



report on
Research
Health



2007



*Islamic Republic of Iran
Ministry of Health
And Medical Education*

***Report on
Health Research in***

The Islamic Republic of Iran

*Ministry of Health and Medical Education
Research and Technology Division
Public Relations Department*

2007



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***Report on Health Research
In The Islamic Republic of Iran***

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Part 1

Introduction

The Ministry of Health and Medical Education, which handles the Health Research System (HRS), was established 20 years ago, when the healthcare and medical education systems were integrated. The ministry is responsible for health sciences education and provision of health services. Most of its responsibility falls on 43 medical universities and schools and 158 research centers across the Islamic Republic of Iran. These academic centers are responsible for delivering health care services to the public. Most medical research centers are affiliated to these universities.

The Ministry of Health and Medical Education has provided a fair amount of health resources in keeping with Primary Health Care (PHC) principles. Currently, Iran benefits from a public health system whose free services are extended to almost the entire nation.

HRS, as a system for planning, coordination, monitoring and managing health research resources, promotes research for effective and equitable national health development.

The main goals of health research are advancement of scientific knowledge and utilization of knowledge to improve health and health equity.

The WHO has defined HRS as "people, institutions, and activities whose primary purpose is to generate high-quality knowledge that can be used to promote, restore, and/or maintain the health status of the population. It should include the mechanisms adopted to encourage the utilization of research."

Functions of the Health Research System

The following functions are proposed as putative attributes of a well-functioning health research system:

1. Stewardship Function
 - Define and articulate a vision for a national health research system
 - Identify appropriate health research priorities and coordinate adherence to them
 - Set and monitor ethical standards for health research and research partnerships
 - Monitor and evaluate the health research system
2. Financing Function
 - Secure research funds and allocate them responsibly
3. Creating and Sustaining Resources
 - Build, strengthen and sustain human and physical capacity to conduct and absorb health research

4. Producing and Using Research
 - Produce scientifically validated research output
 - Translate and communicate research to publicize health policy, health practice, and public opinion
 - Promote the use of research to develop drugs, vaccines, devices and other equipment to improve health

Health Research System in the Islamic Republic of Iran Stewardship

Outlook for two decades from now

"Iran is a developed country, with Islamic and revolutionary identity, inspiring the Muslim world with constructive and effective interaction on the international stage."

The bodies, currently active in policymaking, are:

- 1) The Islamic Consultative Assembly (Parliament)
- 2) The Supreme Council for Cultural Revolution
- 3) High Council for Science, Research and Technology
- 4) Research and Technology Division at the Ministry of Health and Medical Education (MOHME)

According to the documentation available, the High Council for Science, Research and Technology in general and its Health, Social Welfare and Nutrition committee in particular, play a major role in formulating health research policies. The council is headed by the president of the republic. Officials in charge of relevant governmental organizations such as the Ministry of Health and Medical Education and the Ministry of Science, Research and Technology also have a seat on the council.

MOHME is responsible for working out strategies and plans to implement these policies.

Ethics

The National Committee for Research Ethics was formed in 1998. One year after its establishment, regional committees on ethics of medical research were formed at medical universities and research centers in the country. Research projects require approval not only by the relevant research council but also by the ethics committee of the institution to which the center is affiliated.

Prioritization

Here is a look at the prioritization process in Iran as far as medical research is concerned:

The first national priority setting was conducted between 1992 and 1994 by the medical commission of the National Research Council (NRC). First five major fields were delineated by the medical commission of the NRC including basic sciences, clinical sciences, public health, drugs, and nutrition.

In 1996, research policy committees emerged with the participation of faculties of medical universities and outstanding experts in six different fields: clinical sciences, basic sciences, pharmaceutical sciences, nutrition and rehabilitation, medical equipment and industry, and educational and healthcare services system.

The commission defined ten priorities for medical research in line with the decision of the NRC to shore up the “National Research Program”.

Need assessment and priority setting in provinces

Cultural and social diversity in the country coupled with diversity of the health indices in different parts of the country have prompted the Research and Technology Division to evaluate the health needs of every province in order to determine regional research priorities.

In 2001, the division released an executive guideline entitled “Ensuring Priority Setting for Health through Need Assessment in the Region.” This executive guideline was implemented in seven medical universities. These universities were chosen based on three factors: commitment, interest and enthusiasm for cooperation on the part of university directors.

After making some modifications to these guidelines in order to adjust them to the needs of the regions involved, and with the cooperation of provincial stake-holders, this program was implemented. In line with these guidelines, the committee brought together the board of university directors, scientific groups, and other organizations which deal with health-related issues such as the Ministries of Education and Culture, the Physical Education Organization, mass media, municipalities, representatives of the public (women’s groups, youth groups and elderly groups, and representatives of the private sector and NGOs. The committee takes care of the following:

- a. Political, technological and logistical support
- b. Implementation of programs
- c. Preparation of a final priority list
- d. Monitoring and evaluating provincial projects

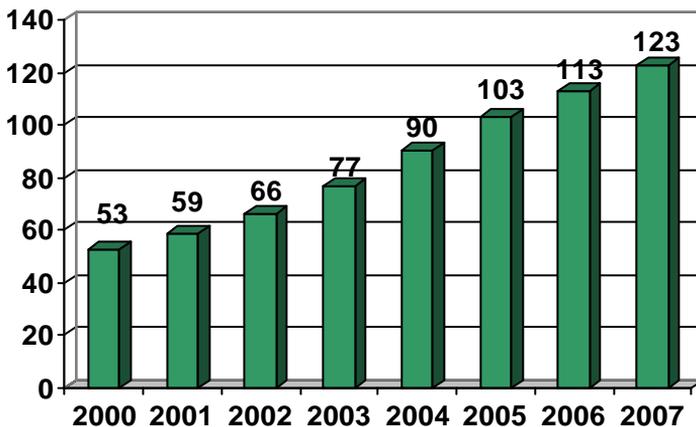
Evaluation

Given the systematic approach to the process and implementation of HRS, the following organizations are involved in the Monitoring and Evaluation (M & E) of HRS functions:

- High Council for Science, Research and Technology
- The Research and Technology Division at the Ministry of Health and Medical Education

Now, the research and technology division monitors all HRS functions in medical universities on a six-monthly basis, and evaluates medical universities and medical research centers each year (using specific forms). Medical universities receive written and personal feedback based on these M & E activities. Based on the results of M & E activities, medical universities and research centers with the highest rankings could be nominated for awards at the Razi Medical Science Festival and for an independent or

increased budget. Conversely, centers with spiraling M & E grades may have their licenses revoked. International agencies supervise the spending of funds allocated to joint programs. They also assess the production and publicize the results of such projects.



