

Study Protocol

Inpatient Data, Inevitable Need for Policy Making at National and Sub-national levels: A Lesson Learned from NASBOD

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Abstract

Background: Estimating burden of disease, injuries and risk factors is crucial for health policy decision making. The Burden of Diseases (BoD) studies provide data about the magnitude and distribution of health problems among the population at national and sub-national levels. The BoD studies are designed to use secondary data for estimating prevalence and incidence of diseases, injuries and risk factors. However, due to the scarcity of data sometimes it becomes unavoidable to collect data from medical records. Among all needed source of data, including surveys, registries, censuses, inpatient and outpatient data, hospital data are an essential source for BoD studies. Hospital Data Survey (HDS) aims to estimate the prevalence and incidence of diseases and injuries that led to admission to hospitals. This paper aims to describe the required steps for data gathering, sampling, analytical methods, and other needed procedures for HDS.

Study Design: The designed questionnaire includes demographic data, current health status, diseases, injuries and co-morbidities with their ICD10 codes, curative procedures, and treatment. A pilot study was conducted on 302 medical records from 6 hospitals to evaluate the validity and reliability of the questionnaire. Sampling frame was designed and probability proportional was used after being tested in the pilot study. In the next step, we will collect 367500 medical files from 863 hospitals (0.5% of all inpatient records in hospitals from 1996 – 2013). The HDS is the first national study in Iran that is gathering data through an online-offline web-based system based on electronic version of the questionnaire which makes the process of data cleaning and analyses more comfortable.

Keywords: Burden of disease, collection, data, hospital, Iran, NASBOD

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Introduction

Estimating the burden of disease, injuries and risk factors is crucial for health policy decision making. The Burden of Diseases (BOD) studies provide data about the magnitude and distribution of health problems among the population at national and sub-national levels.

Although there are considerable studies at global, regional, and country levels that estimated the burden of diseases, injuries and risk factors,¹⁻⁷ there are a few trend analysis of prevalence and incidence of diseases, injuries and risk factors exposures at sub-

national level in developed and developing countries. In the country profile report, GBD has provided estimations of the prevalence of diseases at national level in Iran,⁸ however, National and Sub-national Burden of Diseases, Injuries and Risk Factors from 1990 to 2013 survey (NASBOD)⁹ aims to provide estimations at different levels in which results will be affected mainly by data rather mathematical models. Personal medical records are essential sources for BOD studies. The Hospital Data Survey (HDS) is a sub-component of National and Sub-national Burden of Diseases, Injuries and Risk Factors from 1990 to 2013 survey in Iran (NASBOD) which aims to estimate the prevalence and incidence of diseases and injuries that led to admission to hospitals. In addition, this comparative study investigates medical coding quality in terms of precision and completeness in inpatient hospital records over the study years.

Current Hospital Information System

Iranian electronic hospital information systems called Admission Discharge System 9 (ADS9) were established to deal with accounting processes in hospitals and were created by several different IT companies with different standards. Incompatibility and limitation in converting data from a system to another are some of the difficulties induced by ADS9.⁹ The hospital information systems were primary intended for accounting purposes and the required health information such as ICD10 code is mostly missing.^{10,11} Hence, high degrees of incompleteness and incompatibility of systems make ADS 9 a useless data source for NASBOD. The other health information system that was developed by department of Statistics and Information Technology of Iranian

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Ministry of Health is SEPAS standing for Iran's Electronic Health Record Website in Persian. This system aims to integrate every piece of health related information for each individual in order to improve health care services standards, increase the level of data access around the country, and assist health system management efficiently. However, as NASBOD is targeting the whole country and this new system is in its early stage of development, covering only 28 out of 863 hospitals, it is not comprehensive enough to be employed in NASBOD. Thus, HDS is aimed to collect required inpatient data from all over Iran and to study the trend and distribution of inpatient cases based on the cause of diseases at national and sub national levels in Iran during 1988 to 2013.

Materials and Methods

To measure loss of healthy life years known as disability-adjusted life years, DALYs, there is a need for data about the comprehensive list of disease distribution by sex, age and region as well as deaths and major risk factors. Data sources included the vital statistics, national censuses, health examination surveys, and published epidemiological studies are used. However, there is no reliable data on morbidities which led to admission to hospitals. To overcome this limitation HDS has been designed to collect data from every single hospital that is providing inpatient services across the country regardless of its ownership public or private sectors. To carry out the task, we conducted three practical steps including: 1-designing, testing and applying a valid tool to collect required data, 2-training courses about the process of HDS administration for people who are involved in three different organizational levels including (down to top) hospitals, Deputy of Treatment of Medical Sciences Universities, and Non-communicable Disease research center, 3-monitoring the HDS progress in three organizational levels as shown in figure 1. In this study, all universities of medical sciences and their affiliated hospitals in both private and public (educational and local) sectors have been included.

