

DX strategy by building and promoting utilization of the comprehensive healthcare database

Abstract

Society 5.0 is a human-centered society that highly integrates cyber space and physical one. We aim to overcome the challenges of the information society (Society 4.0) so far, overcome the sense of blockage through social change, and make each person comfortable and active. For people with disabilities, ICT is useful not only as a support device, but also as a driving force in labor for individuals with a sense of purpose to shift to independent living in the community. Therefore, since the ratification and entry into force of the Convention on the Rights of Persons with Disabilities (2014), efforts to re-evaluate persons with disabilities as “living people with support needs” and to prepare a social support environment have been expanding.

In Japan, a super-aging society where the disease structure has shifted to NCD, mortality is not the only outcome measure required for quality evidence-based care. It is necessary to have data to grasp the outcomes considering the viewpoints of service users and the social aspects of care, develop measurement scales, and connect them to the current care system operation. A comprehensive healthcare database can be expected to be constructed by adding Disability Database to EHR/PHR, which is medical big data, to enhance outcome information, and connecting mobile devices to incorporate the perspectives of patients, parties, and families. The main requirements for providing high-quality health, medical, welfare, and long-term care services for the QOL improvement measures of all individuals according to the actual conditions of each region toward the comprehensive community support system that will shift to 2025 will be: The national government needs “(1) collection / accumulation of disability data / enhancement of comprehensive DB, (2) development of analysis model / human resource development utilizing comprehensive DB,” and, what is needed for local governments is “realization of efficient and effective measures to be carried out in collaboration with industry, government, academia and residents based on regional diagnosis utilizing big data such as comprehensive DB.” In this way, we will be able to push forward with the promotion of DX through a comprehensive database toward a vibrant and advanced health country that Japan is aiming for in “Healthcare 2035.”

Keywords: DX (digital transformation), comprehensive healthcare database, disability registry, PHR (personal health record)

Volume 5 Issue 3 - 2021

Tachibana Tomoko

Center for Public Health Informatics, National Institute of Public Health, Japan

Correspondence: Tomoko Tachibana, MD, MPH, PhD, Center for Public Health Informatics, National Institute of Public Health, 2-3-6 Minami, Wako city, Saitama prefecture 351-0197, Japan, Tel +81-48-458-6206, Fax +81-48-469-0326, Email tachibana.t.aa@niph.go.jp

Received: April 11, 2021 | **Published:** May 12, 2021

Introduction

In recent years, not only prevention but also patient care has become a global health and public health issue in chronic disease control.^{1,2} GBD2010 (2010 Global Disease Burden Study³) showed “mental and behavioral disorders, musculoskeletal disorders, and increased burden due to diabetes.” This clarified the shift to non-infectious diseases as a new challenge to the healthcare system. In Japan, the transition to a comprehensive community care system is underway by 2025, prior to achieving the 2030 Agenda of the SDGs (Sustainable Development Goals⁴). In order to eliminate disparities and breaks between fields and aim for a diverse symbiotic society,⁵ it is important to have a society in which vulnerable people can live and obtain information in the same way as healthy people.

On the other hand, in Japan, since 2001, efforts have been started so that all citizens can actively utilize IT (information technology) and enjoy its benefits to the maximum.⁶ In recent years, in Japan, Society 5.0⁷ has been proposed as the new future society following the information society (Society 4.0) so far. Society 5.0 is a human-centered society that achieves both economic development and resolution of social issues through a system that highly integrates cyberspace and physical space. ICT (Information and Communication

Technology⁸), which refers to how to utilize IT, is expected to be a promising means of overcoming barriers to financial independence, for example, in the employment and employment of persons with disabilities. By utilizing the developed ICT as not only one of the support devices but also economic independence means of employment/working, we can expect a role as “a driving force for individuals to establish an independent living with a sense of purpose and move to the community.”⁹

Chronic injuries and illnesses are significant causes of disabilities. In order to achieve the rehabilitation principles of “restoration” and “reconstruction of life” based on “human rights protection for persons with disabilities,¹⁰” people will need social support bases to leave the protected environment and become independent while accepting illnesses and disabilities. In 2001, with the publication of the ICF (International Classification of Functioning, Disability),¹¹ the concept of disability was applied to all people. It can be said, since the ratification and entry into force of the Convention on the Rights of Persons with Disabilities in 2014, efforts to re-evaluate persons with disabilities as “living people with support needs” and to prepare a social support environment are expanding in Japan. From this, it is the issue to grasp the outcomes considering the viewpoint of service

users and the social aspect of care, develop a measurement scale, and connect it to the operation of the care system.

