

April 6, 2022

Morito Monden, President of the Japanese Association of Medical Sciences and the Japanese Medical Science Federation

Toshio Nakagawa, President of the Japan Medical Association

Joint Statement on "Preventing Unfair Discrimination and Social Disadvantage by Genetic and Genomic Information"

The realization of "genome medicine" that enables more effective and efficient diagnosis, treatment, and prevention of diseases, suitable for each person's constitution and disease state, is spreading to various medical fields. Genomic medicine is based on individual genetic and genomic information. Practical applications of genomic medicine have already been made in the fields of cancer and intractable diseases. The benefits of this technology include the selection of treatments suitable the person's condition and rapid diagnosis. In addition, we are conducting research on the application of genomic medicine to multifactorial diseases, such as diabetes, obesity, cardiovascular diseases, immune and allergic diseases, and psychiatric and neurological diseases.

On the other hand, it has been pointed out that it is necessary to improve the social environment for people to receive genomic medicine with peace of mind because genetic and genomic information of the germ cell line is innate, does not change throughout our lives, and can be passed on to descendants. If patients are treated inappropriately, patients and their relatives could experience unfair discrimination and social disadvantage in various situations other than medical care, such as insurance, employment, marriage, and education.

The World Declaration on the Human Genome and Human Rights (1997) adopted by UNESCO, to which Japan is a member, states that the human genome is the heritage of humanity, and every person has the right to respect for their dignity and human rights, regardless of their genetic characteristics. Since the 2000s, rules for the handling of genetic and genomic information in fields other than medical care have been established in countries other than Japan, mainly in the insurance and employment fields. With the implementation of genomic medicine, discussions on the review of such rules have been underway in those countries.

However, the *Act on the Protection of Personal Information*, which requires consent for the acquisition of personal information and provision to third parties, is the only way of implementation for the social environment in Japan. The prevention of unfair discrimination and social disadvantage is not stipulated in any form of laws or voluntary rules. In Japan, a universal health insurance system has been established, and there is no requirement to present genetic and genomic information when applying for public health insurance. However, the rules concerning the handling of genetic and genomic information in the underwriting and payment practices of private insurance, such as cancer insurance and life insurance, are unclear and we are waiting to see whether the industry will self-regulate. In addition, the handling of personal genetic and genomic information remains unclear in employment, placements, job responsibilities, and health checkups of workers in the workplace.

Currently, whole-genome analysis research is being promoted by national policy. Genome analysis and genetic testing of patients and their relatives are being rapidly developed in the medical field. However, in Japan, as mentioned above, the possibility that patients and their family members will be subject to unfair discrimination and social disadvantage based on genetic and genomic information cannot be dispelled, and the parties concerned will be very anxious. This concern may spread not only to patients and family members, but also to many healthy people who are currently unaware of the connection with heredity.

It is also possible that the public will refrain from participating in medical research involving genome analysis or the use of genetic testing, and this may pose a barrier to the development of new drugs and the introduction of genomic medicine using genetic and genomic information in Japan. In addition, as there are ethnic group differences in the relationship between the genome and disease, if we delay the development of new drugs and genomic medicine using genetic and genomic information in Japan, it may bring long-term disadvantages to the public.

All health care practitioners should be aware that when handling genetic and genomic information, it may include information that could lead to unfair discrimination and social disadvantage for patients and relatives in various settings other than medical care, such as insurance, employment, marriage, and education.

The Japan Medical Association, the Japanese Medical Science Federation and the Japanese Association of Medical Sciences are committed not only to education and research, but also to preventing unfair discrimination and social disadvantage in the realization of medical care. To ensure that genomic medicine expands in Japan and that citizens can benefit from it with peace of mind, we request the government, supervisory authorities, insurance companies, and related organizations that may handle genetic and genomic information to comply with the following requirements to prevent unfair discrimination and social disadvantage due to genetic and genomic information:

1. The Government of Japan shall promptly establish laws and regulations to prevent unjust discrimination and social disadvantage by genetic and genomic information. Relevant ministries and agencies shall hold a meeting to consider how to use such information in social and economic policies, including insurance and employment, while preventing inappropriate handling of personal genetic and genomic information. They should consider measures that are in line with the actual circumstances of Japan.
2. Supervisory authorities should encourage businesses, such as insurance companies and related organizations that handle genetic and genomic information, to promptly implement self-regulation considering the handling of genetic and genomic information and to establish a system for providing guidance and supervision, so that the content is easy to understand for consumers.
3. Businesses and affiliates of insurance companies that may handle genetic and genomic information should open discussions on the handling of genetic and genomic information, and promptly review and publish voluntary measures.

[Note] Definition of Term

The Ministry of Health, Labour and Welfare in “Concrete Measures for the Realization and Development of Genomic Medicine” (2016), defines genomic information as meaningful interpretation by referring to nucleotide sequences and genetic information as genomic information that is passed onto descendants.

We would like to acknowledge the following contributors to the translation:

- Katherine Cheung
- Mei-Chen Chang
- Gratien Dalpé
- Yann Joly
- Chisato Yamasaki

The original can be found at:

<https://www.mhlw.go.jp/file/05-Shingikai-10601000-Daijinkanboukouseikagakuka-Kouseikagakuka/0000140440.pdf>