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Information Systems Supporting Health-promotion Activities Focused on the Individual

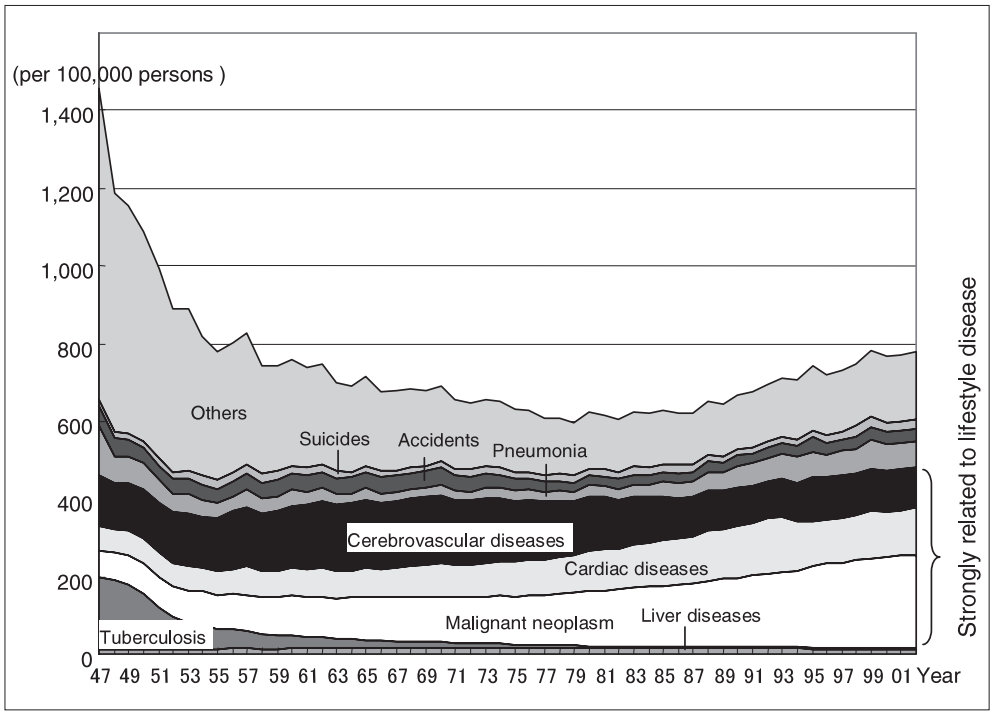
MAKOTO TACHIKAWA *(Affiliated Fellow)*

1 Introduction

With improvement in living environment and changes in lifestyle, particularly the Westernization of the diet, Japan's disease structure has shifted weight towards lifestyle-related disease such as hypertension and diabetes. As seen in Figure 1, deaths strongly related to these illnesses are increasing. Lifestyle-related disease is focused on in medicine in accordance with this trend, but as can be seen in Figure 2, Japan's healthcare costs are continually increasing both in total expenditure and as a percentage of the national income. To contain rising healthcare costs, the provision of effective and efficient care for lifestyle-related disease is necessary.

Care for disease requires activities not only from healthcare service providers, but also from healthcare consumers*1 in general. These activities are necessary in treatment, and even more necessary in primary prevention*2 (health-promotion) activities, where there are