In 2011, the WHO (World Health Organization), in collaboration with the World Bank, notified governments of the importance of disability. At the same time, a world report of scientific information analysis has been produced on disability and provided as “behavioral recommendations” at the national and international levels.¹² In 2020, the WHO warned that disability is a public health problem and reported that “more than a billion people, or about 15% of the world’s population, have some form of disability.” It is presumed that they live with it.” The importance of data collection and analysis was emphasized,¹³ and it was proposed to include persons with disabilities in healthcare monitoring. In addition, ongoing research is being conducted on the needs, barriers, and health outcomes of people with disabilities. In order to realize a community-based society, it will be necessary to create a social environment in which people with risks and vulnerabilities can live the same lives as those without them, and obtain the necessary information.

Current status of health information services (EHR/PHR)

By accumulating “prognosis (results) information of trauma medical care” for each municipality, we have been considering the construction of a disability database and the promotion of data utilization.^{14,15} And, we have been exploring the ideal image of society for a vulnerable country to become a health-advanced country, and how to build and promote the utilization of a comprehensive medical database.^{16,17} Electronic management of health and medical information has progressed, and the anonymized electronic receipt NDB (National Database)^{18,19} is positioned as medical big data such as medical care (medical practice, etc.), DPC, dentistry and dispensing. From 2009, NDB has been accumulated after anonymization where all electronic receipts and specific medical examination data can be matched and can be used by third parties such as local governments and researchers. In addition to this, big data on long-term care has been added, making it possible to analyze electronically held health and medical information, which was difficult in the past.

Since then, the use of ICT has further progressed in the medical field, and EMR (Electronic Medical Record) has first penetrated as an “electronic medical record.” Compared to conventional paper-based medical records, it is superior in searchability and long-term storage, but information is often stored only in individual medical institutions. EHR (Electronic Health Record)^{20,21} records all personal medical care and health / long-term care information in electronic media. The information is shared and utilized among medical institutions and has been introduced all over the world,²² while PHR (Personal Health Record) is for patients themselves, which is a health record for managing health. PHR also contains the same information as EHR. Furthermore, the patient him/herself can record and manage information such as symptoms, medication history, and test values such as blood pressure and body weight from his/her own point of view.

However, when building a “lifetime” PHR system for individuals, it is necessary to enhance it as information that can be used as outcome data to build “evidence to verify the effectiveness of health and welfare policies.” This is because most of the data currently available as outcome information is long-term care insurance data, so it is necessary to add data related to the health of people to whom measures are still considered. In other words, an information platform is needed to voluntarily collect, accumulate, analyze,

evaluate, improve, and so on, the data of individuals with symptoms and disorders regarding various health status images. The disability database can be information for enhancing outcome data for the current EHR/PHR platform. Therefore, we would like to propose to add the disability database to the current EHR/PHR to promote the construction and utilization as a comprehensive healthcare database for all people.

The comprehensive healthcare database has the following implications and perspectives