Data Collection

In this study, hospital is defined as a health centre with at least 32 beds equipped with clinical facilities and specialists in general level in four internal, surgery, pediatrics, and obstetrics wards. We collected data about individuals who were admitted to one of the hospitals across the country at least for 6 hours. To calculate the sample size, we considered 0.5 % of inpatient cases per year in each hospital. We used admission list to select the records from hospital filling system, to choose the first sample, we select a random number between first 100 records. To calculate a constant value to be added to the first number, we divided the number of inpatient records by the sample size for each study years. This process continues until reaching the last number of a given sample size.

After selecting study medical records, data will be imported from records to the study tool. It is a valid questionnaire (paper based and electronic versions) and an online website. The questionnaire (Appendix 1) has 5 main sections including: hospital characteristics, patient's general information, disease characteristics (primary and final diagnoses, and external causes), co-morbidities, treatment interventions, inpatient characteristics and discharge, death and mortality and final cost. Each section consists of several subsections. To evaluate questionnaire validity and reliability, a pilot study was conducted in six hospitals in two different prov-

inces (Tehran and Kurdistan). To check the questionnaire's inter and intra reliability and validity, data about 302 records for test and 302 records for re-test were gathered in two times with two weeks gap to check questionnaire's inter and intra reliability and validity. Result of test-retest analysis showed that there is sufficient validity for the study's tool. The questionnaire was reliable since the lowest rate of Cronbach's alpha for each test-retest pair was 0.82. People who are in charge of completing the study questionnaire are coders who work at medical record ward of hospitals and they collect selected patient records; coders could either fill offline questionnaire or use web-based version through this link : <http://194.225.213.69>.

Project Implementation at National and Sub-national levels

In order to manage HDS at national level and expand it throughout the country, three main steps have been taken including: logistics support, training, and monitoring. As presented in Figure 1, they are administrated in a cascade form where Non-communicable disease Research Centre (NCDRC) supported medical universities, and then universities supported related hospitals in terms of these three components. It is worth mentioning that NCDRC was permitted by Iran ministry of health to run HDS from Iran ministry of health as a main part of NASBOD.⁹ HDS team at NCDRC trained eager researchers who are involved in other research projects in order to get their support for monitoring. Moreover, three workshops were held at NCDRC to teach theoretical and practical topics of the project to the directors of medical record until at deputy of treatment of 45 medical universities. At sub-national level, same process were conducted by medical universities; at this level, medical record unit of deputy of treatment administrated training, monitoring and logistics activities for coders at hospitals. All filled questionnaire will be collected and after data cleaning, accumulated data will be used in analysis phase of NASBOD.

Discussion

Hospital Data Survey aims to provide estimates on the distribution of diseases, and injuries among those who admitted in hospitals from 1996 to 2013 at national, provincial, and district levels in Iran. We did not use ongoing health information systems in hospitals since they are mostly focusing on accounting needs rather than clinical and epidemiologic requirements. The total sample of 357,000 medical records provides enough power for any hypothesis testing at the district level. The other advantage of this study is the time period that the study covers. Since the data are representative for Iranian population admitted in hospitals, changes over time provides useful information for policy makers on epidemiologic transition of diseases and changes in behavior of clinicians. The Hospital Data Survey is a unique source for evaluating the hospitals performance based on their outcomes rather than their inputs and processes, which is common way of evaluation of hospitals in the hospital governance program.^{13,14} The other component of Hospital Data Survey, which focuses on the procedures, might be helpful to exploring the quality of diagnostic and curative services. The survey provides data on the expenses of each service and the share of insurance and individuals on the expenses that will help in establishing a new payment system for clinicians. HDS has faced several limitations in practice such as insufficient number of medical coders in medical record ward of hospitals, untrained people especially for medical coding, low speed inter-

