

## Research Paper

# Determining the Minimum Data Set of Amblyopia Electronic Health Record



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## ABSTRACT

**Objective** To collect, store, and distribute the electronic health records of patients with amblyopia, it is important to determine the data elements. The present study aims to determine the minimum data set (MDS) for electronic health record of patients with amblyopia in Iran.

**Methods** This is an applied study that was conducted in 2020. To identify data elements, a search was conducted in PubMed, Scopus, Google Scholar, Web of Science, Scientific Information Database (SID), Magiran and Barakat knowledge system and the records of patients with amblyopia were examined and consultation with ophthalmologists in Farabi Hospital was done. Then, a questionnaire with two sections of "demographic information" and "suggested MDS for amblyopia" was prepared based on a five-point Likert scale. After confirming the validity and reliability of the questionnaire, it was completed by 20 experts from the amblyopia clinic of Farabi Hospital who were selected using a convenience sampling method. Data analysis was done using descriptive statistics in SPSS software. The data elements with an agreement score >3 were selected for the MDS of amblyopia.

**Results** Out of 98 proposed data elements, 92 were included in the MDS for amblyopia and were classified into 6 categories of demographic data, clinical data, type of strabismus, sensory tests, doctors' prescriptions, and treatment plan.

**Conclusion** It seems that the integration of information for patients with amblyopia in Iran and the improvement of their information management can be possible by determining the MDS for their electronic health record. By storing and retrieving standard electronic health information based on a minimum data set, it is possible to compare information, obtain high-quality information, and increase the effectiveness of medical services.

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## Extended Abstract

### Introduction

**E**ye health and preventing it from becoming lazy is very important. Lazy eye or amblyopia is a decrease in visual acuity in one or both eyes without a physical cause or specific pathological factors, which is considered as an acquired impairment in childhood. Usually, the quality of life of children with amblyopia is reduced compared to normal children and their academic performance is affected. Visual acuity test is a common method of identifying visual impairments in children, which is performed by doctors and health experts in health care centers. Studies have shown that the Iranian integrated health system (SIB system) is inefficient to meet information needs of users due to reasons such as poor programming and system design, inability to properly use the large amount of collected data, and lack of familiarity of users. Some health care organizations in developed countries have emphasized the use of minimum data set (MDS) for collecting, storing and distributing health data in order to prevent the collection of unnecessary data. Since no study has been conducted in determining the MDS of amblyopia in Iran, the present study aims to determine the MDS of amblyopia in Iran in order to create a suitable platform for facilitating the sharing of patients' information and improving the quality of documentation in the electronic health records.

### Methods

This is an applied study conducted in 2020 using quantitative and qualitative methods in six steps. In the first step, the determination of data for the proposed MDS was done using the Delphi technique and searching in PubMed, Scopus, Google Scholar, Web of Science, Scientific Information Database (SID), Magiran and Barakat knowledge system. In the second step, the records of 150 patients with amblyopia in Farabi Hospital were examined and consultation with ophthalmologists was done. In the third step, a questionnaire including two sections of "demographic information of experts" and "MDS of amblyopia cases" was prepared based on a five-point Likert scale. In the fourth step, the content validity and face validity of the questionnaire were confirmed by 6 experts in ophthalmology, health information management and medical informatics. In the fifth step, the reliability of the questionnaire was examined and confirmed (Cronbach's  $\alpha=0.88$ ). In the sixth step, 20 experts from the amblyopia clinic of Farabi

Hospital were selected using a convenience sampling method and the questionnaires were provided to them. The criterion for inclusion of each data element was being in the range of 3-5; those with an average score of 3-2.5 were entered into the second round of Delphi. In this study, all the data elements obtained an agreement score above 3; as a result, the Delphi test was performed in one step. Some data elements including language, religion, ethnicity, type of insurance, insurance number, and type of torsional strabismus were removed from the list according to experts' opinions and finally 92 data elements were approved. There were some corrections regarding the separation of data elements according to the opinion of experts. Data analysis was done using descriptive statistics in SPSS software, version 20.

### Results

In this study, 75% of the participants were male, 45% had a work experience <5 years, and 35% were ophthalmology residents. The approved MDS for amblyopia included 6 categories of demographic data, clinical data, strabismus type, sensory tests, doctor's prescription, and treatment plan. In the category of clinical data, the patient's medical history had the highest score (4.75). The data element of strabismus type included type of strabismus, deviation pattern, chin position, head tilt towards the left or right, nystagmus, and face turn. The data element of sensory tests included six categories where the Bagolini subtraction test (4.05) and the ability to perceive depth or three-dimensional vision (Stereopsis) obtained the highest scores. The lowest means in the data elements of doctor's prescription and treatment plan were related to neurology consultation (3.65) and orthoptic practice (3.4), respectively.

### Discussion

Determining the MDS of amblyopia cases is an effective step towards the integration of the information of patients in Iran, and can lead to the improvement of information management of patients with amblyopia, increased efficiency in health care, effective communication between health care providers and decision makers, and the possibility of comparing information. By determining the MDS for amblyopia in accordance with the social and health conditions of Iran, it becomes possible to store and retrieve the standard information of these patients for improving the quality of health care and increasing the effectiveness of medical services. Some of the limitations of the study included the doctors' lack of time to provide us advice and the illegibility of patients' medical records. Moreover, the

determination of the MDS was only limited to patients referred to Farabi Ophthalmology Hospital. To obtain the opinions of doctors, we had to use phone call or email. To solve the problem of illegibility in medical records, we had to ask for help from nurses and some doctors. Further studies are recommended to determine the MDS for amblyopia at the national level.

## Ethical Considerations

### Compliance with ethical guidelines

This study has ethical approval of [Tehran University of Medical Sciences \(TUMS\)](#) (Code: IR.TUMS.SPH.REC.1398.290).

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### Authors' contributions

Study design, methodology and funding: Leila Shahmoradi; Writing-review and editing: Roya Naemi and Maryam Ebrahimi; Sources: Mina Akbarian and Maryam Ebrahimi; Supervision: Leila Shahmoradi and Roya Naemi; Review of reading and writing of the original draft: all authors.

### Conflicts of interest

The authors declared no conflict of interest.

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