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Who is the secondary use of medical and other information for?

Utilized not only for drug discovery and medical device development, but also for improving the quality and efficiency of medical care

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Summary

- On April 1, 2024, the revised Next Generation Medical Infrastructure Act came into effect (promulgated on May 26, 2023). As a result, the environment has become one in which electronic medical record information of cooperating medical institutions can be used for secondary use in R&D in the medical field, and unlike before, newly pseudonymized processed medical information can be used in addition to the existing anonymously processed medical information¹. In addition, it is now possible to provide anonymously processed medical information based on the Act and public databases such as National Database of Health Insurance Claims and Specific Health Checkups of Japan (NDB) and Japanese Long-term Care Database to researchers for consolidated analysis, enabling them to conduct research based on, for example, medical examinations before and after hospitalization.
- In order to accelerate R&D in the medical field in the future, it is important to make pseudonymized information available for secondary use for public DBs related to medical and nursing care. Pseudonymized information makes it possible to follow and analyze the effects of treatment and medication over time, including rare cases. The further expansion of a consolidated public DB will also enable lifelong and even intergenerational research and development for almost the entire population.
- However, the secondary use of pseudonymized information in public DBs must be balanced with the protection of individual rights and interests. In this regard, instead of not obtaining the consent of the individual for secondary use, the direction is to establish an agency to protect the rights and interests of the individual and to set certain restrictions on the environment for data analysis.
- In addition to increasing the transparency of secondary use, it will be most important to return the results of data utilization to improve quality and efficiency of medical care in a timely manner in order to gain the full understanding of those who provide medical and other information.

Attention

This report is a summary translation. The official document is only in Japanese.

¹ Medical information that has been processed in such a way that individuals cannot be identified unless it is matched with other information.