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> Research shows that investing in primary care is the best way to achieve a more inclusive healthcare system.

06.09.2019

Tags:

Sweden, Healthcare, Digitalization, Patient Registers, Data

The National Board of Health and Welfare is the public authority responsible for ensuring that people have access to good health and social care on equal terms in Sweden. Its Director-General, Olivia Wigzell, explains how the Board delivers on this mission, in particular through the development of national care guidelines. She also discusses the role of the Board in government initiatives to enhance register-based research, leverage opportunities offered by digitalization and reform the primary care sector in the country.

Could you start by introducing our international audience to the role that the National Board of Health and Welfare plays in Swedenâ??s healthcare landscape?

The National Board of Health and Welfare is considered the primary health agency in Sweden. We are responsible for the governance of both the health system and social services, and our mission is to ensure people have access to good health and social care on equal terms. As such, the range of our tasks is broad.

Among other things, we issue licenses to practice for personnel in 22 occupational groups, including pharmacists, doctors, psychologists, and dentists. We can also revoke those licenses and limit the right to prescribe medicine through a special judicial body.

Moreover, we are responsible for compiling and analyzing Swedenâ??s official health and social care statistics. As part of this work, we administer various national health data and social service registers, some of them dating back to the 17th century.

We not only produce statistics but have a normative and regulatory function as well. We draw up national clinical guidelines for different therapeutic areas and regulations on various issues, for instance, patient safety, based on the best knowledge available. While regulations are binding rules, clinical guidelines are a support tool for decision-makers and provide recommendations about treatments and methods to help management and personnel enhance quality and safety in health and social care. We draw up national guidelines in areas affecting large numbers of people and in which substantial resources are required â?? for example when there are large regional differences in the quality or accessibility of care. Today there are guidelines within 18 areas including cancer, diabetes, dental care, and schizophrenia. We also direct the Committee for knowledge-based guidance â?? a collaboration with eight other authoritiesÂ â?? which is intended to drive the development in the area of health and social care.

Last but not least, follow-ups and evaluations constitute the very core of our development work within health and social care. We measure the effects of our own work as well as those of other national initiatives. Through these evaluations, the Board can also determine the status of health and social care from a national perspective. The National Board of Health and Welfare also follows up and evaluates how laws are implemented and the effects that political decisions have on the population. Among other things, we evaluate how well health and social care practitioners follow our national guidelines, the impact of national reforms and the availability of personnel in health care.

To what extent are national guidelines responsible for improving medical outcomes across the country?

To quite a high extent I would say. Developing and implementing national guidelines is a five-step process. We first evaluate the best available knowledge, develop recommendations, work with implementation to ensure their concrete use, develop indicators and then follow-up implementation over time based on those indicators. We also develop target levels in our national guidelines, which indicate the desired level of implementation of medical interventions for patient groups.

We develop the guidelines with the help of experts from the regions, most often following a multisectoral approach. Then the regions carry out implementation plans based on the national guidelines. Based on the follow-up, we can see which recommendations are well implemented and which ones are not, furthermore we can track the evolution of health gaps between regions and other variables such as gender and socioeconomic status.

Guidelines are one of many other factors affecting the quality and equality of care, making it difficult to single out their effect. This being said, it is undeniable that national guidelines have had a positive effect. The national guidelines on stroke care are a good example. Our 2018 performance assessment showed that some of the recommendations in the national guidelines for stroke, especially regarding secondary prevention, have had an impact on stroke care. Preventive measures, such as medical treatments for high blood pressure, atrial fibrillation, and high blood lipids have increased significantly since 2009 when the first stroke guidelines were published. In addition, our recommendation that patients should receive treatment within a specific stroke unit at the hospital is followed by almost all regions. Since 2009, stroke mortality has decreased by 32 percent, which is notable progress. The guidelines on cardiovascular diseases are also well implemented.