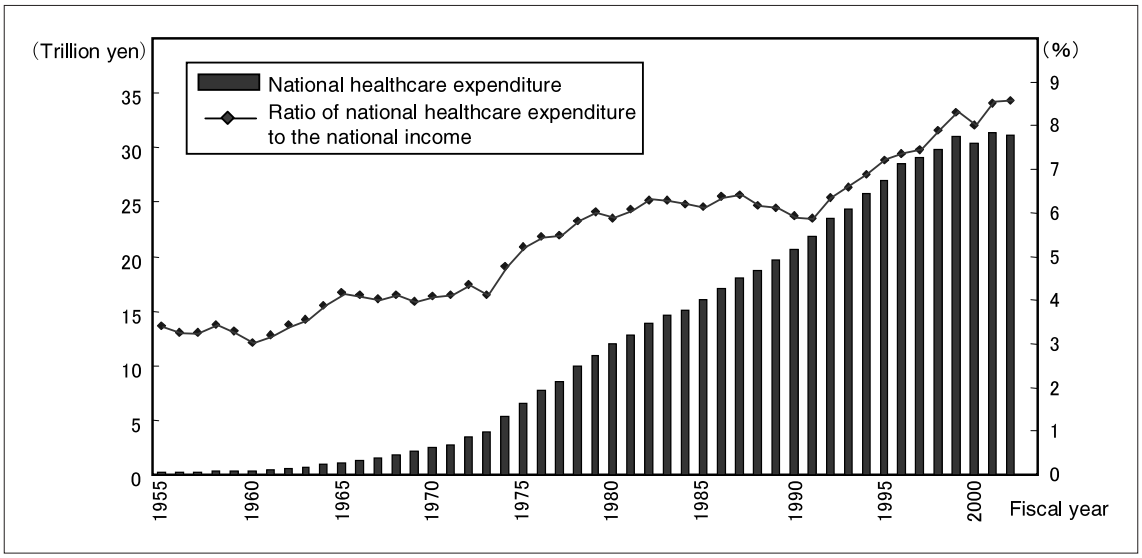
Figure 1 : Annual changes in mortality number classified by major causes of death



Source: Author's compilation based on 2004 "Annual Report on Health and Welfare" (Ministry of Health, Labor and Welfare) and 2004 "Annual Statistical Report of National Health Conditions" (Health and Welfare Statistics Association)

Makoto Tachikawa Senior Specialist, Research Institute for System Science, Research and Development Headquarters, NTT Data Corporation

Figure 2 : Japan's national healthcare costs



Source: Author's compilation based on each year's "National Health Care Expenditure" and "Annual Report on Health and Welfare" (both by Ministry of Health, Labor and Welfare)

fewer opportunities for intervention from the provider. As the term 'lifestyle-related disease' makes clear, these diseases strongly depend on long-term lifestyle habits, limiting the approaches of the healthcare provider side. Therefore, the individual healthcare consumer must proactively and voluntarily participate in his or her own healthcare. In fact, under the National Health Promotion Movement in the 21st Century (Healthy Japan 21) promoted by the Ministry of Health, Labor and Welfare since 2000, health is essentially achieved through the individual's view of health, and each individual should be active[1] in maintaining their own health. In addition, according to the Health Promotion Law enacted in 2003, Japanese people are required to take an interest in and understand the importance of a healthy lifestyle, to be aware of their health over their lifetime, and to promote their own health[2].

For most individuals, however, it is not easy to change the lifestyle habits of many years, even if it benefits their health. Furthermore, continuing and enhancing improved habits over the long term is difficult in practice, so it requires appropriate support from outside sources. This support cannot be merely moral support, but must also be science-based and rational. In other words, the support must enable individuals to assess their own health objectively, predict future health risks, and take appropriate action. Information is key in this support.

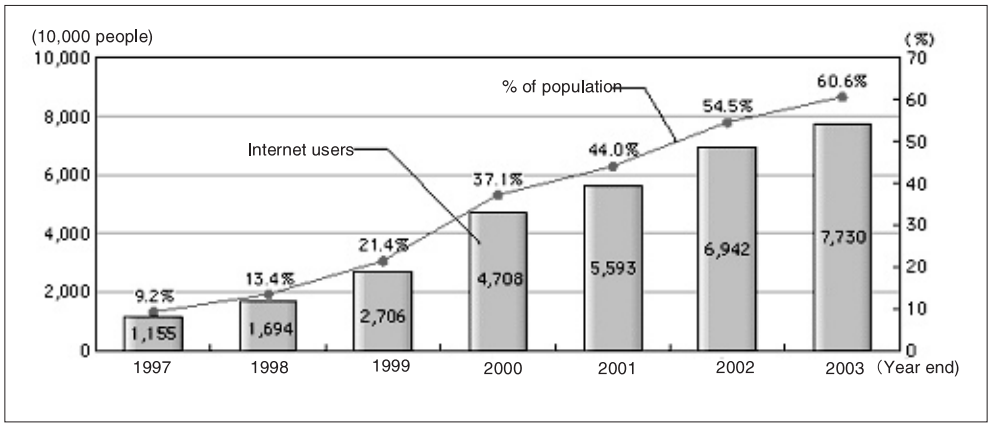
Considering this background, this article looks at information systems supporting individual health-promotion activities hereafter. The information technologies required in this field are not limited to the most advanced. Indeed, because the field requires the participation of the general public without specialized knowledge, the information technologies appliedmust be fully mature and available at lower cost .

