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GUEST EDITOR COMMENTARY

Learning Health Systems

The value of learning health systems in disease control and aging

Closing guest commentary:

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We are living in an unprecedented revolutionary age of science and technology. Real-time databases of disease-specific registries are expected to dramatically and efficiently accelerate clinical research studies. The use of real-world data to augment data from randomized clinical trials is gaining traction and support globally. The article entitled "The Global Academic Research Organization Network: Data Sharing to Cure Diseases and Enable Learning Health Systems" in this issue describes the activities of the Global ARO Network, including a workshop with participants from Asia, Europe, and the United States. This network represents the global expansion of the ARO Council and global disease-specific consortia that collaborate on disease-specific registries. Such networks enable research on a global scale to test drugs and medical devices from academia, ushering in an age where we can collaborate on research and obtain approval for new therapies simultaneously around the world. The formation of global networks for patients with rare diseases is an essential step toward overcoming such diseases, and we now have a more specific picture of the expanded role that these networks play in realizing global learning health systems.

Not only can learning health systems be beneficial in identifying the best treatments for individuals with specific diseases, but there is a role for functioning learning health systems to be more broadly applied to identifying ways to prevent diseases by leveraging and learning from the data from healthy individuals. In developed countries, aging populations pose an increasing social burden and a threat to the vitality of the society, particularly when many of the elderly are inflicted with chronic or debilitating diseases. The slogan, "society in which people in their 100s can remain active," presages a society where no one is bedridden.* This idea may seem like an impossible dream, like eternal youth and immortality. However, there is an important role of learning health systems in resolving the age-associated dilemma of extending life, along with quality of life, and controlling diseases that prevent most elderly individuals from being independent and active centenarians.

Major threats to maintaining independent living include stroke, heart failure, dementia, and musculoskeletal problems. Elderly individuals who suffer debilitating repercussions from these threats typically populate the beds of nursing homes and hospitals or need full-time caregivers; they are unable to care for themselves, and the opportunity to benefit from preventive measures is no longer an option. These individuals and the society that cares for them would clearly benefit from more robust research data on factors that prevent individuals from becoming incapable of caring for themselves, compromising their quality of life and thus increasing the burden on society.

Conducting robust research on the effects of lifestyle changes such as nutrition, exercise, sleep, and state of mind is difficult; these studies are unlike randomized clinical trials that are conducted to test the efficacy and safety of a new drug. Not only are there more variables, but the research "subjects" may not be as motivated since they are not yet experiencing a problem, and they frequently prioritize their work or their own lifestyle choices over what they know to be healthy choices. They may be gradually invoking damaging effects on their immune homeostasis mechanisms without realizing the negative impacts until it is too late. For example, they may not get sufficient sleep or have a nutritious diet when they are working or

*https://advances.tri-kobe.org/.

studying hard. Chronic inflammation due to unwise lifestyle choices can cause stroke, musculoskeletal problems, atherosclerosis, osteoarthritis, and other diseases that become increasingly difficult to treat as they progress.

In this age of rapid data generation and new technological advances, an important opportunity presents itself in terms of realizing learning health systems that apply not only to patients but to individuals who are currently healthy. By combining new technologies such as wearable devices with appropriate data standardization, harmonization, and knowledge sharing, it is possible to gain knowledge that indicates how to prevent or deter some of the typical chronic diseases of the elderly. Appropriate management of an individual's lifestyle has become possible through daily monitoring by wearable digital health devices, many of which have recently been put into practical use and are spreading throughout the world. This has enabled real-time monitoring of individual's daily exercise, diet, sleep, heart rate, pulse pressure, and ECG. Oxygen levels, glucose, and degree of glycation can also be measured and monitored. Thus, individual biometric data can be collected on a real-time basis and compiled into a database. In addition to personal health management, if people receive regular check-ups and screenings and have various imaging and marker tests, changes can be evaluated over time more precisely and risks predicted before symptoms appear. This will help raise an individual's awareness and should encourage them to modify their behavior appropriately. As individual health management spreads, we will surely see significant improvement in health conditions of the elderly. Diseases will still exist, however, and ill patients must still be diagnosed and treated at hospitals.

Another source of real-time data is electronic medical records. In developed countries, most of the medical records of patients are already in the form of electronic health records (EHR). Theoretically, it should be possible to extract necessary clinical information of an individual from EHRs, as well as sharing data with other facilities. However, adequate standardization and implementation of data sharing principles, including privacy and security, are still on the way to practical and widespread use. Case studies in this theme issue—*Learning Health Systems: Connecting Research to Practice Worldwide*—have described the historical path and emerging methods along with remaining challenges to streamline the use of EHR data for research. Responsible and meaningful data sharing should provide invaluable information including the natural history, type, condition, stage, and course pattern of a disease, as well as its prognostic factors, prediction of therapeutic effects, side effects, and recurrence. This learning will help us to more readily reveal improvement in prognosis after introducing a new treatment or lifestyle change, as well as its limitations.

Standardization of individual participant data,[†] appropriate data management practices such as those required for data center certification,[‡] and harmonization are requirements for utilizing real-world data for a learning health system. New methods and technology advances will also be necessary, in addition to EHRs and mobile devices, to optimize the learning from real-world data. Automating the extraction of necessary information from EHR data, natural language processing, machine learning, and artificial intelligence (AI) are top areas of interest for healthcare systems engineers around the world. Another set of science-based technological advances will include tissue engineering, stem cell therapy, biological technologies that use self-repair mechanisms, and nerve regeneration or stimulation.

While technical problems of these new systems are being overcome, integration of medical information by specific disease should become possible. The amount of such real-world data is enormous; not only will it be useful in analyzing individual patients, but it will also provide invaluable information as a reference for prognosis simulation. If it becomes possible to use real-world data through data sharing, two universes that have traditionally been divided—the universe of clinical practice and the universe of clinical research—will be integrated into one; through this progress, diagnostic accuracy in daily practice should improve dramatically, and the rate of treatment success should also increase significantly. This trend will be accelerated by disease-specific, hospital-based registries. If such registries are implemented, and the data is available real-time, various types of research studies can be set up and completed more efficiently. This indeed can create an "ecosystem" for preventing diseases that are common in aging populations as well as improving treatment outcome. The goal is to significantly shorten learning health cycles and enable useful global learning health systems.

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[†]http://bmjopen.bmj.com/content/bmjopen/7/12/e018647.full.pdf.

[‡]http://www.ecrin.org/activities/data-centre-certification.