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DESIGNING BIRTH DEFECTS MINIMUM DATA SET IN IRAN

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ABSTRACT

Introduction: Birth defects are a known cause of mortality in infancy and the subsequent period. In fact, birth defects are structural changes that can affect almost every part of a child's appearance or function, or both. These defects are the fifth-most cause of mortality before 65 years, and an important factor of disability in the community. The aim of this study was to determine the minimum data set of birth defects to enhance their management.

Methods: This study is practical and descriptive, and was conducted in 2016. Birth defects minimum data set resources (print and electronic) in selected countries were studied. According to their similarities and differences and internal needs, a model for a birth defects minimum data set was designed. According to expert opinion, the model has been validated by Delphi technique in two phases.

Results: This minimum data set has six general areas including neonate risk factors, mothers risk factors, economic and social risk factors of mother status, delivery risk factors and malformation history in family. This model has a total of 35 data elements.

Conclusion: The Birth Defect Minimum Data Set plays an important role in improving health and enhancement of birth defect management and is also a cornerstone of access to integrated electronic health records. Therefore, it is recommended that this minimum data set is considered for a national system of mothers and neonates, to provide comprehensive collected information about birth defects and anomalies in Iran.

KEYWORDS: Birth Defect, Minimum Data Set, model

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