2 Growing awareness of the role of information in health-promotion activities

(1) The penetration of evidence-based medicine (EBM)

In the field of medical treatment, the term "evidence-based medicine (EBM)" has been widely used for the past 10 years and more. EBM attempts to carry out effective treatment based on evidence obtained through a specific process. It is defined as the "conscientious, explicit, and judicious use of the current best evidence in making decisions about the care of individual patients"[3]. The EBM process comprises 5 steps: converting information needs into answerable questions; tracking down with maximum efficiency the best evidence with which to answer them; critically appraising this evidence for validity and usefulness; applying the results of this appraisal in practice; and evaluating its

Figure 3 : Number and percentage of Internet users in Japan



http://www.johotsusintokei.soumu.go.jp/whitepaper/ja/h16/index.html
Source: 2004 White Paper: Information and Communications in Japan (Ministry of Internal Affairs and Communications)

performance.[4]

EBM, which began in Canada in the early 1990s, was rapidly adopted in Japan, and in 1999, a specialized journal began publication*3. Since 2001, the Ministry of Health, Labor and Welfare has also been preparing and providing clinical practice guidelines as part of its promotion of EBM[5]. In accordance with these trends, the EBM approach has penetrated rapidly, not only in medical treatment but also in nursing and various other sectors of medicine[6]. The public health sector, which is mainly in charge of health-promotion activities, is no exception*4.

(2) Practical understanding of the effects of health-promotion activities

The effects of public health promotions are diverse and complex, and it is harder than with medical treatment to clarify the degree of contribution of each effect. Therefore, the cost effectiveness of health promotions has not been sufficiently assessed[6], while a certain amount of work has been already conducted. For example, according to research on the healthcare cost-saving effect of quitting smoking, based on statistical data on treatment rates, mortality, smoking rates, and epidemiological data on smoking-related diseases, the expected cost reduction rates over 15 years after quitting are 5.5-8.2 percent for men, and 5.1-8.2 percent for women[7]. Another example is a large-scale prospective cohort research project*5 jointly carried out by 11 public health centers nationwide, the National Cancer Center, the National Cardiovascular Center, universities, research institutions, medical institutions, and so on. To clarify the relationship between lifestyle and illnesses such as cancer, stroke, heart attack, and diabetes, this study has collected lifestyle and health information as well as blood samples from about 100,000 local residents and has followed them for more than 10 years[8]. Although some studies including the above are in progress and their results are accumulating, they are so far insufficient to solve the problems mentioned above. To promote public health research, basic data must be arranged as objective information so that an evidence-based understanding of the content and effects of health-promotion activities can be obtained.

3 Support for health-promotion activities through information systems

With the growing awareness of the importance of information in health-promotion activities, there is a movement to respond through the use of information systems. As an underlying factor, we can point to the rapid penetration of information technology in society, exemplified by the Internet, as seen in Figure 3. This means that individuals are coming into contact with and connecting with a lot of information. Information technologies are being applied to health-promotion activities, now that the focus in information has shifted to individuals who can utilize their personal health information

in various ways. Below, I describe trends in information systems supporting health-promotion activities in terms of inputting information, processing it, and outputting it.