Financing

The governmental sector is the source of a vast proportion of health research funding in Iran. Each year the non-governmental sector funds only between 3 and 6 percent of all health research projects in the country.

Under the spending package for 2007, all governmental organizations have to spend between 1 and 4 percent of their budget on research, based on their priorities.

The percentage of the Gross Domestic Product (GDP), which has been allocated to health research, increased from 0.01 in 1991 and 0.1 in 2004, to 0.9 percent in 2006.

Supporting and Empowering Environment

The total number of active academic members in medical science universities is 11,984. Some 68% of research faculty members are fellows and 32% tutors. In addition, 85% of research faculty members are active within the medical university system and 13% are outside the university system. All researchers have access to Pubmed. The ground is prepared for implementation of joint projects by local and foreign researchers. Karolinska is an institute which cooperates with Iranian researchers.

Seventy percent of the researchers cooperate with fellow researchers in implementation of joint research, publication of data and exchange of information.

Knowledge production and utilization

The number of major biomedical projects increased from 3,912 in 2003 to 6,942 in 2006. Some 22% focus on basic science, between 14 and 16% are in the field of health research and the remainder focus on epidemiological, productive, qualitative, and analytical issues as well as clinical trial.

The figure below shows the development of biomedical journals between 2001 and 2007.

Part 2

Reports on the Activities of Research and Technology Division to Develop the Health Research System (1994-2007)

In keeping with HRS functions, the policies and programs implemented by the Research and Technology Division since 1994 include:

Networking

- Create and develop research networks in the following fields:
 1. Molecular Medicine
 2. Medical Biotechnology
 3. Herbal Medicine
 4. Pharmacology
 5. Stem Cell
 6. Traditional Medicine
 7. Cancer
 8. Mental Health
 9. Ophthalmic Disease
 10. Tropical Disease
 11. Neuroscience
- Building capacity among researchers and members of research networks
- Designing and implementing 115 research projects in the network
- Establishing two research banks, a cell line bank and a DNA bank
- Formulating strategic planning for research networks
- Establishing monitoring and evaluation systems for research networks
- Establishing a regional network for genomics and biotechnology in cooperation with EMRO (with Iran leading the network)
- Preparing for an international congress on genomics in cooperation with the Molecular Research Network and Medical Biotechnology (The plan has secured the approval of the Cabinet.)

Capacity Building

- Conducting 339 training workshops on Research Methodology, Information Technology, Research Management, Ethics in Research, Research Utilization, Evidence-Based Research, Clinical Trials, Methods of Performing Needs Assessment, Priority Setting, etc.

Monitoring and Evaluation of Research Activities in Medical Universities and Research Centers

- Monitoring the research activities in medical universities every six months
- Evaluating the research activities of medical universities and research centers on a yearly basis

Development of Health Centers in terms of Quality and Quantity

- Increasing the number of medical research centers in the country, (from four centers in 1994 to 158 centers in 2007)
- Creating a research center data bank
- Providing a research framework for medical research centers in the country

Number of Research Centers

| Year | Clinical Sciences | Basic Sciences | Research Centers in Total |
|-------------|--------------------------|-----------------------|----------------------------------|
| 2004 | 55 | 44 | 99 |
| 2005 | 64 | 51 | 115 |
| 2006 | 71 | 57 | 128 |
| 2007 | 92 | 66 | 158 |

Establishment of relations with industries that are relevant to the health of the community

- Establishing six 'incubators' in such fields as drug production, biotechnology and medical equipment, monetary support and special counseling on these matters
- Supporting research designs related to industries in different medical universities across the country
- Following up and observing the appropriate implementation of the national project – 12 nanotechnology items in the field of health and treatment
- Facilitating researcher use of special benefits and equipment in different research centers through establishment of a Nano-laboratory network
- Developing expertise in formulating standards for medical instruments and equipment

Strengthening Student Involvement in Health Research

- Providing monetary and technical support for student research committees in all medical universities across the country
- Organizing a nationwide seminar for university students
- Supporting 778 theses conducted by university students at Master's and PhD levels
- Launching Internet sites and student research committees in medical universities throughout the country
- Sending members of student research committees to international conferences

- Preparing and formulating a declaration of ethics for student research committees
- Establishing six collaborative networks for student research in the country
- Nominating best student researchers for the 13th Razi Research Festival

Establishment of research units by creating clinical research centers in training hospitals

- Establishing 23 centers to develop clinical research
- Formulating strategic planning to set priorities for research, capacity building for students and clinical faculty members, and organize programs for clinical research

Promoting Ethics in Medical Research

- Organizing a national committee on ethics for research in medical sciences
- Evaluating the 89 research proposals on ethical evaluation presented by different universities
- Formulating a research ethical code

