



Developing Data Elements for Research Information System in Health; a Starting Point for Systems Integration

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(Received 25 Jul 2012; accepted 17 Nov 2012)

Abstract

Background: This study defines necessary data elements required for the research information system in the domain of health, and its level of accountability to national health research indicators from the experts' perspective is being explored.

Methods: This qualitative study was conducted based on comparative approach using the focus group method. Data were collected through 6 semi-structured group discussions held at the Undersecretary for Research and Technology, Ministry of Health and Medical Education, Tebran, Iran. For this study, 48 researchers were selected for the group discussions. All interviews and group discussions were recorded and transcribed. The Data analysis was performed simultaneously using Strauss and Corbin method.

Results: Based on content analysis, the necessary data elements identified for the National Health Research Information System designed for all databases were the following: organizations, researchers, journals, articles, research projects and dissertations. Also, extracted from the focus group discussion were three main themes regarding data elements of these databases for the National Health Research Information System: 1) essential elements for each database 2) the system's data elements accountability to the national indicators in the domain of health research and 3) recommendations in the direction of optimizing the data.

Conclusions: The results obtained from this study can serve as a valuable source in designing research information system in the domain of health within the country and in the region as well.

Keywords: Databases, Data elements, Health, Research, Research information system

Introduction

Nowadays, enhancing information management in managing an organization is essential (1). Studies have shown that in the 20th century, 80% of scientific productions were related to science and technology (2). Scientific works requires information, and also the essential part of information is derived from previous works (3).

The world of education, technology, and research is also faced with increasing complexity and universities are the obvious examples of these

changes, research is an area that transversely affects the whole activity of a university (4). The amount of information available in consideration to the current state of knowledge is growing quickly and largely in an uncontrolled manner (5). In Europe, it is estimated that the cost of research duplication alone is approximately 20 billion Euros per year (6). But today every institutions and knowledge centers are well aware that research process must be managed similarly to education

process (4). On the other side, industrial and service innovations have compelled the academia in pushing the boundaries of research and development. Government decision makers and policymakers and research centers need to have easy access to research data (7) therefore, the possibility of exchanging information must be propagated in order that research information clients are able to access information through a uniform and equal interface (7, 8).

With the increasing pace of information technology, researchers are faced with a fundamental problem; information in the repository, information system and or the virtual information are presented in different formats and possess different qualities (sometimes contradictory) (9). In order to exchange information and integrate them in a system, common data elements in between these integrated resources must be defined in order that the possibility of communication and application of needed directions for these data sources will be implemented (10).

With the development of national programs, the need for an integrated information systems and a uniform data collection in order to provide continuous, accurate and timely information throughout the country should be apparent in a manner that the possibility of program planning and evaluation of disparities in providing services must be available and be quickly identified. Therefore, data element in all cases must be collected at the national level. These data sets not only guarantee the integrity and suitability of the information collected but similar developments in areas related to decision making will be reflected in an extensive level (9).

Comparison of data used for different purposes such as conceiving international validity, local implementation of research studies and statistical analysis must be made possible. However, data elements that are meant to limit the number of elements that can be collected are not considered (10). Also, for the reason that there are ambiguities in text reports and or the possibility that some specific and important cases might not be reported, therefore, the data elements to be considered a collection of specific terms in a form of a

check list, short terms should be set (8). Integration of data elements for communication in the field of research at the global level is necessary and can be considered a step before designing an information system. In the absence of data elements, information systems will not be able to do the required performance (11, 12). Large number of data elements due to the absence of proper collection have resulted to the loss of valuable data (13). Also, at present, information systems in an organization and research center can act as managerial sensory organ and the organization will be helped in outlining the current view and strategic vision.

Therefore, knowledge of data elements required and being accountable to research indicators in the domain of health is of great importance in designing a national health research information system and qualitative research is an appropriate method in evaluating data elements related to information resources such as articles, dissertations, research projects and etc., thus, this qualitative study aiming to determine the proposed data elements for the national research information system taking into consideration the indicators in the field of research was designed and implemented.