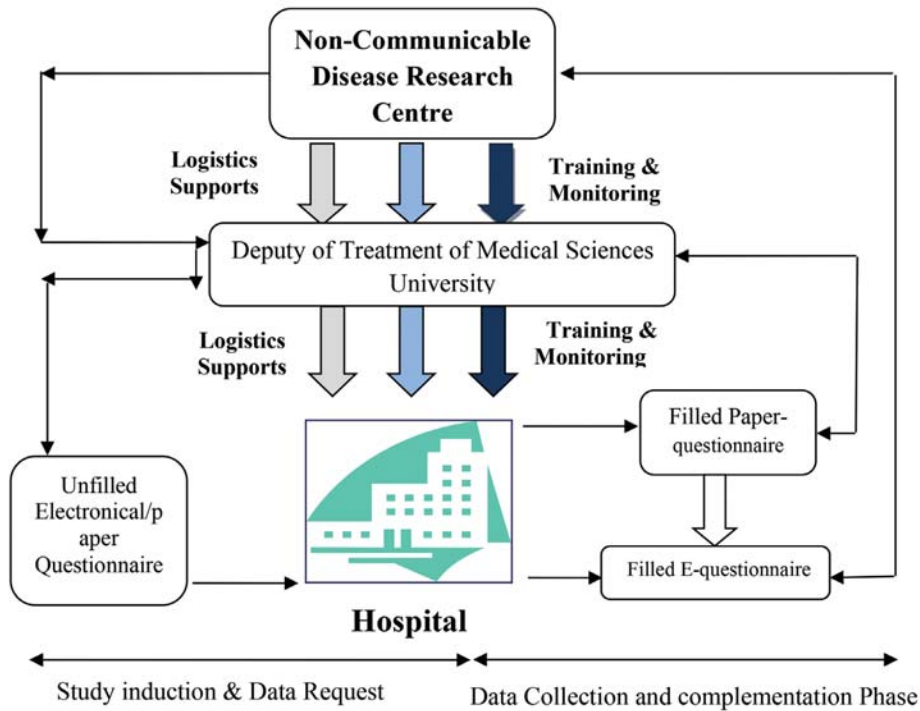


Figure 1. The schematic diagram of hospital data project in frame of Burden of disease and injury study: Logistic support, training and monitoring are three cornerstone steps of HDS.

net, limited facilities and equipment. We have used proper strategies to overcome these confines during this study such as expansion the project time, recruiting medical records students, swapping the hospital staffs to cover hospitals with bigger value of bed occupancy rate and applying offline system to overcome internet pace limitation.

In other countries, different methods were applied to provide sufficient inpatient data in order to estimate burden of disease and injuries. In New Zealand, Health Tracker system has been applied; it is an integrated electronic system which focuses on hospital cost along with each case registration. In more detail, it is composed of different data sources linked from National Minimum Dataset (hospital events), National Non-admitted Patient Collection (outpatient and emergency department events), Laboratory Claims Collection, Pharmaceutical Collection, National Travel Assistance Claims, Primary Health Organization Enrolment Collection, Mortality Collection, and New Zealand Cancer Registry.¹⁵ In Mexico, to conduct national and sub-national burden of disease, injuries and risk factors different data sources were applied. Beside death and morbidity rates calculated by censuses and mortality statistics, WHO estimation of incidence, duration and disability weight was applied to calculate YLDs. Lack of complete and comprehensive inpatient data availability as an important data source has been mentioned as a project limitation.² Also, for the study conducted for Burden of disease and risk factors estimation in Australia, a range of data sources, methods and assumptions were applied. Incidence rates for different disease were calculated from electronic system of disease registry easily.¹ However, South Africa encountered several problems during conducting Burden of Disease and injuries project due to poor electronic health information system. In this country, the only part of health information system which became automated is death registry; in spite several years' post-apartheid government endeavors, still many prob-

lems such as under registration of deaths and misclassification of causes as a result of poor certification practice remain.¹⁶

Lack of an integrated electronic system to gather inpatient data in poor and developing countries, has caused several difficulties for both inpatient and outpatient data collection. In Iran, although there are electronic hospitals information systems in hospitals, clinics and medical centers, various layouts and structures may induce complications which prevent using all inpatient data in a unique format. Shortage of an integrated information system led us to conduct HDS; this caused loads of costs and at the end we have only data access to specific 15 years. There is an urgent need of integrated electronic health record in order to create great circumstances to collect different types of patient data correctly and completely. To meet this end, SEPAS has been designed as a project to develop the health information system. This under progress project has a particular priority in Iran health Ministry and is being followed as the greatest plan of IT in health area to provide health data consistency throughout Iran in Health, Treatment and Research & Development Deputyship.