Development of International Cooperation

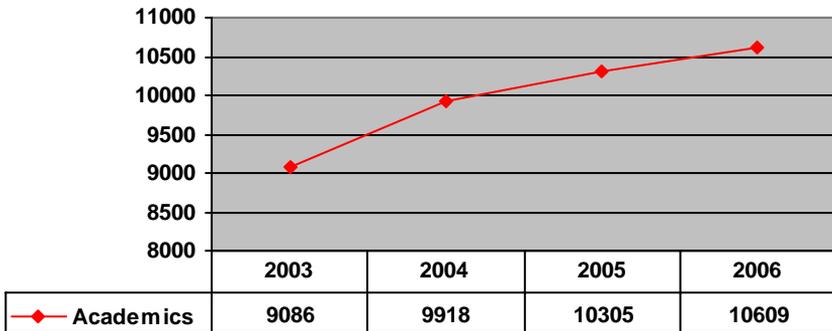
- Promoting cooperation with international organizations such as the WHO on research designs and the two-year JPRM (Joint Program Review Mission)
- Exchanging knowledge and technology and forging scientific cooperation with Karolinska Institute in implementation of 18 joint research projects in different fields agreed to by both parties, and exchange of students, transfer of technology, etc., through written agreements
- Designing beneficial programs in cooperation with the network of specialists outside the country
- Organizing joint symposiums to be attended by Iranian and foreign researchers

Part 3

Health research- Input Indicators

- Academics
- Research Budget
- University Budget
- Training Workshops

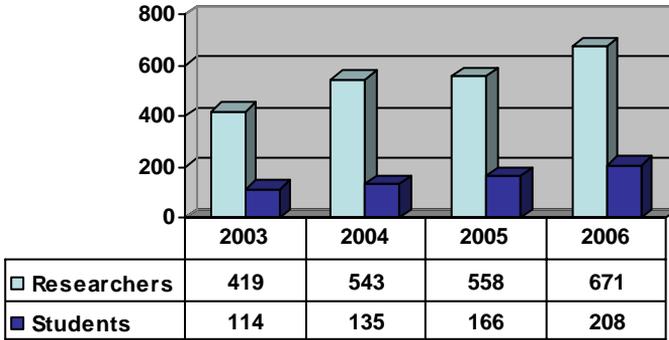
Number of Academics (2003-2006)



Budget (2003-2006)

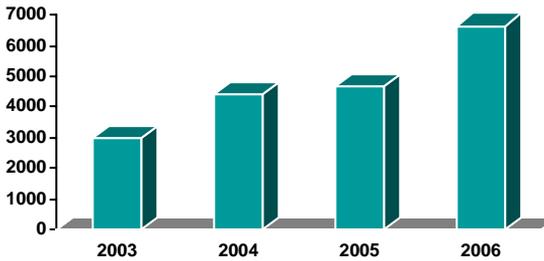
| INDEX \ YEAR | 2003 | 2004 | 2005 | 2006 |
|---------------------------------|---------------------|---------------------|---------------------|----------------------|
| Research budget (Million Rials) | 161382.5 | 241483 | 213548 | 399963 |
| University budget (U) | 8919426 R/U= 1.8 | 16253661 R/U=1.4 | 23488253 R/U=0.9 | 29605680 R/U=1.35 |

Number of Training Workshops for Researchers and Students (2003-2006)

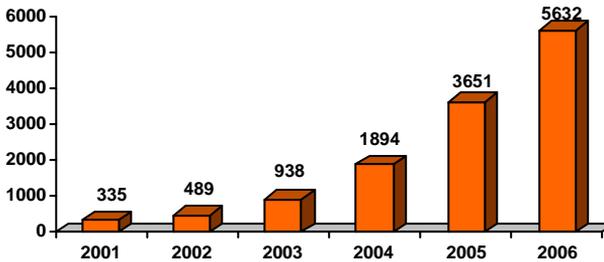


Health research- Output Indicators

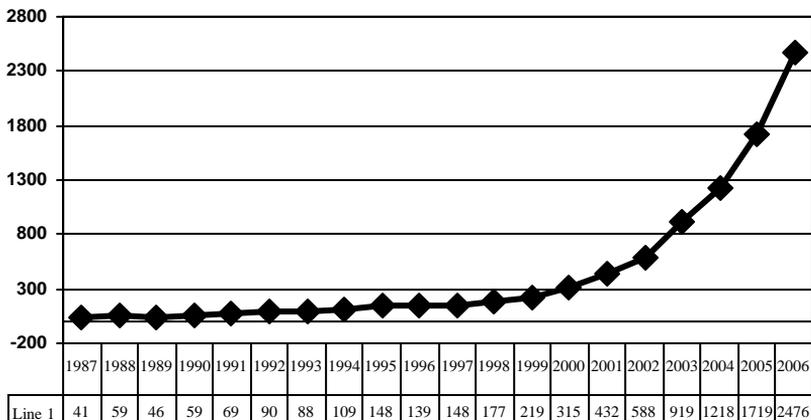
Total Number of Iranian Articles Published (2003-2006)



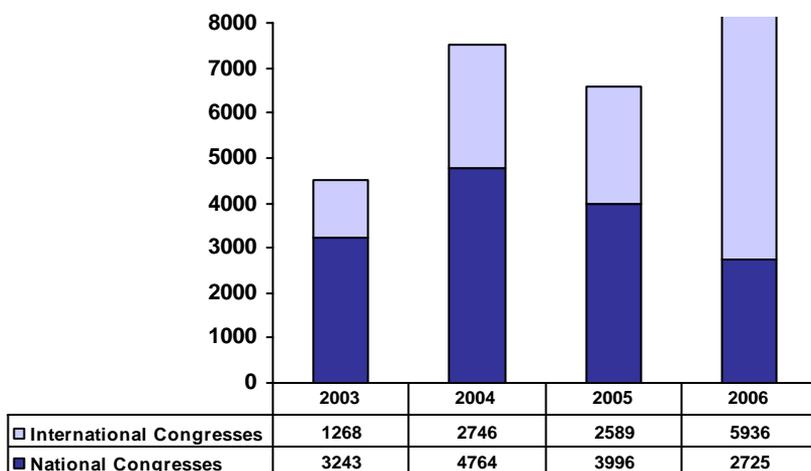
Number of Biomedical Articles Published in Indexed Journals