Individual significance

- I. It is expected that the quality of EHR/PHR will be improved and enhanced by enhancing outcome information.
- II. Information infrastructure for health measures” will be completed. In the region, there are already examples of social innovation projects undertaken by industry, government and academia to solve health issues in their own region using their own health big data analysis.²³ This clarifies the division of roles between the national and local governments. In other words, the national government will promote the construction, management, and utilization of EHR/PHR (data standardization, analysis model presentation, human resource development, enlightenment, etc.). Municipalities can use data to drive evidence generation. This makes it possible to promote the division of roles toward the transition of the comprehensive community care system.
- III. We can re-evaluate measures for persons with disabilities. Re-evaluating persons with disabilities as consumers with support needs can be expected to contribute to the qualitative improvement of independence support measures.
- IV. We can create a field of disability health to get an information infrastructure which will be created to implement independence support measures for persons with disabilities based on same grounds. As a result, it seems possible to unify the policy implementation system into the same measures regardless of the presence or absence of disabilities. Therefore, it is possible to shift the paradigm through DX (digital transformation) in policies related to health measures for persons with disabilities.
- V. By promoting the utilization of “health, medical care, long-term care, and disability” PHR (including EHR), a “common language” can be created to promote the “health of all people” policy. From this point of view, DX is possible as an information base that contributes to health measures in a “coexistence society of all people” regardless of the presence or absence of disabilities.
- VI. If a mechanism for accumulating existing medical and welfare data is constructed as the EHR part of the Disability Registry, researchers such as medical professionals will not have to devote their efforts to the part of “collecting data.” This will enable the comprehensive community care system to focus on the PDCA cycle for evaluating health, welfare, medical and long-term care measures without disparities or breaks in each region.
- VII. It will be easier to include perspectives from various fields such as service providers and parties/persons concerned.
- VIII. Epidemiological information on long-term prognosis/outcomes such as trauma, for which there was not much information so far, can be obtained. This makes it possible to observe and record

long-term pathological information after long-term survival for surgical diseases that are relatively invasive. By doing so, it can be expected to monitor pathological conditions such as reactions/side effects and complications to the treatment of specific diseases in the acute phase, gene damage, and effects on the immune system, such as medical diseases. Japan, which has experienced traffic wars and a super-aging society ahead of the rest of the world, has a responsibility to proactively disseminate medical and welfare evidence of people with risks and vulnerabilities.

DX strategy in comprehensive healthcare database

Society 5.0 is a human-centered society that highly integrates cyber space and physical one. We aim to overcome the challenges of the information society (Society 4.0) so far, overcome the sense of blockage through social change, and make each person comfortable and active. For people with disabilities, ICT is useful not only as a support device, but also as a driving force in labor for individuals with a sense of purpose to shift to independent living in the community. Therefore, since the ratification and entry into force of the Convention on the Rights of Persons with Disabilities (2014), efforts to re-evaluate persons with disabilities as “living people with support needs” and to prepare a social support environment have been expanding.

The comprehensive community care system that will move to 2025 requires an information infrastructure for each municipality to build a society without disparities and breaks. For that purpose, it is necessary to enrich the “disability” data, which has overwhelmingly little information among the lifelong “health care, medical care, long-term care, and disability” data. That’s because it is necessary to add information on the perspectives and social aspects of patients and parties, by increasing the outcome information in the lifetime database.

In recent years, on the other hand, with the spread of mobile devices, the movement to manage and utilize personal health data by oneself with the aim of receiving services suitable for one’s own health condition has spread regardless of the presence or absence of disabilities. By connecting mobile devices to this comprehensive health care database, you can expect to obtain data from the perspective of patients / parties / family. In addition, this comprehensive health care database can be used to minimize the effort of local and field researchers to collect data. Therefore, through data analysis, it is possible to focus on the realization of strategies for solving health issues in each region to which they belong. In order to contribute to the promotion of the PDCA cycle using analysis data in collaboration with the general public and industry, government, and academia in each region, it is necessary to promote the construction and utilization of a comprehensive health care database.

In Japan, a super-aging society where the disease structure has shifted to NCD, mortality is not the only outcome measure required for quality evidence-based care. It is necessary to have data to grasp the outcomes considering the viewpoints of service users and the social aspects of care, develop measurement scales, and connect them to the current care system operation. A comprehensive healthcare database can be expected to be constructed by adding Disability Database to EHR/PHR, which is medical big data, to enhance outcome information, and connecting mobile devices to incorporate the perspectives of patients, parties, and families. The main requirements for providing high-quality health, medical, welfare, and long-term care services for the QOL improvement measures of all individuals according to the

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Acknowledgments

None.

Conflicts of interest

For this study, none of the authors have a COI status to disclose.

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