

**MINIMUM DATA SET FOR CYSTIC FIBROSIS REGISTRY: A CASE STUDY IN NORTHWEST IRAN**Leila R Kalankesh^{*1, 2}, Saeed Dastgiri^{2, 3}, Mandana Rafeey^{4, 5}, Narmin Rasouli¹, Leila Vahedi⁴

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Correspondence:Dr. Leila R Kalankesh, PhD, School of Management and Medical Informatics, Tabriz University of Medical Sciences, Iran, Email: lrkalankesh@tbzmed.ac.ir**TYPE OF ARTICLE:** CONFERENCE ABSTRACT**ABSTRACT**

Introduction: Over the last 25 years, several national registries of CF have been set up. Such systems can be very useful in providing an integrated resource for improving patient care and conducting research on the disease. Minimum Data Set is a common set of data items that should be used to collect and report data in the registry. The principal aim of this research was to determine minimum data set for the CF registry in northwest Iran.

Methods: data items collected by several selected registries of cystic fibrosis were studied and an initial set of data was selected by the researchers. A group of experts including epidemiologists, pediatricians, and CF specialists were asked to review the proposed data elements and score them based on their importance by using a nine-point Likert scale. The items scored as important or highly important by more than 50 % of the experts, were included in final list of minimum data set. Availability of data was evaluated through reviewing medical records of 144 patients hospitalized in a children's hospital located in Tabriz.

Results: overall six classes of data (46 items) were identified in the selected registry systems for cystic fibrosis: patient demographics, administrative data, survival status, diagnostic procedures, genetic and clinical manifestations, and therapeutics. Thirty-two data elements from all six categories of data were approved by the experts as the minimum data set for cystic fibrosis registry system. Availability of data in administrative category and survival class was 100 percent. Collecting data on medications was feasible in 100% of the cases as well. In the class of demographic data, accessibility of patient's name, age, gender, place of birth, and date of birth was 100 percent. In the group of diagnostic procedures, partial availability of data was found for sweat test and genetic test. No data was found on the antenatal screening, exercise tolerance test, and glucose tolerance test.

Conclusion: This work was as a first step toward establishing a CF registry system in Iran. Minimum data set can be also useful in designing electronic registry or electronic patient records for those suffering from CF toward integration of their fragmented records across continuum of the health care systems, in order to improve quality of shared patient care and to facilitate related research. Currently the registry project, as well as the software development, have been approved by Tabriz university of medical sciences.

KEYWORDS: Minimum data set, Registry, Data elements, Cystic fibrosis, Core data set

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