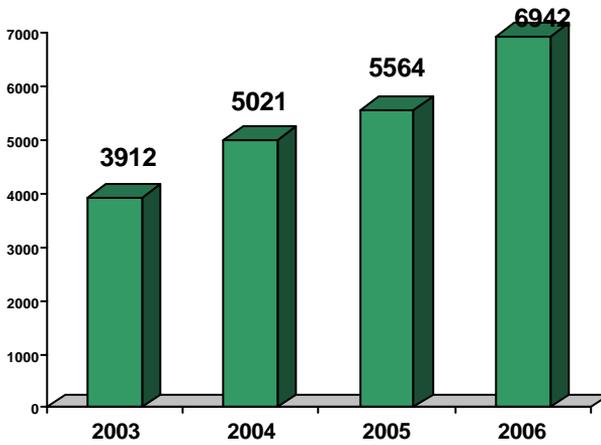
Trend of Iranian Biomedical Articles Indexed in Medline/Pub med (1987-2006)



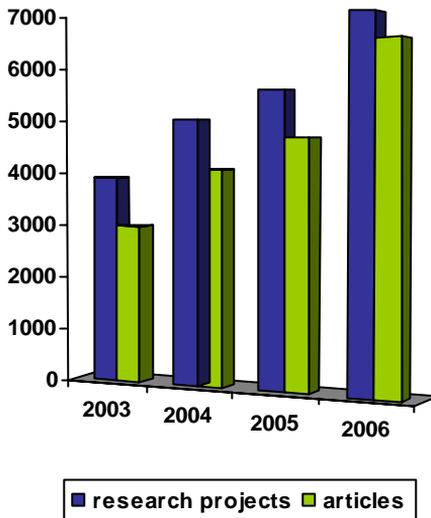
Number of Articles Presented in National and International Scientific Congresses (2003-2006)



Number of Biomedical Projects in the Islamic Republic of Iran (2003-2006)



Trend of Research Projects and Biomedical Articles in the Islamic Republic of Iran (2003-2006)



Part 4

An Experience: Integration of Medical Education into Health Services System

In 1985 an important reorganization took place in the country; medical universities and health sciences were separated from the Ministry of Education and incorporated into the Ministry of Health, thus creating the Ministry of Health and Medical Education and Health Services. The integration involved two phases:

Phase I (1985-1993): After launching the new ministry, a first group of medical universities were created. These universities together with the Provincial Health and Medical Organization in each province were under the supervision of the Ministry of Health. In other words, all measures in connection with rendering health services, medical education and research were to be under the supervision of the ministry.

Phase II (1993 – until present): In this phase, medical universities and Provincial Health and Medical Organizations were integrated. These universities are responsible for training the health department workforce, doing health research and providing health services.

The integration has resulted in the following:

- An increase in the number of medical schools
- An increase in the number of physicians
- An increase in life expectancy
- Improvement in the healthcare system

In addition, the move has also had special effects on research. Research results have been used in decision making and in making policies regarding health matters.

It has brought into existence the Research and Technology Division at the Ministry of Health. Since its foundation, many different programs have been implemented nationwide among them: 1. Introduction of the healthcare delivery system which paved the way for more applied research by universities; 2. Shoring up the capacity of health experts, and the department of health; 3. Implementation of a two-phase research project on health and diseases to put together the country's epidemiological information. This method enables researchers to learn from each other's experiences. In fact, health experts are now able to develop a deeper insight into research. 4. Creation of a research committee for university students to encourage them to join the health research system; 5. Family planning which had been one of the biggest challenges of the country began to be handled by universities. In fact different types of researches and application of research results helped solve this problem; 6. Implementation of applied research to the following: IDD (Iodine Deficiency Disorders), ORT (Oral Rehydration Therapy), substance abuse, thalassemia, malaria, health problems, health volunteers, etc. These researches have resulted in changes to some laws and regulations, as well as emergence of new planning and policies in the country; 7. Development of a death registration

system which takes account of the cause of death. The country has used this information in working out programs to prevent accidents and injury; 8. Determination of the country's research priorities in the health care system, while stressing the presence of all stake-holders; 9. Networking of the research with an emphasis on the presence of the users; 10. Proposing new ideas and modern approaches in research such as community-based cooperative research; 11. Creation of research committees in the health system within universities throughout the country and leading research in the direction of solving health problems; and 12. Looking at the implementation processes in an expertly and scientific manner.

To sum it up, the integration has resulted in the expansion of research and the use of research results for decision-making, planning and policymaking. It has also resulted in interdepartmental cooperation especially in the area of community- based research.

Part 5

Major national surveys resulting in interventions in the healthcare system

1- Title

Healthy town, healthy village in line with Basic Development Needs

Project Manager: Dr.Ahmad Joneydi Jafari

Colleagues: Bagher Shoaliyeh/ Zahra Salimi

Problem and necessity to conduct survey

Despite the socio-economic progress the world has posted of late, the gap between nations and communities within a nation still persists. Analyses show that such a gap has its roots in failure to pay attention to major indicators such as training and skills, housing, income, security and food supply in development plans. Studies on health inequalities also suggest that the health gap between the poor and the rich is widening.

Millennium Development Goals view health as the driving force of development. The programs worked out following the Millennium Goals summit suggest that governments around the world have committed themselves to providing healthcare. To that end, the Eastern Mediterranean office of the World Health Organization put forth the Community Based Initiative, a strategy which sets out plans for healthy towns and healthy villages in line with Basic Development Needs. It also takes account of the role of women on the development stage.