Author's contribution

General designing of paper: Sharareh R. Niakan Kalhori, Farshad Farzadfar

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Writing primary draft Sharareh R. Niakan Kalhori, Farshad Farzadfar

Manuscript revision Sharareh R. Niakan Kalhori, Farshad Farzadfar

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Appendix 1

Tehran University of Medical Sciences Non-communicable Disease Research Centre (NCDRC)	HDS in frame of NASBOD	Ministry of Health and Medical Education														
Exclusive Questioner Code																
Patient record No..... E-questioner data entry code:	<table border="1" style="width:100%; border-collapse: collapse;"> <tr> <th style="width:12.5%;">province</th> <th style="width:12.5%;">University</th> <th style="width:12.5%;">City</th> <th style="width:12.5%;">Hospital</th> <th style="width:12.5%;">year</th> <th style="width:12.5%;">month</th> <th style="width:12.5%;">patient</th> </tr> <tr> <td style="height: 20px;"></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	province	University	City	Hospital	year	month	patient								
province	University	City	Hospital	year	month	patient										
A. Hospital Characteristics																
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[]	[]	6-Admssion Year.....														
[]	[]	5- Admission Year.....														
[]	[]	[]	[]	[]	[]	4. Hospital										
B. Patient Characteristics and Address																
7-First Name.....8- Family name9-Father Name.....10- ID No.....11.National Code..... 12. Insurance Code:																
19-Place of residency: 1-urban.....2- rural.....3- other.... 20- City of residency 21- Province of residency..... 22- Patient Phone Number...	13- Date of Birth..... 14. Patient Age..... 15- Infant or under- 1 year old child? Yes <input type="checkbox"/> No <input type="checkbox"/> 16- Age of Infant or under 1 year old: <table border="1" style="display: inline-table; margin-left: 20px;"> <tr> <td style="width: 40px;">Month.....</td> <td>Day</td> </tr> </table>		Month.....	Day												
Month.....	Day															
23- Foreign Patient? 1- Yes..... 2-No..... 24- If Yes Which Country?.....	17- Gender: 1- male..... 2- female..... 3- others 18- Marital Status: 1- Single.....2- Married.....3- Others.....															
25- primary Diagnosis																
No coding	Explanation	25-4: New Allocated Code	25-3 – ICD book	25-2: previously allotted code	25-1 Primary Diagnosis											
<input type="checkbox"/>																
26- Final Diagnosis																
No coding	Explanation	26-4: New Allocated Code	26-3 - ICD book	26-2: previously allotted code	26-1 Final Diagnosis											
<input type="checkbox"/>																
<input type="checkbox"/>					-In case of multiple Truma											
<input type="checkbox"/>					-In case of multiple Truma											
27- External Causes																
No coding	Explanation	27-4: New Allocated Code	27-3 - ICD book	27-2: previously allotted code	27-1 Name of casulty											
<input type="checkbox"/>																
28- Co-morbidities																
No coding	Explanation	28-4: New Allocated Code	28-3 - ICD book	28-2: previously allotted code	28-1 Name of Comorbidity											
<input type="checkbox"/>					1											
<input type="checkbox"/>					2											

No coding	Explanation	28-4: New Allocated Code	28-3 - ICD book	28-2: previously allocated code	28-1 Name of Comorbidities	
<input type="checkbox"/>						3
<input type="checkbox"/>						4
<input type="checkbox"/>						5
<input type="checkbox"/>						6
<input type="checkbox"/>						7
<input type="checkbox"/>						8
<input type="checkbox"/>						9
<input type="checkbox"/>						10

29- Treatment Intervention

No coding	Explanation	28-4: New Allocated Code	28-3 - ICD book	28-2: previously allocated code	29-1 Treatment Intervention		
					29-1-1secondaryly	29-1-1Primarily	
<input type="checkbox"/>							1
<input type="checkbox"/>							2
<input type="checkbox"/>							3
<input type="checkbox"/>							4
<input type="checkbox"/>							5
<input type="checkbox"/>							6

30- Prescribed Medications

30-2 Outpatient Medications			30-1 Inpatient Medications		
	5		1	5	1
	6		2	6	2
	7		3	7	3
	8		4	8	4

C. Admission Discharge Characteristics

31- Disaster Due to:
 1-Flood..... 2- Earthquake.....3- Storm..... 4- Tondar..... 5- hypothermia..... 6- War.....

33- Complementary Insurance: 1.Yes 2- No

32-Insurance Type
 -No Insurance..... -self advocacy..... - Komite Emdad
 - Khadamat Darmani.... -Taamin Ejtemaei..... -Nirooye Mosalah.....

D. Death and Mortality

No Coding	40- Code for Death reason based on Final Diagnosis	39- Death reason based on Final Diagnosis	38- code for death reason based on death certificate	37- death reason based on death certificate	36- InpatieDuration	35- discharge Time...
<input type="checkbox"/>						

E. Final Cost:
 42: Total Cost:.....Rials
 44- insurance/company Contribution.....

43- patient contribution:.....
 45- complementary insurance.....