3-1 Collection and aggregation of health-screening data on an individual basis (data input)

Health screening (checkup) begins with health screening for newborns, and is carried out by demographic category such as region, school and employment. Traditionally, there are a number of checkup methods by various checkup organizations. There are few interchangeable checkup data among the different methods and the different organizations holding the data. This is why when a person moves to a new area, school, or job, data transference from the previous organization rarely occurs even during a single life stage.

In solving this problem, there is a movement to gather and preserve checkup information on an individual basis and to manage it using information systems. Both from a medical and an information-processing perspective, checkup methods and data transfer protocols need to be standardized to facilitate this movement. Regarding standardization from a medical perspective, the Ministry of Health, Labor and Welfare is planning research to prepare the foundations for effective secondary prevention(See *2) by designing checkup categories, precise control of checkups, and criteria for checkup data[9] under its new health-promotion initiative Health Frontier Strategy set to begin in fiscal 2005. From the perspective of information systems, the Japanese Association of Healthcare Information Systems Industry (JAHIS) has proposed a "Health Data Markup Language (HDML)" as a standardized data transfer protocol[10].

The construction and operation of databases that chronologically accumulate individual checkup data, grasp changes over the years, and permit remote access have already begun*6. Currently, the main users of such services are members of the National Federation of Health Insurance Societies. Insurants (employees) who receive checkups can understand their own health condition, see changes in it over time, and predict future changes using the database. In the future, such services may link with individual disease data on electronic medical records that enable changes in health condition over the years to be seen.

3-2 Calculating individual disease onset risk (data processing)

Managing individual checkup information in unified way by, for example, quantifying physical changes with aging could make a major contribution to raising individual health awareness. To obtain scientific and practical effects, the accumulated health data must be used to clarify the individual risk of disease onset.

In October 2004, Kyushu University and NTT Data Corp. jointly developed a system for predicting the onset risk of lifestyle-related disease individually through personal checkup data[11]. The system used the method of the Framingham Study*7 with the data of about 2,600 participants' over the past 12 years as part of an epidemiological study carried out by Kyushu University in Hisayama Town, Fukuoka Prefecture, over almost the past 40 years. This Hisayama Town study has extremely high rates of physical examination (over 80 percent of all residents aged 40 and over), follow up (over 99 percent of those examined), autopsy (about 80 percent of those who die undergo autopsy to determine the cause of death), providing very precise epidemiological data. Based on a disease-risk-calculation formula derived from these data, the system takes checkup data such as age, weight, blood pressure, amount of exercise, electrocardiogram results, cholesterol, and blood sugar, then predicts the onset risk of lifestyle-related diseases (stroke, ischemic heart disease, diabetes, hypertension, etc.) over the following 10 years. Most existing systems for predicting the onset of disease based on epidemiological data handle a single lifestyle-related disease. In contrast, this system calculates the onset probability of a variety of lifestyle-related diseases on an individual basis and expresses the results in easy-to-understand graphs and charts.

Another approach to understanding onset risk

through the relationship between individual genetic information and disease is also underway*8. The research is to identify specific genes related to the onset of lifestyle-related diseases. There are two major approaches in preventative medicine: population strategies that target entire groups such as regions and occupations, and high-risk strategies that concentrate medical resources on individuals at high risk. The disease onset risk calculation mentioned above would promote the latter strategy. It helps use healthcare resources more effectively, and not only the individual but also the groups to which he or she belongs will benefit,.

3-3 Support systems for health-promotion activities (data output)

Merely understanding individual lifestyle-related disease onset risk is insufficient. Learning how to avoid confirmed risks will produce real results. Most healthcare consumers, however, lack specialized knowledge about health promotion, so even if they understand the importance of health promotion in general, few know how to incorporate it into their own healthcare. Furthermore, most habits must be continued in the long term, even after the individual recovers well again.

Therefore, customized outside support based on each person's health condition and lifestyle is needed. Traditionally, customizing processes were extremely expensive, but with information technology, this can be done is relatively easily, with cost awareness and user friendliness. For example, there are now one-to-one services offering personalized e-mail and web pages using an interactive approach to support customized "health-building" programs that include information on smoking, drinking alcohol, exercising, and eating*9. There is an emerging system in which users take digital photos of their daily meals and send them by e-mail to a center where registered dieticians analyze the meals and provide advice on a better diet*10.