Methods

This is a qualitative study based on "comparative" approach designed and conducted in 2012. In this approach, data elements from the databases of organizations, researchers, journals, articles, dissertations, research projects, in the National Health Research Information Systems of several countries namely, United States of America, Australia, Netherlands and Japan were reviewed and compared. These countries were randomly selected among countries from different continents having national information research systems. Data were collected through literature review of electronic resources and incomplete data were completed by asking the opinions of the responsible person of the national health systems mentioned above through e-mail communication.

Also in this study, focus group discussion (FGD) was conducted in order to gather more data. Key informants were researchers currently employed in the medical universities of the country (Deputy for Research) who have 5-10 years executive experience. Considering that the medical universities in the country are divided into 3 group based on their ranking (type 1, type 2 and type 3 respectively), 2 universities belonging in each group were randomly selected in such a way that type 1 universities Tehran University of Medical Sciences and Kerman University of Medical Sciences were selected, from type 2 universities, Uremia and Kermanshah Universities of Medical Sciences were selected and from type 3, Ilam and Shahre-Kord Medical Universities were chosen. A total of six FGD's were implemented (2 focus group discussions in each group) each group consisting of 5-8 participants. The reason for this approach is the understanding that participants will be more comfortable sharing ideas knowing that they belong to the same level(14) and in order to obtain homogenous groups and more group dynamics (15).

All interviews were conducted by the principal investigator after setting the time frame and providing the necessary explanations to the participants. At the beginning of the interview, after explaining the purpose and the processes of the study, the participants' written consent to participate in the study were taken. Two moderators from the Deputy of Research and Technology who have experienced in qualitative research were employed to direct the discussion, encourage participation of the participants, maintain flexibility and to control the time of the session. Interviews approximately lasted about 1 to 1.5 hours until saturation of concepts was reached. Transcripts of the interviews were audio recorded and comments were observed in the initial analysis.

The instrument used in this study is a guided questionnaire composed of 6 questions covering the study's objectives. In order to establish its validity and reliability following its development based on related literature review, this questionnaire was submitted to two experts in this area for

final evaluation then a pilot study was implemented.

In the first phase of data analysis, the main focus was in the comparison of tables containing the different common elements contained in the aforementioned national research information systems in order to determine common elements as well as their differences. Meanwhile, on the study using FGD, data analysis was done using content analysis. Interviews were transcribed and analyzed manually. Texts were reread and codes were identified. Coding scheme was derived theoretically based on the defined framework of the study. Moreover, themes and subthemes were identified providing basis for generating new codes or modifying the codes developed by induction. Comparison and integration of similar codes lead to novel comments and ideas. Reliability was established through the level of similarity between research findings with separate results extracted by another expert's coding and analysis. Codes were classified into categories and sub-categories and the views of key informants were presented into the following themes: organizations, researchers, journals, articles, research projects and dissertations. In addition, data elements produced as an outcome of this comparative study together with 13 national indicators in the domain of health research were sent to all participants.

At the end, final results of the group discussion in the meeting held at the Deputy of Research and Technology on the 5th of July 2012, with the presence of seven authorities from the area of research information systems who were not participants of the FGDs was introduced.

Ethical issues

This study was approved by the Ethical Committee of Tehran University of Medical Sciences. Participation in this study was voluntary and informed consent was obtained from all of participants. All information obtained from the participants was keep confidential.

Results

Following data analysis, from the six sessions of FGD and based on the objective of the study the six themes mentioned above were identified. Also, each of the major database were evaluated based on 3 major parameters namely 1) data elements required for each base in the national health research information system 2) accountability of data elements of this database to national indicators in the domain of health research and 3) recommendations for system optimization.

Organizations

Majority of the participants have agreed that following data elements must be included in an organization's database; name of the organization, date established, electronic address, local directory, title of publications, fields of research, recent research results, number of patents and the number of approved scientific conferences. One of the participants have pointed that "physical information of an organization defines all areas of an organization and an area of a building is part of the field 'which is unnecessary and of less importance". Also data elements of this database is responsive to the following indicators: "number of active research centers in the domain of health", "number of research parks in the field of health", "number of incubator centers and technology units in the field of health" at the national level, and also is responsive in a part to the indicator "health research funding".