In Iran the healthy town program got underway in 1991. Nine years later the healthy village program came on stream. On the back of the success these programs achieved, later evaluations, both local and foreign, showed that there was close cooperation between government institutions and the public and that senior officials lent support to the pilot program conducted in 16 universities across the country.

Interventions the study resulted in or expected to result in

One major achievement of the program was an increase in public knowledge about economic, social, cultural and health-related issues and about public mobilization to contribute, directly or indirectly, to executive programs. It also promoted the culture of interdepartmental cooperation to implement public programs and raised awareness in the ranks of policymakers, planners and development experts. Implementation of different economic, cultural and social projects by members of the public with the assistance of the government helped tap into the financial and technical potential of the public. In fact, their contribution to questions which directly affect them resulted in decentralization, self-reliance and deregulation. Alleviation of poverty and disparity along with empowerment and job creation helped narrow the gap between disadvantaged and developed areas, thus paving the way for administration of justice and promotion of healthy lifestyles. The project is currently underway in 20 towns and 37 villages.

2- Title

Monitoring the prevalence of goiter Necessity to conduct survey

The growth-related problems associated with iodide deficiency resulted in the study which was designed to compile a report on the incidence of goiter in the country and evaluate interventions designed to prevent those problems. The first such survey was conducted in 1996. The second came five years later. And a third is currently underway.

Interventions the survey resulted in or expected to result in

Producing and distributing iodized salt in the country, making it binding on salt producers to impregnate their products with iodine and educating the public to use iodized salt are among measures taken in this regard. A resolution released at the close of a joint meeting of the WHO, UNICEF and other international organizations in 2000 identified the Islamic Republic of Iran and Tunisia as the only countries which had managed to control the disorders associated with goiter.

3- Title

Children Anthropometry and Nutrition Indicator Survey (ANIS) Necessity to conduct survey

Malnutrition of children is a major health-related problem of the country. Besides, malnutrition follows different patterns in urban and rural areas and even in different provinces. That is why the problem of malnutrition needs detailed planning and interventions. The first Anthropometry and Nutrition Indicator Survey (ANIS) on a provincial level, conducted in 1998, provided health officials with basic data to work out plans to improve child nutrition and resulted in regional interventions. Six years later another provincial survey was conducted to evaluate children's growth and factors affecting it, namely the scope of mothers' awareness and their conduct. In addition to evaluation, the move was designed to help work out regional plans to narrow the gap between different regions and improve nutrition promotion plans.

Interventions the survey resulted in or expected to result in

Presently a food safety project is underway. Besides, the study led to interventions such as introduction of supplementary products, enrichment of flour, control of infectious and parasitic diseases and extensive education. These programs remain ongoing.

4- Title

Micronutrients in Iran (2001) Necessity to conduct survey

The important role micronutrients play in the growth of children and young adults along with the significance of targeted intervention prompted officials to design and launch a national survey on micronutrients such as iron, zinc and vitamins A and D in vulnerable groups of the country.

Interventions the survey resulted in or expected to result in

The study led to interventions such as introduction of supplementary products, enrichment of flour, and nutrition education which remain ongoing. Besides, a food safety program is being conducted.

5- Title

Death registration system

Necessity to conduct survey

Having a clear-cut picture of death and disease in society in order to identify and counter their underlying causes is a major strategy to increase life expectancy and promote human health. That is why the health department has decided to survey death indicators on the basis of age, gender and cause on national, provincial and metropolitan levels.

Interventions the survey resulted in or expected to result in

The project was first implemented in Bushehr province in 1998. It was later expanded to four, 10, 18, 23, and 29 provinces excluding metropolitan Tehran. So far four reports have been released.

All those involved in healthcare, one way or another, can use the results of the survey to work out plans to increase the life-expectancy of citizens, push down mortality rates and provide healthcare.

The results of the survey are used not only in drawing up relevant regulations and directives but as reference on the international stage.

6- Title

Integrated Monitoring and Evaluation System (IMES)

Necessity to conduct survey

When it comes to planning all healthcare providers need information on how successful they have been in meeting their stated objectives. In other words, planners need an information management system to see how effective their plans have been in settling the health-related problems of society.

To that end, designing operational programs and systematizing family healthcare programs in universities became part of the agenda in 1998. The experience of drawing up such programs by universities between 1998 and 2001 revealed the deficiencies of the planning which mostly drew on expert views and not on evidence and causes. A comprehensive system to provide officials and decision-makers with an overview of existing indicators was conspicuous by its absence.

The absence of Integrated Monitoring and Evaluation System (IMES) to serve as a centerpiece of intervention programs was the most important problem the healthcare system was facing. An integrated system which took account of technical and scientific considerations was designed and implemented in 2004.

Interventions the survey resulted in or expected to result in

The national study resulted in emergence of a huge data bank. Collecting, filtering and organizing the data took almost seven months to complete.

The survey also produced a report on healthcare provision indicators and the logistical system. That report was in turn based on another which was 700 pages. The Integrated Monitoring and Evaluation System is now about to release its final, comprehensive report which is expected to be used by health planners.

7- Title

Iran Demographic and Health Survey 2000

Necessity to conduct survey

The Demographic and Health Survey, on both provincial and national levels, was conducted in 2000 through interdepartmental cooperation. It was designed to introduce unity to the figures jointly used by the Ministry of Health and other institutions and to work out new indices needed for national development plans.

Interventions the survey resulted in or expected to result in

All healthcare providers affiliated to the Ministry of Health and Medical Education need an overview of the change in relevant indicators in order to evaluate their programs. Besides, all other institutions involved in healthcare, one way or another, use the results of the survey, especially when it comes to literacy, employment, migration, age, family welfare, reproduction, family planning, children's health, etc, to make planning.

The report has been published in both Farsi and English.

8- Title

National survey on burden of disease

Necessity to conduct survey

Because prioritization and planning in the healthcare system need to be based on qualitative evidence, it was decided that the burden of disease in the country be determined.

