Report

Iranian National Diabetes Research Network Project: Background, Mission, and Outcomes

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Introduction

Diabetes is a noncommunicable disease with worldwide distribution. It meets all the three criteria for a public health disorder:

- A high disease burden;
- Changing burden suggesting preventability; and
- Fear that things are unknown and out of control.

On the other hand, it is one of the major causes of death and disability, so it leads to the important area of research on prevention, screening, and early intervention.1-3

Iranian Ministry of Health (MoH) has designed a health system for more equitable allocation of health resources based on Primary Health Care (PHC). It is an integrated and stratified health care system, and national or multicentric preventive programs should be implemented in this system. According to MoH reports in 2004, 5,513 physicians worked in the PHC system. As the health systems moves towards greater coverage with more addressees, the traditional approaches to clinical research will fail.3,4

Research without systematic planning dissipates resources and intellectual investments and must be barred by a managed network.

Now (after a four-year period of implementation of our research network) we are going to report the findings and profits, the lessons learned from our experience, the obstacles we encountered, and future directions.

Background and structure

Having considered the above-mentioned problem, Endocrinology and Metabolism Research Center (EMRC) — a research center with 13 years experience, which is affiliated to Tehran University of Medical Sciences and is a member of International Diabetes Federation — invited local (provincial) research centers that were active in diabetes surveys to enter into a session for proposing solutions for systematic planning.

EMRC suggested that a national diabetes research network be created as a preliminary project. So, Iranian National Diabetes Research Network (INDIRAN) Project has emerged as the infrastructure for research in diabetes. Deputy for Research and the National Advisory Committee on Noncommunicable Diseases of MoH endorsed the network in 2002. In primary sessions, the executive framework and the approval protocol for research projects were established. Then, in regular sessions, research priorities were approved for designing of common projects according to Figure 1.

INDIRAN is a group of research centers throughout Iran, which collaborate in diabetes research projects with cooperation of international and ministerial advisors. Permanent secretariat is located in EMRC. Sessions held regularly twice a year to make direct contact between the members and advisors and also to provide opinion sharing. But in the other times, there is a two-side relation between the provincial members and network secretariat while observant organizations and international advisors connect EMRC directly. The descriptive organization chart is shown in Figure 2.

Goals

INDIRAN has emerged as an integrated and systematic national framework to encourage research in different aspects of diabetes mellitus
and to find novel and effective treatments for it and assessing those treatments in clinical trials. It aims to decrease morbidity and mortality of diabetes and its complications via three-level prevention and finally to increase hope to life in diabetics.

Detailed objectives
- Strategic and operative planning
  - To promote quantity and quality in diabetes research (these two objectives are the same. When you promote quantity and
quality, you will develop it).
- To reduce parallel surveys in diabetes field.
- To produce a template for successful research at local and national levels.

- **Data collection**
  - To ascertain the current state of knowledge in the field of diabetes in Iran.
  - To identify the research teams in Iran working in the field of diabetes and the research teams with the best output in quality and quantity.

- **Organization and proceeding**
  - To analyze collected data uniformly by a team of experts.
  - To set up a database for research teams affiliated to INDIRAN.
  - To plan and organize research projects according to priorities.
  - To follow up the performance of ongoing projects according to the schedule.

- **Training**
  - To hold sequential and educational workshops for diabetes research teams.

**Outcome**
Although our network is very young, our outcome-despite of deficiencies — is hopeful.

Because INDIRAN improved and expanded its plans according to the mentioned objectives, such as Core Data Set to be a wealth of data for researchers throughout country. Also, setting standard diabetes clinics with the aid of standard clinical guidelines was done to link research and practice. Line up diabetes software facilitated support clinical decision making, form a Supporting Society of Diabetic Patients, and educational website. And finally the publications support diabetic patients and so on. Some of the results are explained descriptively below:

**Projects**
These national or multicentric projects that are addressed below are just some of the completed or ongoing projects:
- Prevalence of diabetes in Iran (completed),
- Diabetes education and prevention program,
- Life style modification, Pattern of current care in diabetics,
- Burden of diabetes in Iran (completed),
- Epidemiologic survey of diabetes complications,
- Evaluation of quality of life in diabetic patients,
- Identification of cost-benefit of intervention in diabetes risk factors.

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**Figure 2.** Organization chart of INDIRAN (UMS* = University of Medical Sciences).
Iranian Diabetes Guidelines (IDGs)

Current studies show that many people with diabetes do not receive preventive care. This is due to a variety of attitudinal, educational, and systemic barriers. Changing physicians’ behavior is a crucial step in scientific management and, therefore, in improving the outcomes. Clinical Practice Guidelines (CPGs) have emerged as a means for this purpose and for reducing variation in care. IDGs were designed for the Iranian physicians who manage diabetic patients. IDGs cover the management of all types of diabetes and their acute and chronic complications in primary, secondary, and tertiary care levels, screening, and lifestyle modifications.