Researcher

In evaluating the researchers' database, participants have unanimously agreed that the following fields must be included in the database; name of the researcher, field of specialization, related research, academic experience, researches, publications, achievements, awards, inventions, training courses, skills, personal electronic address and electronic address of related organization and access to publications and projects.

Also majority of the participants have agreed to the addition of another field in the data base hav-

ing the following elements; job title, academic rank, employment background, status of employment, relevant organization or institution, university, council or association memberships, participation in congresses, number and codes, topics, mailing address, phone and fax.

Again in this respect, one of the participants has expressed that "in this unstable market where bank accounts can be exploited, who is willing to provide his account number in the database?"

Elements of this database is responsive to the two key indicators at the national level namely 1) number of active researchers in the field of health 2) number of registered patents and inventions concerning health issues. Also this database provides a comprehensive report relating to the number of researches conducted with segregation of the titles and the number of active researchers in the domain of health segregating the organization or research institutions and compilations of research achievements.

"Before conducting a research it is better that a researcher should make an assessment regarding his topic, has this research been done before?" If already done, better make use of the results and make his planned research project as a basis towards completion of the first research. How many researchers have been conducted in Iran regarding iron deficiency anemia? Despite these researches, how come we are still facing this problem?" This database serves as a common denominator of per capita funding for every researcher.

Journals

Regarding the journal database, all participants have expressed that these following elements fundamental and should be given consideration in designing this database. These elements include; title, publisher, publication type, journal's scientific rank, name of index, impact factor, relevant organization, issue and codes, subject, URL address, access to full text, copy right, language and the journal's format.

Also data elements such as the status and frequency of publication, date, journal's identification, journal category, description and the journal's

introduction were also agreed by the majority of the participants to be included in this database.

One of the participants has expressed that "I must stress this important point that subject classification in a journal database should be done in accordance to the national Thesaurus in order to meet the demands of the users and better user's retrieval of information."

Elements of this database are responsive to the two key indicators at the national level namely: 1) number of scientific research journals in the field of health 2) the number of Iranian Medical Journals index in accredited international databases. Also this database can provide comprehensive reports about the subject areas of the journal so that basing on these journal publication schedules other special issues will be considered.

One of the participants in this study have expressed that "majority of the scientific journals published are in the field of medicine whereas there are only 2 journals published related to health management and in my opinion, this is very insufficient".

It was suggested that in order to optimize this database components the following should be added to this database: citation, budget, acronym, method of subscription, journal inventory segregated by issues and volumes.

Articles

In connection to the database fields regarding articles, title, authors, title of the journal where the article is published, article citation information, date, URL address, access rights, abstract, location, language and the format of the article were the elements unanimously agreed by all participants, also the fields on co-authors, publishers, volume, issues, start page and end page, organizational affiliation, article identification, authors' identification, keywords, classifications, URL address in all texts, title of conference and the date of presentation were the elements that received the highest agreement by majority of the participants.

One of the participants in this study have pointed that "The standard number, PubMed identification, national library number, relevant research code, author identification, resource identifier to

connect article with research, dissertations and or other databases is of great importance to this database" other participants have also agreed to his opinion.

Data elements of the database are responsive to the indicator "number of articles published in local medical journals having academic research rankings". These data elements are not accountable to these two indicators: 1) number of Iranian medical articles index in international databases to the total number of accredited articles in ISI 2) the ratio of Iranian medical articles indexed in ISI to all Iranian articles indexed in ISI. The reason for this unaccountability is the absence of this specific data element "International article index" in this database. Therefore in order to calculate the above 2 indicators it is necessary that this element be added to the article database. Also, in order to calculate the overall indexed Iranian articles, it is of utmost important that proper program planning be done so that a connection will be established between the database of the Ministry of Science and Research Technology and the Ministry of Health and Medical Education.

Research Projects

All of the participants in this study have considered the following data elements to be very important in developing a database for research project: title, principal investigator, type of project, organization performing the project, role of the organization, URL address of all research text, access rights, abstract, language and research project format. Other additional fields considered important by the majority of the participants include the following; co-authors, publisher, credibility of the project, status of the project (current- completed), relevant research groups, referral to ethical committee, person responsible for preparing data, relevant organizations, project start date and date finished, date of project registration, date of agreement, data of final report, duration of the project, organization's number, number of collaborating organization, number of the project, identification (author, source, location), categories and keywords.

