Medical Science Data Sharing

Chinese Academy of Medical Science

Depei Liu
Program name: Medical Data Sharing Network

Program number: 2005DKA32400

Recommended by

Ministry of Science and Technology
Ministry of Health
Health Department of PLA’s General Logistic Department
State Administration of Traditional Chinese Medicine
State Food and Drug Administration
Program name: Medical Data Sharing Network

Program number: 2005DKA32400

Applied by:

Chinese Academy of Medical Science
Chinese Center for Disease Control and Prevention
China Academy of Chinese Medical Science
General Hospital of PLA
Information Center of State Food and Drug Administration
Academy of Military Medical Science of PLA
1. Create a Medical data sharing network that is physically well distributed, clearly arranged, logically highly unified and fully shared.

2. Create four scientific data centers—basic medicine, clinical medicine, public health and traditional Chinese medicine, including about 300 databases.
3. Establish the standard and specification system, resource planning system and platform-support system for medical science data sharing.

4. Through the construction of sharing network and data centers, provide information to the government for health policy decision, and to scientific field for health care, medical research and education, and health improvement for the whole population.
This program is a cross-subject and cross-industry large-scale project that is co-undertaken by several departments. Its features are:

- Basic medicine & Clinical medicine combination;
- Prevention, Control & Treatment combination;
- Medicine & Pharmacy combination;
- Chinese medicine & Western medicine combination.
Leading group
• organization and coordination
  • body and property protection
  • managing mechanism

Scientific Panel
overall plan
• supervision & management
• exam and acceptance

Work group
Plan execution
• Schedule arrangement
• work guidance

Program office

Data center

Sharing network management center

Local node
Sharing Policy and Service System

- Constitute Serial Standards for Medicine and Health Data Sharing.
- Enact provisional management methods for biomedical database selection and data convergence.
- Work out a reward/punishment system for biomedical data sharing service.
“Eleventh Five-year” Plan for Medical Science Data Sharing Network

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General Center

Sub-program

Program management

Need analysis

standards and norms

Resource system construction

Technology platform construction

Pharmacy data resource conformity

Sharing node construction

Program management

“Eleventh Five-year” Plan for Medical Science Data Sharing Network
Resource construction

Resource survey, classified description, resource manual compilation, resource management and sharing function regulation

- **Data set making**
  - Observing data standards
  - Definition of data set standardization
  - Physical property design of data set

- **All-purpose database**
  - Observing metadata standards
  - Grouping design for data items

- **Theme database**
  - Observing specialized model in the field
  - Theme design for data warehouse

- **Physical center for sharing network**
  - Management and application of all-purpose database

- **Physical center for sharing network**
  - Management and application of data warehouse

- **Provide data-set-based special display services**

- **Provide data-integration-oriented all-purpose display services**

- **Provide theme-oriented data searching services**

- **Provide all-purpose, convenient resource-conforming tools**

- **Resource plan**

- **Resource design**

- **Design and development of resource planning software**
Data Resource Conformity

- Organize current data resources on the basis of data resource survey;
- Collect data from work data and make them into sharing data set;
- Converge sharing data sets in data centers;
- Integrate data from data centers to form theme database;
- Converge metadata in the medicine and health data sharing network.
Standard construction

1. Study and stimulation of specialized data standards for medicine and health (including data element, metadata, data mode, classification and coding standards);
2. Compilation of internal and external terms, codes, and mode standards in the field of medicine and health;
3. Design and study of theme domain model, special concept modal of data center and data set EM model in the field of medicine and health;
4. Designing and development of standard execution software;

Compile criteria for standardized work in medicine and health and set up dynamic preservation and synchronous update system for the standards according to standards used by Ministry of Science and Technology

Metadata
- Data element
- Data mode
- Classification and coding

Data discovery
- Data visit
- Data expression
- Data operation

Standard construction serves in the entire process of constructing the physical center for resource platform.
One sharing network:
Medical Science Data Sharing Network

News

Meeting and Announcements
2005-09-17

Home page navigation:
- Medical Science Data Sharing Network
- Management Guide
- Add Search

Medical Science Data Sharing Network

Stem cell research
Clinical education
Pharmacology
Biomedical engineering

Survey

Satisfaction with the website:
- Very satisfied
- Satisfied
-基本满意
- Not satisfied

Submit
Check
Four Data Centers
Foreword

- China has granted a lot of research expenditure on biomedicine, including 863 and 973 Programs and national natural science foundation, through which a large amount of scientific data were accumulated.

- Under the support of data sharing program of Ministry of Science and Technology, the grand program of Medical Science Data Managing and Sharing Service System was started in 2003.
• 2002: research and investigation
• 2003: project was set up; feasibility study (7.2 million, 2003DEA2C015)
• 2004: listed as key program of National Science and Technology Basic Conditions Platform Construction (18.72 million, 2004DKA20240)
• 2005: listed in the 11th five-year plan for scientific and technological development (61.92 million. 2005DKA32400)
Specialized team for biomedical science data sharing includes:

1. standardization staff
2. computerized automation staff
3. informationization management staff
4. data sharing application staff
4. data sharing research staff (master and doctor)
## Sub-programs of Medical and Health Data Sharing Network

