 1. Data obtained from the review.

Data classes	Data items
History	Sex, age, ethnicity, specialties of previous physicians visited, current medications, past vitiligo treatments, presence of other skin diseases, family history of vitiligo, presence of other autoimmune diseases, allergies to foods/medications/airborne/contact allergens, exposure to hair dye/cleaning solutions/rubber/chemicals, triggering factors, sunscreen use, social history including occupation and tobacco/alcohol use, location of the first lesion, evolution of lesions, symptoms at sites of lesions, presence and number of halo nevi, patient-reported body surface involvement
Skin examination	Height, weight, body mass index, Fitzpatrick skin type, vitiligo type, lesion locations, body surface area involvement, Vitiligo Area Scoring Index (VASI) score, Vitiligo Extent Score (VES), presence of secondary characteristics, signs of disease activity: confetti-like depigmentation, trichrome depigmentation, leukotrichia, Koebner score, vitiligo disease activity score, photography
Quality of life questionnaires	VitiQoL, SF-36, SF-10
Biological samples	Serum, plasma, skin biopsy samples

categories of history (19 data items), skin examination (16 data items), quality-of-life questionnaires (three data items), and biological samples (three data items) (Table 1).

3.2. Evaluation of the medical records of patients with vitiligo

A total of 100 data elements were identified at this stage. The management part consisted of demographic data (21 items). The clinical part consisted of seven sections, including diagnostic data (three items), family history data (four items), clinical evaluation data (four items), medical history data (12 items), complication data (four items), diagnostic procedures data (22 items), and therapeutic procedures data (30 items) (Table 2).

3.3. Design of a proposed model of the data elements

Analysis of the interview results led to the identification of 10 data classes, 14 subclasses, and 124 data elements. The identified data classes were demographic data (15 items), contact data (six items), provider data (two items), diagnostic data (four items), family history data (five items), clinical evaluations data (four items), current disease status data (17 items), complications data (16 items), diagnostic procedures data (23 items), and therapeutic procedures data (32 items).

3.4. Validation of the data elements using the Delphi technique

The demographic characteristics of the participants are presented in Table 3. The MDS for vitiligo was divided into administrative (with three sections) and clinical parts (with seven sections). The number of data items for the administrative part was 23, and the number of data items for the clinical part was 101. After two rounds of the Delphi survey, the final number of data items for the administrative part was 18, and that for the clinical part was 109 (Tables 4 and 5).

In the first Delphi round, 105 items were approved out of the 124 items that could be assessed. More specifically, five items (occupational status, zip code, father's name, religion, and marital status) were rejected because the agreement was less than 50%. Moreover, 14 items (ID number, nationality, ethnicity, diagnostic code in ICD-10, family history of premature graying of hair, blood type, diabetes, history of stress before lesions occurred, name of the possible complication caused by the disease, assessment of the patient's genital involvement, assessment of the patient's sexual functions, punch biopsy, assessment of biological samples, mycological examination) received 50–75% agreement. In addition,

Table 2. Data elements in the records of patients with vitiligo in Iran.

Axis	Data classes	Data items	
Management data	Demographic data	First name, surname, sex, age, nationality, date of birth, job, type of insurance, date of admission, province of residence, city of residence, address, phone number, cellphone number, physician name, facility name, occupational status, father's name, religion, marital status, zip code	
Clinical data	Diagnostic data	Diagnosis, date of diagnosis, diagnostic code in ICD-10	
	Family history data	Name of skin disease, family history of vitiligo, family history of autoimmune disease, family relationship with the patient	
	Clinical evaluation data	Height, weight, blood type, diabetes	
	Medical history data	Name of drug/food/airborne allergens, current drugs, previous vitiligo treatments, history of other skin diseases, history of autoimmune disease, history of using sunscreen, history of smoking, history of alcohol consumption, history of repigmentation, history of sunburn before lesions, history of premature graying of hair/eyelashes/eyebrows and beard before the age of 35 years, history of trauma to the skin at the site of the current lesion about 2–3 months before the onset of pigmentation	
	Complications data	Name of the possible complication caused by the disease, date of onset, date of end, complication results	
	Diagnostic procedures data	Lab test	Date of test, test result, test name
		Specialized evaluations	Assessment of the patient's genital involvement, assessment of the patient's sexual functions, evaluation of the quality of life by VitiQoL and DLQI questionnaires, eye examination, punch biopsy, photography, mycological examination
		Skin examination	Skin type based on Fitzpatrick scale, skin color, loss of tissue color inside the mouth and nose, vitiligo type, observing lesions under the light of special examination lamps (wood's lamp), existence of halo nevi, location of the first lesion, Vitiligo Area Scoring Index (VASI) scores, signs of disease activity: confetti-like depigmentation, trichrome depigmentation, leukotrichia, Koebner score
	Therapeutic procedures data	Medication prescriptions	Drug name, dosage, start date, end date, date of changing/stopping the drug
		Surgery	Name of surgery, date of surgery, surgery result, code in ICD-9-CM
Combination therapies		Topical steroids with phototherapy, calcineurin inhibitors with phototherapy, surgery with phototherapy, oral psoralen with phototherapy, topical psoralen with phototherapy, tofacitinib	
Phototherapy		Used method, dosage, average dose per session, start date, end date, duration of use, side effects	
Other treatments		Cryotherapy, laser therapy, cell therapy, psychotherapy, sunscreens, cosmetics, camouflage, depigmentation	

Table 3. Demographic characteristics of the participants in the Delphi technique.