"We do agree to include the field on project budget in this database but, myself who is a researcher am I willing to announce the project budget?" (Study participant).

Data elements of this database is responsive in calculating a part of the national health indicators namely; the ratio of research funding in health and treatment to the total budget allocated for health and treatment, per capita research fund to researchers, health research funding, ratio of health research funds to the GDP, the ratio of health research funds to the country's research budget.

One of the participants has expressed that "research funds are spent in some other matters (purchasing equipments, facilities and etc.) an amount of the budget which is supposed to be solely spend for research projects."

Another participant has pointed that "you should see the components of budget expenditures and the budget allocated for research to be spend instead in buying books? In designing a system? Paying the personnel's salaries?"

As a result, in order to determine the above indicators, research components must be identified and the budget allocated for that purpose must be specified. This database can be used in obtaining budget specifically allocated for research projects. Also, this data base will show the frequency of research topics and the supporting organizations actively participating in research activities.

It is also proposed that research projects that resulted to dissertations, original articles, and or presented in conferences should be indicated in this data base.

Dissertations

Majority of the participants have agreed to include the following data elements as essential components to the database on dissertation: title, authors, advisor, and type of dissertation (Bachelor, Master and PhD), profession, authors' e-mail address, URL address (sources- text source), access rights, abstract, language and format. Also the inclusion of the following fields such as publisher, number of pages, title of journals where articles resulting

from student's theses are registered, title and location of the conference where thesis is to be presented, name of organization, date of thesis submission, number of organization, number of IranDoc database, identification (author, source, location, national library) and rankings were approved by the majority of the participants.

Another participant in this study has expressed that "I think that it is necessary that data element regarding dissertation funding, meaning the implementation of research grant projects by the Ministry of Health and Medical Education with the purpose of allocating research budget to outstanding students in conducting their dissertation be included as a field in this database so that a better program planning will be implemented in this regard.

National indicators in the field of dissertation database have not been taken into consideration. However, this database in the sense that it contains such data element as budget allocation therefore this can serve as satisfactory solution in some part of research budget allocation. Also, according to one of the participants in this study, "this database, the dissertation in which an article has been produced and these articles presented in conferences or published in journals, show them to me" It was also suggested that data elements on physical descriptions of a thesis (that include layout, images and attachments) be added to this database. As the last step, final results of the group discussion in the meeting held at the Deputy of Research and Technology on the 5th of July 2012, with the presence of seven authorities from the area of research information systems who were not participants of the FGDs was introduced. Majority of the authorities (61.5%) have expressed that the proposed model can be implemented to a large extent while a smaller percentage of the authorities (15.4%) have expressed that this proposed model can be fully implemented and 19.2% have expressed that this model can be implemented in a very small extent. In this regard, one of the participants has expressed that "with the presence of bandwidth and IT infrastructure and tele-communications in the country and its complexity, this proposed model cannot be fully

implemented and if implemented, the users will encounter many errors both in registering information and during searching for information.

Discussion

The necessary data elements extracted from the participants point of views and their accountability to national health indicators are the most important components in establishing a national health research information system. Integrating data elements is an essential step in implementing a national health research information system (16) and through these data elements, outputs, significant reports and valuable future will be available (17, 18) and in this direction, results of this study have shown that the available data elements contained in the databases do not fully meet the need of the national indicators in the field of health research therefore, it is important that necessary data elements be included in the national health research information system database.

Several studies have shown that in order to determine the data elements of existing databases in the national system, most countries have employed various meetings with the presence of experts in different fields such as; researchers, epidemiologists and statisticians, also opinions of national and international organizations which are pioneers in research were reviewed (19, 20).

In this study, data elements were determined after performing literature review at international level and then were submitted to the committee for evaluation and for further revision. In this direction, the study conducted by Biering et al. in 2011 has confirmed this method (21).