<table>
<thead>
<tr>
<th>No.</th>
<th>Sub-program name</th>
<th>Task</th>
<th>Unit or team in charge</th>
<th>Person in charge</th>
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<tbody>
<tr>
<td>1</td>
<td>General team</td>
<td>Standardization and integration</td>
<td>Chinese Academy of Medical Sciences</td>
<td>Liu Depei</td>
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<td>Pharmacy data resource conformity and sharing service</td>
<td>Pharmacy data resource conformity and sharing service</td>
<td>Information Center of State Food and Drug Administration, Institute of Materia Medical of CAS</td>
<td>Hong Xiaoshun Du Guanhua</td>
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<td>Local nodes of sharing network and data sharing service</td>
<td>Network node construction and service in province, city, county and three regions for minor ethnic groups</td>
<td>Workteam, Xiang Ya Hospital, Beijing Hospital for Elderly, Attached Hospitals of Hebei North University, Institute of Nationalities</td>
<td>Lin Ling Yuan Hong et al</td>
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</table>
Construction of General Center

- Data resource conformity
- Standards and norms
- Technology platform
Process for data resource construction of sharing network

1. Define data resource range
2. Data resource classification and description
3. Data resource manual compilation
4. Data resource investigation

5. Proving of sharing Resource feasibility
6. Sharing task plan
7. Task application and evaluation

8. Sharing task assignment

9. Data set making, Convergence Management and sharing
10. All-purpose database design and sharing
11. Theme database design and sharing
12. Sharing resource management
Overall Framework for Technology Platform Construction
Example:
Map Display of natural source of schistosomiasis
Example:
The Database for National Death Surveillance
Example:

Background introduction to The Database for National Death Surveillance

(The Database of National Disease Surveillance)

1989年，中国预防医学科学院在世界银行项目的支持下，根据分层整群随机抽样的原则，重新组建
和优化了各区县的报告监测点，并进行了《(The multi-stage cluster sampling) 影响疾病监测工作的几个问题》的
调查。全国共有近200个监测点，这些监测点分布在城市的各个角落，包括医院、学校、工厂、
社区等。这些监测点的数据收集和分析，为国家的疾病监测和防控提供了重要的数据支持。

最后形成的疾病监测系统由分布在31个省（自治区、直辖市）的148个疾病监测点组成，每个监测点有3-1000万监测人口（占中国总人口的1%）。由于该系统是根据分层整群随机抽样的原则建立的，其监测结果可
以在中国1000万监测人口中实现基本的疾病监测目的，包括监测人口的出生、死亡（含死
亡因病）和疾病的情况。该系统每年收集近5万疾病个案，10万出生个案，对监测数据进行分析后，每年以报
告的形式发布监测结果。

每年疾病系统进行医院传染病数据收集，以确保医院传染病报告质量；每年在各监测点进行一次出生
活产率调查，并利用“健康-经济-社会”模型，建立健康评价以改变健康数据。出生和死亡样本方式病
例分类符合率（ICD-9）超过90%。全国疾病监测系统死亡监测系统的常规报告项目包括在婴儿死亡率计算的
修正，达到较合理的结果。根据全国疾病监测系统在不同年代人群的年龄因素分布计算的联合因
合指数值均小于0.001的年龄性别组合，估计和实际值相似。

1993-2000年全国疾病死因监测数据库，包含有三个数据库（出生数据库、人口数据库、死亡数据库）

数据随机化技术：建议使用IE6.0，分辨率600*800。
Example:
Chinese death rate at different age groups because of bronchus lung cancer (Year 2000)
Example:
Map display of national death surveillance.
Basic Database for Traditional Chinese Medicine

### Database Content

#### Search Functionality
- **Database Name**: 基础数据库 (Basic Database)
- **Developer**: Microsoft Internet Explorer
- **URL**: http://share.cintcm.com/baseview/baseview.htm

#### Table Example

<table>
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<th>药理作用分类</th>
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<td>防风</td>
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</tbody>
</table>

#### Instructions
- **Description**: The database provides comprehensive information on Traditional Chinese Medicine, including drug properties, indications, and usage. Users can search by specific keywords or categories to find detailed information.
- **Navigation**: The interface includes search filters and字段 (fields) for enhanced query accuracy. Users can refine their search by selecting specific criteria such as drug name, property, or category.

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**Note**: The database is part of the 中医药科技信息数据库 (Chinese Traditional Medicine Information Database) system, offering a wealth of data for researchers and practitioners.
Database for Pharmacological Experiments of Traditional Chinese Medicine
## Database for Chemical Experiments of Traditional Chinese Medicine

### Query Results:

<table>
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<tr>
<th>Experiment Object</th>
<th>Experiment Site</th>
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Database for Toxicology of Traditional Chinese Medicine
Database for Adverse Effects of Medicine
医药卫生科学数据共享工程——药学主体数据库
Conclusion

1. It has established the standard and specification system, sharing resource system and platform-support system of medical science data sharing in China.
2. The Sharing Network for Medical Science Data under construction consists of four scientific data centers and about 300 databases.
3. The Data Center of Traditional Chinese Medicine has apparent regional characteristics.
4. We have good cooperation with foreign countries in biomedicine and Public health research.
5. We are going to establish a network for China-America cooperation in biomedicine data sharing:
   • Work out serial standards and norms for international data sharing of biomedicine.
   • Conduct surveys and need analysis of international data resources of biomedicine and constitute plans.
   • Create a network joint-research environment for international biomedicine; carry out global coordination in scientific research.
   • Provide data sharing services to world wide for their health policy decision, health care, scientific research and education and health improvement for whole population.
Suggestion

Under the general framework of CODATA, set up branches for medical and health science data sharing system. They are to be responsible for organization of international academic activities of biomedical data sharing.