4 Issues of stimulating health-promotion activities usng information systems

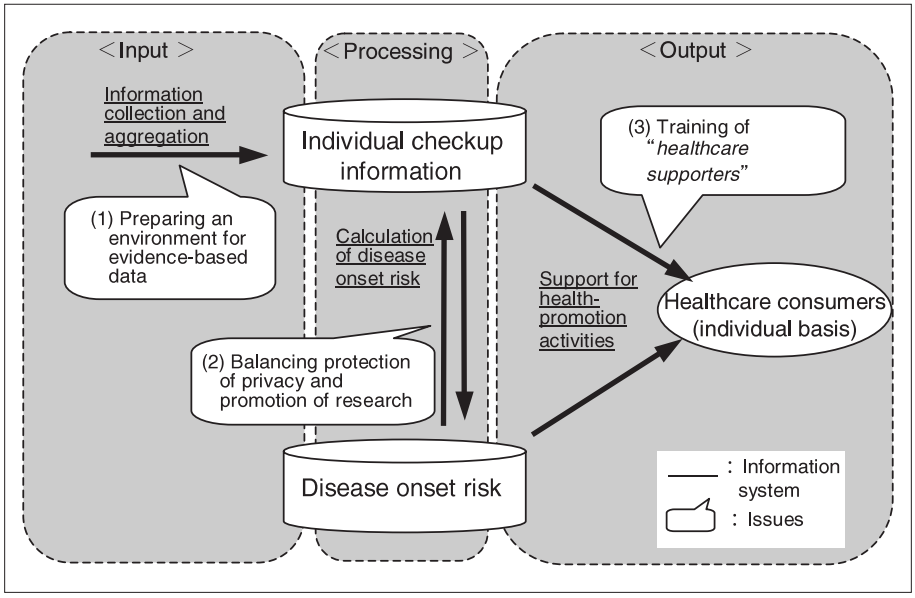
The interrelationships among the information systems supporting health-promotion activities that target individuals described so far are shown in Figure 4. Issues of stimulating health-promotion activities related each system are shown below; these issues can be divided into three categories: input, processing, and output.

4-1 Input-related system

(1) Preparing an environment for evidence-based data

Underlying the scarcity of health-promotion

Figure 4 : Interrelationships and issues with information systems supporting health-promotion activities



activities compared to treatment activities is the misunderstanding that health promotion is relatively less important. In addition, it is not sufficiently proved how health-promotion activities contribute to reducing medical costs as described above. A major cause is the lack of evidence-based data on the effects of health-promotion activities. The measures described in this article constitute some first steps, but this approach is still not widely diffused in Japanese society. Full use of evidence-based data requires aggregating data related to health management on the basis of each entity and epidemiologically verifying the effects of health-promotion activities based on these data. Neither activity cannot be accomplished by a single organization over a short period of time, so an environment enabling cross-organizational action should be prepared. To collect data for a much longer period in the future, a social system such as that shown in Figure 5 must be created.

4-2 Processing-related system

(2) Balancing the protection of privacy and use for research

Personal-information related health promotion is sensitive, so it should be handled very carefully. However, excessively strengthening the protection of personal information will hinder progress in research, interfering with social benefit. To advance research and promote individualized health risk understanding, we must be able to use personal information under agreed rules. Society must therefore reach a consensus concerning information usage between balancing the protection of privacy and the promotion of research.