IDGs are the first practical guidelines for management of diabetic patients in Iran and have been implemented in health care system under supervision of MoH.

Supporting Society of Diabetic Patients

Supporting Society of Diabetic Patients was founded in order to involve further supporting non-governmental organizations (NGOs) in diabetic patients care such as “Charity Foundation for Special Diseases”. This society has installed an around-the-clock diabetes hotline in Iran. Also a diabetes institute is under construction in collaboration with some NGOs in Tehran. The Institute of Diabetes consists of research and interventional divisions such as Islet Transplantation Unit, Cell Culture Laboratories, Animal Room, and Cardiology. Nephrology, Ophthalmology, Podiatry, and Obstetrics and Gynecology Clinics.

Educational website and publications

An educational website in diabetes-related subjects for different audit, entitled “Iranian Diabetes Education Website” has been established. Two major characters have been considered in its designing: simplicity in use and attractiveness in presentation. The initial stages of establishing the website have almost been completed. The preliminary website (includes diabetes news, questions and answers, medical consult, and other educational fields) was inaugurated at World Diabetes Day (14th November 2005) in Persian. The website can be found at the address: www.ide.ir.

Meanwhile, various educational booklets in the field of diabetes have been published for general population and distributed all over the country.

Future programs and limitations

Diabetes software and core database

The key to the proper management of diabetes is to have the access to the data of each patient and his/her progress, and finally a correct perspective of our diabetic society. There is some evidence and it is a common experience that medical guidelines are neglected, even if the target audience (e.g., physicians) initially read them. The ideal is probably to incorporate the guideline into a protocol-driven workstation so that the user cannot escape the guideline when managing a patient.

INDIRAN has been evaluating available Electronic Health Record (EHR) management software since 2002 to achieve the mentioned goals. Finally, EMRC outlined approved EHR according to IDGs for decision support. It was planned for use in standard diabetes clinics and is utilizable for registration, data recording, and follow-up with mentioned characteristics that make it appropriate for a core data set. The pilot software is currently in use in some member centers and will be used in all diabetes clinics of INDIRAN.

Characteristics and advantages:

- Technologic characters: equipped with UPS, regular back up to center, data oriented design, database engine: access, language: visual C;
- Decision support making;
- Structured data entry; e.g., tree format with check lists or drop lists; and
- Ability of advanced search, scientific-analytic report (by data export to SPSS and variable curve illustration) and scanning and storing of related photos.

This part is publicizing the Hakim Software. We are not sure if it is suitable to publicize it in this way in a scientific journal.

Evaluation of guidelines

Successful outcomes for established diabetes care depend on a structured system of care with a well-trained multidisciplinary workforce. The efficacy of IDGs performance for changing general practitioners’ and internists’ behavior in the management of diabetes is a topic for study. Policy makers in health care system need to have information about the likely benefits and costs of diabetes guideline implementation. Therefore, we are currently accomplishing a study to assess the
efficacy of IDGs in improving the care of diabetic patients and also to assess physicians’ compliance towards CPGs.

Obstacles
Despite accomplished efforts, there are still significant differences between the capital and provincial members of INDIRAN in view of facilities and personnel. So, some projects are not operable in some centers. Also, in a number of provinces there is no active research center in the field of diabetes to perform national projects in collaboration with INDIRAN.

Conclusion
A key challenge in type 2 diabetes is how to implant preventive programs within the primary health care system. This will require definition of the groups at risk and consideration of the balance of effort at individual and public health levels. We will need to monitor the incidence and prevalence of diabetes as key outcomes of efforts to reduce the disease risk through population and societal strategies. Therefore, research networks have been proposed as one method to stimulate the rigor, quantity, and usefulness of health services research. And the scientific products of such networks, which can be judged through their publications, make valuable contributions to the evidence base.

Although research networks have been studied in literature but most of publications introduced Practice-Based Research Networks (PBRNs) and the only few networks in professional fields attended to a special aspect such as core data set or compilation clinical guidelines. We tried to structure a research network in a subspecial field - diabetes- with considering nearly all aspects of it. Our network emphasizes on both research and utilization of those research on health care (based on evidences). Because those who have diabetes today will gain more benefit from successful implementation of our current knowledge into everyday care than from the only effort in basic diabetes research which will benefit potential patients of tomorrow.

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