Interventions the survey resulted in or expected to result in

The project is complete and its preliminary results have been offered to health officials. The full report, which is now being published, is expected to be used as a criterion in healthcare prioritization on a national scale.

9- Title

Availability of healthcare in the Islamic Republic of Iran

Necessity to conduct survey

Policy makers and planners, on a national level, always draw on the performance of the healthcare system to prioritize services. That was why in 2002 the Ministry of Health and Medical Education decided to draw up a report on the performance indicators of the health system so that the overall system could be evaluated on the basis of these indices.

Interventions the survey resulted in or expected to result in

Results of the project released in 2005 have been used to gauge the availability of health services, to determine how fair healthcare expenses have been, how the health system responds to the non-health needs of the public and how it respects the rights of individuals, and remove the deficiencies of the system.

It is the first survey in which the Ministry of Health and Medical Education has reviewed its performance when it comes to availability of public and private health services.

10-Title

Cancer registration system

Necessity to conduct survey

Cancer is the third leading cause of death in Iran. In 1984, the Islamic Consultative Assembly (parliament) passed legislation which made registration and reporting of cancer mandatory. The data collected between 1986 and 2004 suggests that cancer registration has posted both qualitative and quantitative growth in recent years. A review of the registration process as far as both quality and quantity are concerned comes in annual reports.

Interventions the survey resulted in or expected to result in

Reports have been published on the performance of the system between 1986 and 2004. In these reports the department dealing with cancer has said it plans to expand to 80% cancer registration on the basis of pathology reports in 10 provinces and remove the deficiencies associated with the system.

11-Title

Risk factors in non-infectious diseases in the Islamic Republic of Iran

Necessity to conduct survey

Non-infectious diseases currently account for 43% of the burden of disease. Their ever-growing trend has placed them on course to claiming the first spot. As a result, knowledge about the distribution of risk factors in society is a must; so is it necessary in development of national prevention and control programs.

Interventions the survey resulted in or expected to result in

The study, in keeping with 'steps' proposed by the World Health Organization, is conducted on a yearly basis. The first such study in 2004 was designed to pave the way for creation and or improvement of the system dealing with non-infectious disease in the country and determine different indicators on non-infectious disease on both national and provincial levels. Removal of deficiencies associated with methodology in later studies has propped up the process.

12- Title

Promotion of PHC Coverage in Urban Areas of the Islamic Republic of Iran by Women Health Volunteers (WHVs)

Lead Researcher: Professor Hossein Malekafzali

Colleagues: Dr. Naghavi, Dr. Asgari Nasab, Dr. Madani

Date of research: 1990 – 91

Place of research: Shahr-e Ray, South of Tehran

Sponsor: WHO

Statement of the problem: Since 1985 active PHC services have been delivered to Health Houses. But in urban areas the health system used to be inactive, that is to say people had to visit health personnel in Urban Health Centers for PHC services. In 1990 a project was carried out in South of Tehran in order to mobilize the community to render PHC services active.

Hypothesis: Women Health Volunteers (WHVs) will promote PHC services punitively and qualitatively in urban areas.

Methodology: In Shahr-e Ray district which is located south of Tehran four Urban Health Centers were selected and for each center a population of 12,000 was defined. During census women who were literate were selected as WHVs. Each WHV takes care of 50 neighborhood families. WHVs should take training courses at the Health Center. They have five duties with regard to families under coverage:

- 1- Promoting health education especially when it comes to MCH and Family Planning
- 2- Encouraging families to refer to Health Centers
- 3- Collecting health information from families under coverage
- 4- Participating in research activities in defined populations
- 5- Being involved in social development of the local community

Results: Results show that PHC coverage was significantly higher in intervention areas than control areas, both quantitatively and qualitatively. For example the percentage of unwanted pregnancy was much less in intervention areas than control areas.

Result Dissemination: The results were applied quickly throughout the country with the support of the WHO, UNICEF and UNFPA. At present the country enjoys the services of 100,000 WHVs who render PHC services to 10 million people in the suburbs of big cities and small towns.

Relevancy to Bamako Conference: This case study consists of Objectives 2, 3 and 4 of Bamako.

13- Title

Health Research of Substance Abuse Prevention and Treatment Office (SAPTO)

In Recent Years

Final Researches

1. Epidemiology of substance abuse in Iran. (Shahmohammadi, Yasami, et al, 2001)

This was the first epidemiologic study of substance abuse across the country. The sampling has been done in emergency rooms of medical universities' general hospitals. The study provided invaluable data regarding substance abuse and indicated that health system should involve in substance abuse services more actively.

2. High risk behavior among prisoner population. (Bolhari, 2005)
The study assessed substance abuse and high-risk behaviors including IDU among prison population. The study provided strong evidence in support of the necessity of substance abuse services including harm reduction in prisons.
3. Comparative efficacy of low-dose MMT and high-dose MMT in treatment of opioid dependent patients (Razzaghi, Mokri, 2004)
The study supported the feasibility and effectiveness of high-dose MMT for treatment of opioid dependent patients. The results of this study have provided a framework for future regulations for establishment of MMT clinics in the public and private sector.
4. Prevalence of and factors associated with HIV-1 infection among drug users visiting treatment centers in Tehran, Iran (Zamani, et al, 2006)
5. High prevalence of HIV infection associated with incarceration among community-based injecting drug users in Tehran, Iran (Zamani, et al, 2006)
These two studies highlighted the significant correlation of history of substance abuse in correctional settings with HIV/AIDS infection. The results emphasized the need to implement high quality substance abuse treatment and harm reduction programs across the prisons.
6. Needle and syringe sharing practices of injecting drug users participating in an outreach HIV prevention program in Tehran, Iran: a cross-sectional study. (Vazirian, 2006)
This was the first study that has indicated a correlation between service utility in needle/syringe programs and lower needle and syringe sharing. The study concludes that effectiveness and cost-effectiveness of harm reduction components including NSP and education is very important.
7. Profiles of risk: a qualitative study of injecting drug users in Tehran, Iran (Razzaghi, et al, 2006)
The study assessed ethnographic characteristics of IV drug users in Tehran. With respect to high risk behavior, housing status and employment, authors identified three categories of patient and discussed appropriate health intervention for each one.