Characteristics		Number of Participants	
		First round	Second round
Specialty	Dermatologist	30 (83.4)	15 (79)
	Health Information Management	3 (8.3)	2 (10.5)
	Medical Informatics	3 (8.3)	2 (10.5)
Sex	Female	20 (55.6)	10 (52.7)
	Male	16 (44.4)	9 (47.3)
Age group (years)	30–40	13 (36.1)	6 (31.5)
	40–50	14 (38.9)	11 (58)
	50–60	6 (16.7)	2 (10.5)
	>60	3 (8.3)	-
Work experience (years)	<10	8 (22.2)	3 (15.8)
	10–20	22 (61.1)	13 (68.5)
	20–30	4 (11.1)	2 (10.5)
	>30	2 (5.6)	1 (5.2)

the experts suggested nine items (hypothyroidism, feeling depressed, lack of protection from sunlight, skin injury/trauma, topical radiation, stress, improper diet, premature skin aging, and hearing impairment) as the items to be included in the second Delphi round. In the second round of the Delphi technique, of the 23 items that could be scored, 22 items

were approved, and one item (mycological examination) was rejected. Finally, 127 items were approved as the final MDS for the vitiligo registry. The classification of these data items is given in Tables 6 and 7.

4. Discussion

According to the results, 127 data elements were identified and divided into administrative and clinical parts. The administrative part had three sections: demographic data (11 items), contact data (five items), and provider data (two items), and the clinical part had seven sections: diagnostic data (four items), family history data (five items), clinical evaluation data (six items), current disease status data (22 items), complication data (18 items), diagnostic procedures data (22 items), and therapeutic procedures data (32 items). Together, these parts constituted the MDS for establishing a vitiligo registry in Iran.

In Dallas, Texas, the University of Texas Southwestern Medical Center has developed a registry to collect data on vitiligo cases. The Dallas Vitiligo Registry maintains a large database of baseline and longitudinal data, including patient demographic profiles, disease history, quality-of-life measures, clinical outcome measures, and a repository of biological samples linked to the clinical database. The MDS has four sections in this database, including medical history, skin examination, quality-of-life questionnaires, and biological samples [17]. The final MDS agreed upon in our study was very similar to those of this research, except that the MDS generated in the present study covered a broader range of data.

Table 4. The administrative data part for the MDS for vitiligo.

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	15	4	3	8	0	0	3	11
Contact	6	1	0	5	0	0	0	5
Provider	2	0	0	2	0	0	0	2
Total	23	5	3	15	0	0	3	18

Table 5. The clinical data part for the MDS for vitiligo.

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%<	
Diagnostic	4	0	1	3	0	0	1	4
Family history	5	0	1	4	0	0	1	5
Clinical evaluations	4	0	2	2	0	0	4	6
Current disease status	17	0	1	16	0	0	6	22
Complications	16	0	1	15	0	0	3	18
Diagnostic procedures	23	0	5	18	1	0	4	22
Therapeutic procedures	32	0	0	32	0	0	0	32
Total	101	0	11	90	1	0	19	109

Table 6. Administrative data elements for a vitiligo MDS.

Data classes	subclasses	Data items
Demographic data	-	First name, surname, ID number, sex, age, nationality, ethnicity, date of birth, job, type of insurance, date of admission
Contact data	-	Province of residence, city of residence, address, phone number, cellphone number
Provider data	-	Physician name, facility name

Skin examination was among the essential items in their registry, which was also an important data item in our study for collecting diagnostic data.

Vitiligo causes numerous cosmetic problems which can lead to severe impacts on the patient's psychological well-being [18, 19]. Given the importance of discussing the quality of life in skin diseases, this data element is present in most MDSs for skin diseases. A registry system should ideally capture all potential patient-reported outcome measures

(PROMs); however, this may be delayed by resource constraints [20]. Some studies suggest using the Vitiligo-Specific Health-Related Quality of Life Instrument (VitiQoL) [21] and the Dermatology Life Quality Index (DLQI) [22]. Therefore, this data element was included in the vitiligo MDS, whereas SF10, Skindex-26, and SF -36 were rejected by consensus.