In classifying information in the research database for the national health research information systems, studies have showed different results. In this study, data elements for this database were generally classified into 2 groups: 1) general information and 2) technical and bibliographic information. General information includes date, abstract, level of access, remarks, publication guidelines, date last updated and the type of abstract. Technical and bibliographic information include, title, level of

access, start date, estimated date of completion, responsible organization, implementing organization, principal investigator, investors, contract data, technical abstracts and subject classifications (22). Data elements in this study were divided into seven general categories that include bibliographic information (which include data elements such as; title, principal investigator, co-authors, publisher, research funding, project status, relevant research groups, project type and referral to Ethics Committee), time information (date started, date finished, date of contract registration, data of final report, duration of the project), information retrieval (organization's code, number of collaborating organization, project number, number of principal investigator, author's identification, resource identification, location identification, classifications, subjects and keywords), access information (resource URL, URL address on all text), physical appearance (language and project format) and description (abstract) has been taken into consideration.

Chancellor office management information system database is composed of several databases in a logical manner based on common data elements and related software. Original database is composed of main area for students, departments, courses, staffs, and faculty members. Each of these databases is broken into smaller groups, given as an example is the student's database that includes demographic data elements, information about students registration and a database designed for students financial aid. Also in this study, identifiers have been emphasized (23).

In this present study, the national health information system research, a combination of various information databases that include organization, researchers, journals, articles, research projects and dissertations with emphasis on location identifier, individual identifier and resource identifier has also been considered. But in this system, student's data base has not been considered. In the researcher's data base, individual or demographic information, location information, information about time, information related to products and activities of researchers, information retrieval, and information access has been mentioned.

Based on the findings in this study and other studies as well, XML has been recognized as the standard in formatting and exchanging data. Currently, use of Thesaurus terms for retrieval of knowledge representation and the use of XML to support in combining complex context from simple context is considered a necessary data element to the dataset (24-27).

In the study conducted by Wattigney and colleagues, the workgroup has agreed that in order to create data elements for registering acute stroke and in order to add data elements to the original list, the members can either express their opinions by answering directly or by raising their hands every time a dataset is proposed. Finally a list of data elements will be presented to the team for the purpose of improving, developing and defining data elements for use and implementation (27). In the majority of studies conducted to determine data elements, qualitative research and panel of experts and a consensus of experts has been utilized. Consensus of opinions has been achieved through personal attendance in meetings, telephone conferences and e-mails (28, 29).

Also, in some other studies information were made available to the general public through the website for a period of 30 days then a survey is conducted to determine whether existing data elements need revision or not? This type of research necessitates implementation of a pilot study for a period of one year (30). Also, in this study qualitative method as well as focus group discussion was employed in order to reach a consensus.

Another study conducted in 2008, the Frida Research Registry has taken into consideration to spread the following five modules: research results, list of research projects, list of researchers, list of organizations and annual reports. In this regard, the 13 modules were reviewed and because of its extensiveness only 6 modules were presented in this study

Conclusion

In recent decades, developing and low income countries have faced fundamental challenges due

to inadequate information and some problems such as lack of support from the government and health research management system at national level have led to inefficient performance in guiding and following up of research activities. However, improving health research management in the direction of reaching maximum return delivery of investments in health research is essential (31).

Gaining the consensus of the group regarding standard data elements brings with it many benefits and compatibility of standard data elements, titles of variables and their definitions which are considered the core instruments for collecting data. Research clients can better compare examples of research and research results based on their financial resources (4-6, 11-13, 32).

The following strategies are recommended to research groups whose activities are aimed towards establishing and developing data elements for a national health research information system: The consensus of the committee composing of all major stakeholders should be used for decision making process in selecting the necessary data elements.

- Use the same data elements previously prepared by others and prepare data elements in accordance to necessary standards
- Consult with various experts especially those who are directly involved in data collection such as coordinators of research activities, registrar and data managers
- Provide a draft of data elements containing structured data together with definitions and their values
- After discussions with all key experts and end users, make use of the decision of the consensus as well as the opinion from foreign experts to confirm data elements.
- After applying the data elements in the data base, it should undergo experimentation through a pilot study
- Annual evaluation must be conducted in order to evaluate the quality of data elements and assess the opinions of end users

Ethical considerations

Ethical issues (Including plagiarism, Informed Consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc) have been completely observed by the authors.

Acknowledgment

This study was part of a PhD. Thesis supported by Tehran University of Medical Sciences (grant No: 674). The authors declare that there is no conflict of interest.

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