Under development

1. Epidemiology of substance abuse in Iran (Rahimi, et al)
2. Feasibility and effectiveness of office-based treatment of opioid dependency with agonist prescriptions (Eftekhar, et al)

3. Rapid situational analysis of substance abuse in Asaluyeh (Saberi, et al)
4. Feasibility and effectiveness of natural opioid (opium tincture) for maintenance treatment of opioid dependency (Mokri, et al)
5. Qualitative study on health system response to methanol micro epidemics in two cities (Hasanian, et al)
6. Development of Drug Abuse Services Information System (DASIS). (SAPTO)
7. Evaluation of screening and mandatory residential treatment of homeless IDUs (Rahimi, et al)

14- Title

Iranian national thalassaemia screening programme

Abstract:

Thalassaemia prevention programme was introduced to the health system when it was used to control of communicable diseases. It also was initiated when many infrastructures for starting a genetics programme were short or lacking, including community based genetics counseling and genetic diagnostics. To solve the problem the programme developed systems and networks and created models not only for integration of other genetics diseases but for linking of different parts of health system including private sectors to the primary Health Care (PHC) system. This method also led to 75% reduction in incidence of the disease and establishment of infrastructures needed for starting a comprehensive genetic programme.^{20,21}

The problem:

Progress in controlling communicable diseases increase the relative importance of noncommunicable diseases, including genetic disorders.¹ In Iran, the development of primary health care over the past 20 years has greatly reduced infant mortality and crude birth rate. Accordingly, in 1991 prevention of non-communicable diseases was added to the primary healthcare programme, and a department for the control of non-communicable disease, including a genetics office, was established within the Ministry of Health and Medical Education. _ Thalassaemia, which is an important health problem in Iran,² was chosen to test the feasibility of the system to establish a comprehensive genetics disease control programme.

Method to approach:

Primary healthcare infrastructure in Iran:

Iran has a primary healthcare network covering³¹ province (figure1). Each medical university of province has a vice chancellor responsible for primary health care. The responsibilities of primary care staff include an annual census of the population covered, health education, family health (prenatal and postnatal care, children, family planning, immunisation), disease control (tuberculosis, malaria, leprosy, etc), simple treatments, and storage of health information.

In Iran, when a new programme is developed, provincial health workers attend an initial meeting at the ministry about programme goals, strategies, and activities, followed by regular updating workshops. Each level of the primary health care system then educates the next level down. Ongoing evaluation is considered equally important. Standardised surveillance data are passed up level by level; each level evaluates its own performance and that of the next level down, and the disease management centre provides feedback to the entire network.

Thalassaemia prevention programme:

The thalassaemia programme was designed to create a model to test the capacity of PHC system to integrate a comprehensive genetic disease control programme and create general infrastructures for prevention of genetic disorders. Screening was included as part of existing mandatory premarital blood tests. Initially, couples at risk were offered only information and genetic counselling because abortion after prenatal diagnosis was not allowed in Iran. Integration into primary care required development of instruments and methods for educating health workers, the public, and target groups and establishment of professional networks to provide genetic diagnostic services, genetic counselling, and evaluation (surveillance).

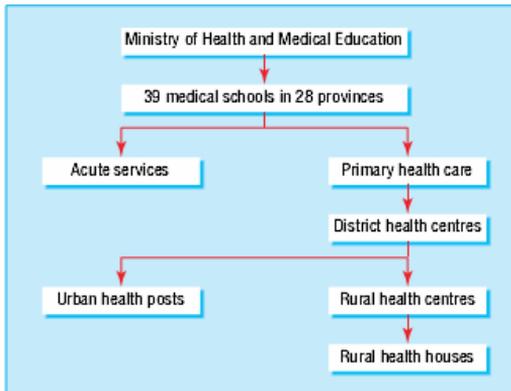


Figure 1: Primary healthcare system (PHC)¹

Creation of systems and networks needed:

Primary care genetic counselling network—Genetic counseling teams consisting of a doctor and a professional with a BSc degree in health studies were established in designated accessible urban health posts in every city. Training, organised by specialists attached to the National Genetics Committee, follows the ethical principles recommended by the World Health Organisation^{9,10}

It includes a distance learning self taught course and face-to-face courses at national level.

System for informing the public and target groups— Many groups in the community need to be prepared for premarital screening. Relevant experts have been recruited into a national multidisciplinary educational committee, linked to corresponding provincial committees, and so on down the system. Classes about thalassaemia are held for high school students and for young men doing military service (because men are the first to be offered screening). The judiciary is linked to the programme through annual meetings for marriage registrars.

Laboratory network for screening:

Governmental and private laboratories equipped to screen for thalassaemia have been recruited into an accredited national professional laboratory network, supervised by a national reference laboratory and directorate for laboratory affairs. There are corresponding structures at the provincial level. Laboratory staff follows national screening protocols based on international guidelines¹¹, participate in quality control, and attend regular educational courses.

System for Evaluation

Evaluation of the programme provide information on numbers of at risk couples identified and their choices concerning marriage and reproduction; numbers of patients with thalassaemia and their age distribution; and numbers and outcomes of prenatal diagnoses, when this service is available¹²⁻¹⁴.

Genetic counselling teams report numbers of carrier couples counselled, their choices, and referrals to DNA laboratories. Health houses and health posts report follow up data on carrier couples and register infants born with thalassaemia. Registers of patients and prenatal diagnoses are being developed. The genetics office computerises and evaluates the data, reports back to provincial health centres, and arranges regular field visits by experts. The surveillance system provides guidance on how to adapt the programme to meet the needs of the community¹².