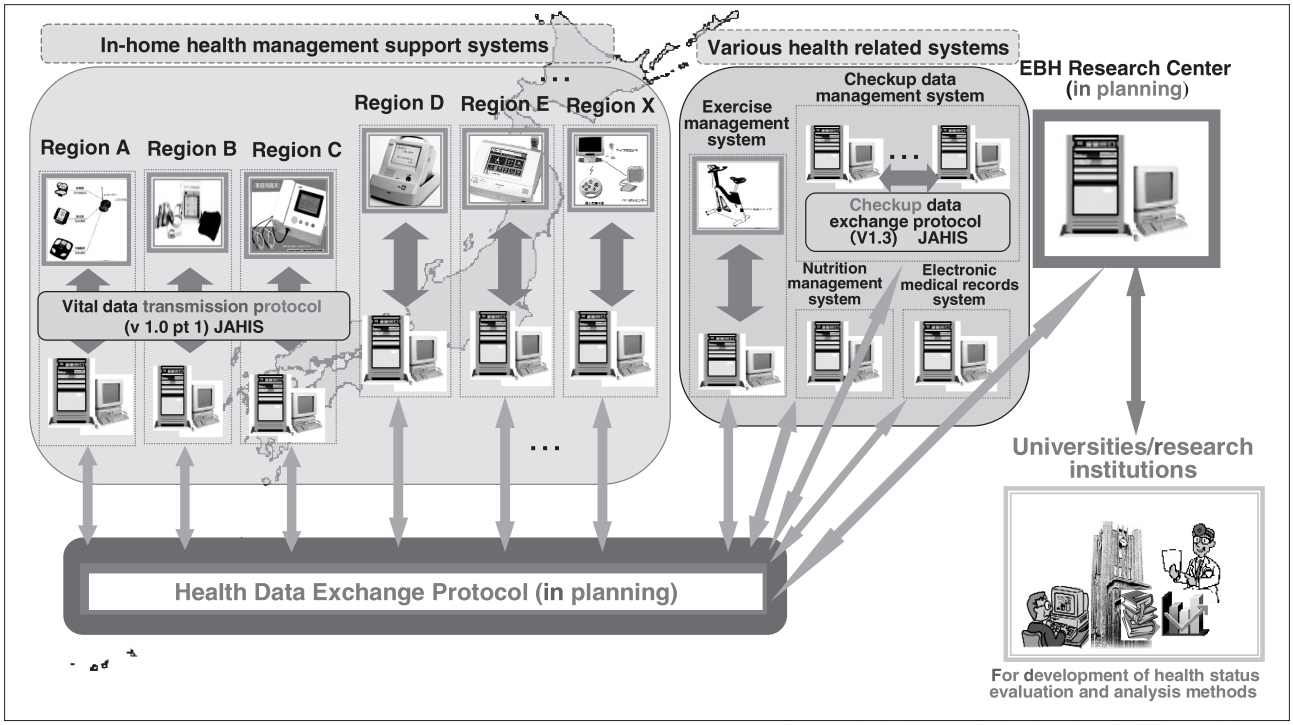
Expanding this concept, the BioBank Japan Project that establishes techniques for Personalized Medicine, is collecting DNA and blood samples from approximately 300,000 people to explore the relationships between genes and the effectiveness of medicine, and genes and disease. Those who provide medical samples are told not to expect any personal return but to consider that they are contributing to their children and grandchildren[12]. We need to spread the concept of making cross-generational contributions from genetic research to all medical research, making it a society-wide value.

4-3 Output (user)-related system

(3) Training "healthcare supporters"

Regardless of advances in information technology, person-to-person approaches are

Figure 5 : The vision of a social data infrastructure for evidence-based data collecting



Source: Author's compilation based on JAHIS materials

still needed. Furthermore, those who can best support an individual's daily life health-promotion activities are not medical specialists or government agencies, but the family and others close to the individual. However, people do not always have such supporters nearby. As the onset of lifestyle-related diseases commonly occurs in middle or old age, health-promotion activities are most necessary at the life stages preceding this, the so-called prime of life. This age group, however, does not have sufficient support. Even if family members or other supporters are nearby, they must be able to select, understand, and obtain the necessary health-support information to support their loved ones. However, that this support cannot always be provided is an issue.