Data on disease activity and severity, such as the Vitiligo Area Scoring Index (VASI), the Vitiligo European Task Force (VETF), and the Vitiligo Disease Activity (VIDA) scores, were included in the MDS for vitiligo registry. This point was brought to our attention by the respondents who participated in the semi-structured interviews. The VASI and VETF tools were proposed to provide more accurate measures of disease severity and criteria for treatment assessment compared with simple clinical photography alone. The VASI provides a relatively simple method to measure repigmentation. With the tools developed by the VETF, vitiligo and treatment outcomes can be assessed using a system that combines the analysis of the disease extent, stage, and progression [23]. Due to the importance of activity and severity data elements, these data elements were included in the MDS.

Table 7. Clinical data elements for a vitiligo MDS.

Data classes	Subclasses	Data items
Diagnostic data	-	Diagnosis, date of diagnosis, method of diagnosis, diagnostic code in ICD-10
Family history data	-	Name of skin disease, family history of vitiligo, family history of autoimmune disease, family relationship with the patient, family history of premature graying of hair
Clinical evaluation data	-	Height, weight, blood type, hypothyroidism, diabetes, feeling depressed
Current disease status data	Medical history	Name of drug/food/airborne allergens, current drugs, previous vitiligo treatments, history of other skin diseases, history of autoimmune disease, history of using sunscreen, history of smoking, history of alcohol consumption, history of repigmentation, history of sunburn before lesions occurred, history of severe sun sensitivity, history of premature graying of hair/eyelashes/eyebrows and beard before the age of 35 years old, history of trauma to the skin at the site of the current lesion about 2–3 months before the onset of pigmentation, history of stress before lesions occurred
	Aggravating factors	Lack of protection from sunlight, skin injury/trauma, topical radiation, stress, improper diet
	Comorbidities	Name of the disease, duration, and treatment
Complications data	Disease complications	Name of the possible complication caused by the disease, complication severity, date of onset, date of end, complication result
	Drug side effects	Drug name, type of complication, complication severity, date of onset, date of end, complication result
	Side effects	Social/mental disorder, sunburn, skin cancer, hearing impairment, depression, ocular problems such as iris inflammation, premature skin aging
Diagnostic procedure data	Lab test	Date of test, test result, test name
	Specialized evaluations	Assessment of the patient's genital involvement, assessment of the patient's sexual functions, evaluation of the quality of life by VitiQoL and DLQI questionnaires, eye examination, punch biopsy, photography, assessment of biological samples
	Skin examination	Skin type based on Fitzpatrick scale, skin color, loss of tissue color inside the mouth and nose (mucous membrane), vitiligo type, observing lesions under the light of special examination lamps (Wood's lamp), existence of halo nevi, location of the first lesion, Vitiligo Area Scoring Index (VASI)/VIDA/VETF scores, signs of disease activity: confetti-like depigmentation, trichrome depigmentation, leukotrichia, Koebner score
Therapeutics procedures data	Medication prescriptions	Drug name, dosage, start date, end date, continuity of consumption, date of changing/stopping the drug, reason for changing/stopping the drug
	Surgery	Name of surgery, date of surgery, surgery result, code in ICD-9-CM
	Combination therapies	Topical steroids with phototherapy, calcineurin inhibitors with phototherapy, surgery with phototherapy, oral psoralen with phototherapy, topical psoralen with phototherapy, tofacitinib
	Phototherapy	Used method, dosage, average dose per session, start date, end date, duration of use, side effects
	Other treatments	Cryotherapy, laser therapy, cell therapy, psychotherapy, sunscreens, cosmetics, camouflage, depigmentation

It is critical to have a vitiligo registry system that collects standardized data elements to identify patients and monitor the disease. The development of an MDS is the most fundamental task in the data collection of a disease registry system to support healthcare providers and to use the data for administrative and research purposes. Therefore, the development of an MDS with information components agreed upon by most experts is essential. Defining an MDS for a vitiligo registry system is an effective step towards integrating these patients' information and improving information management for this disease.

5. Study limitations

This study had some limitations. There was a small number of experts in the Delphi stages. Moreover, only the Dallas Vitiligo Registry was included to determine the MDS. Accordingly, attempts were made to create a comprehensive MDS by reviewing patients' medical records, interviewing experts, and performing two rounds of the Delphi technique. Furthermore, experts who had educational, executive, and research experience with registries and were willing to cooperate in the study were selected from different cities.

6. Conclusion

Given the lack of data elements for vitiligo, this study established an MDS for this disease. Accurate identification and definition of data elements will improve timely and accurate decision-making. This MDS can help the development of a vitiligo registry and improve the quality of care.

Declarations

Author contribution statement

Zahra arabkermani; Roxana Sharifian: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Abbas Sheikhtaheri: Conceived and designed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Zeinab Aryanian; Peivand Bastani: Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Nafiseh Esmali; Azadeh Bashiri; Gholamhossein Mehralian: Conceived and designed the experiments; Performed the experiments; Wrote the paper.

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Data included in article/supp. material/referenced in article.

Declaration of interests statement

The authors declare no competing interests.

Additional information

No additional information is available for this paper.

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