Process of screening:

Marriage registrars refer prospective couples to a designated local laboratory for premarital screening. The man's red cell indices are checked first. If he has microcytosis (mean cell haemoglobin < 27 pg or mean red cell volume < 80 fl), the woman is tested. When both are microcytic their haemoglobin A₂ concentrations are measured.

If both have a concentration above 3.5% (diagnostic of α -thalassaemia trait¹¹) they are referred to the local designated health post for genetic counselling. Microcytic individuals with a haemoglobin A₂ concentration in the normal range are treated with iron and their indices rechecked. All results are sent to the local genetic counselling team. At risk couples attend as many counselling sessions as they need to

Reach an informed decision (an average of 2.5 sessions, range 1-5). Those who marry after counselling are referred to their local health post or health house for follow up until they have completed their family.

Lessons from pilot programme:

At the outset the options for at risk couples were limited to marrying as planned, separating and finding a non-carrier partner, or postponing marriage or childbearing in the hope of a better solution in the future. However surveillance data, supported by the reported experience of the counsellors, soon showed that the population wanted the option of prenatal diagnosis. This led to intensive and widespread ethical discussions, which concluded in 1998 with an authority decision to permit abortion before 16 weeks from the last menstrual period if the fetus is known to be affected.

Creation of network for prenatal diagnosis (PND):

A national DNA laboratory network, including two national genetic reference laboratories and 3 other laboratories experienced with thalassaemia, was initiated in 1999 and began to function in 2001. This network helped to employ few genetic labs in the country to focus on the national program. The number of labs increased as programme developed and more private and governmental laboratories (within the medical universities), were established using method of networking in the programme. Now there are 12 PND labs throughout the country in different regions working with the thalassaemia PND network. The laboratories follow national guidelines, accept referrals from primary care, and return surveillance data. Since the creation of the DNA laboratory network, the number of couples seeking prenatal diagnosis has risen sharply.

Results:

Table 1 summarises national data for the first five years. By the end of 2001, over 2.7 million prospective couples had been screened and 10 298 at risk couples had been identified. After counselling, about half proceed to marriage. Data from the developing national thalassaemia register (table 2) suggests that the affected birth rate had fallen to 30% of expectation by the year 2000.

Table 1 Outcomes in first five years of Iranian thalassaemia prevention programme

| Year | No of couples | | Decision of couples (No (%)) | | | At risk couples |
|-------|----------------|---------|------------------------------|-----------|-----------|-----------------|
| | Tested (1000s) | At risk | Married | Separated | Uncertain | |
| 1997 | 353 | 1 057 | 486 (46) | 473 (45) | 98 (9) | 3.0 |
| 1998 | 520 | 1 534 | 802 (52) | 532 (35) | 200 (13) | 3.0 |
| 1999 | 564 | 2 201 | 1073 (49) | 598 (27) | 530 (24) | 3.9 |
| 2000 | 672 | 2 716 | 1455 (54) | 745 (27) | 516 (19) | 4.0 |
| 2001 | 620 | 2 790 | 1615 (58) | 671 (24) | 504 (18) | 4.5 |
| Total | 2729 | 10 298 | 5431 (53) | 3019 (29) | 1848 (18) | 3.8 |

*Based on a simplified assumption of a 1 in 4 risk of an affected child in affected couples and that at risk couples have the same birth r:

Development:

The Iranian thalassaemia programme is yet to complete. The programme does not detect structural haemoglobin variants such as haemoglobin S, which is common in some provinces. Pilot studies of screening for risk of sickle cell disorders are now in progress. In khozestan province in south of Iran, this is planned as an integrated part of the thalassaemia programme and will be set up in the entire prevalent areas when evaluation results of the pilot programme predict effectiveness of the operation.

Table 2 Number of new patients with thalassaemia major registered at Iranian treatment centres during 1998-2002

| Year of birth | No of new patients reported | % of expected No without intervention* |
|---------------|-----------------------------|--|
| 1998 | 480 | 40 |
| 1999 | 416 | 35 |
| 2000 | 341 | 28 |
| 2001 | 206 | 17 |
| 2002 | 78 | 7 |

*Without any intervention about 1200 affected children would be born each year.

Lessons from experiences:

The programme is economically viable because it works through the established primary healthcare and educational systems, focuses existing (though scattered) genetic expertise on a common objective, using methods of networking and systems of non-physical employments. Couples willingly pay for screening because they want a healthy family and are prepared for expenses associated with marriage. The (governmental) insurance companies pay for prenatal diagnosis because it helps to limit the escalating cost of patient care^{19, 18}. This enables the laboratory network to expand to meet demands. Mass referrals provide laboratories and universities with resources and scientific data, so promoting further development of genetic knowledge and technology in the country, and expanding capacity for other genetic services. This development satisfies the scientists and makes the national programme attractive to them.

Primary care based genetic counseling that proved as effective must be inclusive rather than focused on a single disorder. Hence the network must be developed in terms of quantity and quality. The recognition that thalassaemia screening is simply a first step in the application of genetic knowledge in primary care has been crucial for its acceptance. Having this concept, Iran has started its comprehensive genetic disease control programme in a pilot area. The programme has a basement to help (on demand) genetic part of prevention in service package of every disease control programme integrated in the health system of Iran, including communicable and non-communicable diseases. This part covers genetic interventions for prevention of cancers (especially familial cancers) and cardiovascular diseases. specific part covers diseases which are ranked as priorities in the health system. The heads of the prioritised categories are:

- 1- Hemophilia A, B (Bleeding Disorders)
- 2- Phenylketonuria (Metabolic Disorders)
- 3- Down syndrome (Chromosomal Disorders)
- 4- Neural Tube Defect (Congenital Malformations)



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