One solution would be to create a social system where a large number of personnel are trained as "healthcare supporters" who have the abilities needed to help individuals. Public health nurses already provide some activities of healthcare supporters, but their numbers are too few to be a familiar presence*[11]. Healthcare supporters might not need as much medical knowledge as public health nurses, but they might need higher ability than public health nurses to process information related to supporting health and to supporting the health-promotion activities of healthcare consumers through close communication. One strategy in training healthcare supporters would be to actively utilize enthusiastic volunteers by training them and having them work with public health nurses.

5 Conclusion

Even though the concept of regular health screening in United States is considered weaker than in Japan, the Federal Government is carrying out a number of public health initiatives, beginning with "Healthy People," which was established in 1979. Each initiative clearly addresses issues such as obesity and diabetes, and they are generally intended to show the public how to act from the perspective of prevention. The importance of preparing information is commonly understood, but more than information is provided. For example, in the "Healthier US" initiative that began in 2001, the "Pocket Guide to Good Health for Adults[13]" shows how to promote good communication with doctors and other specialists, record health-related data, daily health-promotion activities, and so on. A noteworthy point in such US initiatives is that they emphasize working on an individual basis.

In Japan, too, the importance of individual-based health-promotion activities is being stressed more than ever, and a number of information systems to support them are being developed. However, there are problems. The cost benefit analysis of health-promotion activities is not sufficiently clear, so services are fragmented. At the same time, to understand the cost benefit effects, a certain amount of growth in services is necessary. A practical means of overcoming this dilemma is to implement the test operation of advanced services and to expand the results obtained. As organizations that manage these operations, company health insurance societies, for example, may be ideal because they have many employees in the "prime-of-life" age group that are most likely to suffer from lifestyle-related disease in the future. They also are suitable from the perspective of quality research.

The market in health-promotion fields is expected to be huge. From now on, all stakeholders in society are required to participate in vitalizing health-promotion activities. Because the field involves individual lifestyles in all their diversity, the private sector should lead the way in providing diverse, creative services rather than the government providing a standardized service. This means the government should neither avoid leading the way, nor should it play a completely hands-off role. It is difficult for the private sector to directly profit from most of the policies stimulating health-promotion activities as described in this article, so the government should take an active part in building infrastructure.

When the government begins to build the infrastructure, it will further the collection of information regarding health promotion. As a result, the effects of health promotion will be widely recognized, stimulating further activities leading to the creation of a virtuous circle. This

may bring not only economic benefit, but may also contribute to the national quality of life, which is a true improvement in social welfare.

Notes

*1 In relation to doctors, hospitals, and other healthcare service providers, patients, their families and those who are not currently receiving healthcare services are collectively referred to as "healthcare consumers" because they may obtain such services in the future.

*2 The field of preventative medicine is composed of: primary prevention, which involves preventing the outbreak of diseases and disorders through a healthy lifestyle; secondary prevention, which diagnoses and treats disease in its early stages; and tertiary prevention, which prevents the advance of disease and supports rehabilitation.

*3 http://www.nakayamashoten.co.jp/ebm/index.htm

*4 In the public health sector, it is called "evidence-based health-promotion or healthcare (EBH)," or "evidence-based public health-promotion (EBPH)."

*5 Research that designates and follows cohorts, identifies the occurrence of targeted disease and death due to that disease, and examines the relationships between those factors and disease

*6 For example, http://www.digi-beam.co.jp/demo/health_new/.

*7 The Framingham Study is a world-famous research study that has been carried out on residents of Framingham, a suburb of Boston, USA, since the 1940s. The primary purpose of the study is to understand the risk factors for cardiovascular disease.

*8 A large-scale research project in Japan attempting to understand the relationship between genes and disease is the BioBank Japan Project that establishes techniques for Personalized Medicine conducted by the Ministry of Education, Culture, Sports, Science and Technology.

*9 For example, http://www.sankenjin.ne.jp/ap/a/a0000.jsp

*10 For example, http://secure01.hs.kddi.ne.jp/shoku365.com/pro/index.html

*11 According to the Ministry of Health, Labor and Welfare statistics, approximately 38,000 public health nurses were employed in 2002. s(Figure 2-56, http://wwwdbtk.mhlw.go.jp/toukei/youran/indexyk_2_2.html)

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