DEVELOPING COLORECTAL CANCER MINIMUM DATA SET: A STARTING POINT FOR SPECIFIC COLORECTAL CANCER REGISTRATION IN IRAN

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ABSTRACT

Introduction: In order to collect the uniform information required to ensure the quality of data and data exchange between health care providers and professional organizations, it is necessary to define a dataset. The main aim of this study was to define the essential dataset required to record colorectal cancer information in Iran.

Methods: For the design of the core dataset, a combination of literature review and expert consensus was used. In the first phase, the draft was proposed based on colorectal cancer literature review and comparative studies. In the second phase, this dataset was evaluated by experts, and their comments were taken. In the third phase, modified data were evaluated again by experts and eventually, this dataset was designed in three main parts: demographic, diagnostic and therapeutic information.

Results: Based on the literature review, a draft set of 85 data elements was designed. In the second stage, supplementary information was offered by professionals that in total, the number of elements amounted to 93 numbers. In the third phase, assessment was conducted by experts, and finally, the core dataset including patients’ demographic information, and referral information, endoscopy, pathology information, diagnosis and treatment were obtained.

Conclusion: In this study, the comprehensive core dataset of colorectal cancer was collected. This dataset in the field of collecting colorectal cancer information can be helpful in exchange of health information. Determining such dataset for similar diseases can help providers to collect standard data from patients and can accelerate retrieval from storage systems.

KEYWORDS: Cancer registry, Colorectal cancer, Standards, Medical Informatics