The therapeutic areas where we have seen relatively less improvement are the ones that span from hospital care, which is managed by the regions, to home care, managed by municipalities, such as mental health and alcohol abuse.

We have an ongoing dialogue with stakeholders, such as patient and professional organizations, to learn more about the need for new guidelines for large patient groups and to evaluate existing guidelines. We continuously involve patient organizations in the developing of guidelines, for instance the the Swedish Epilepsy Association has contributed to the guidelines for epilepsy. We were also one of the first countries in the world to introduce national guidelines for endometriosis. This was a challenge since available studies were limited, so these guidelines are to a large extent based on systematically retrieved forms of best practice.

Medical science is entering a golden age of innovative discovery with the advent of precision medicine, which holds the promise to cure chronic diseases but also challenges established healthcare models. How is the National Board of Health and Welfare adapting to the introduction of advanced therapies and diagnostic methods?

We are always looking at research and best practices, as well as needs for knowledge support within the healthcare sector. If there is a need regarding a new advanced therapy, we will see if we are the best agency to meet that need and, if we are, we will develop some form of knowledge support such as national guidelines. Our national guidelines contain recommendations on interventions for which there is a knowledge gap, but these interventions should only be done in a research context and the clinical physician assumes responsibility. Part of our work is to identify the scientific knowledge gaps and record them in databank which the research councils have access to. They can choose to invest research funds in addressing these knowledge gaps.

In addition, we are currently discussing with the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) about the possibility of providing support for ethical analysis for new advanced therapies.

The pharmaceutical executives and researchers we have interviewed in Sweden all agree that the country presents an ideal environment to perform real-world studies thanks to its national quality registers and national health registers, but that there is still untapped potential. How could Sweden further leverage its national registers for the development of tomorrowâ??s diagnostics, treatment and cure?

Data is well used in Sweden, but since we have a rich source of data, there is an opportunity to increase the use of data even more. We are trying to promote register-based research by making it easier to combine data from different registers in order to perform cross-sectorial research. The Swedish Research Council has developed a metadata Register UtiliÂser Tool (RUT) in order to facilitate access to registry data, our registry data, for example. Using this tool, researchers can draw connections between data from health registers, quality registers, and socioeconomic registers, enabling them to create totally new insights. In addition, we are involved in initiatives to be able to visualize data better using a new user interface and APIs.

The Dental and Pharmaceutical Benefits Agency (TLV) has a government mandate to develop a new value-added pricing model of biopharmaceutical drugs based on real-world outcomes as compared to the results of clinical trials. In order to develop this new model, the TLV is running a pilot project on real-world data analysis together with industry personnel (AstraZeneca and Sanofi). We are currently discussing with the agency to collaborate on this project.

Finally, current national registers primarily include data from the secondary care sector as hospitals were the main care institutions when these registers were first created. However, Sweden, like many other countries, has begun the shift to ensure that primary care becomes the first point of contact with the health sector and has the necessary resources to care for more patients. We still have poorer data in the primary care sector, and few data in the home care setting. At the moment, we have to work in a different way and use the prescription of drugs as a proxy for primary care data, linking the pharmaceuticals delivered at the pharmacies to primary care. The government now wants to implement a primary care reform, which includes national collection of registry data from the primary care sector.

The regions and the national government have agreed to jointly implement a Vision for eHealth 2025. What role will the Board play in this project to ensure Sweden leverages the opportunities offered by digitization to achieve good and equal health and welfare?

The role of the National Board of Health and Welfare in the Vision for eHealth 2025 is very specific. Our most important role is to work towards standardization when it comes to information structure and terminology within medical records and the ways of using technology. We are part of a working group developing a standardized terminology and information structure able to cover all our needs: research, follow-up, patient safety, patient continuity of care, patient participation, etc.

Sweden is committed to achieving the goals of the 2030 Agenda for Sustainable Development. What role does the Board play in this endeavor?

The Board plays an important role because we are working towards many of the 17 Sustainable Development Goals (SDGs), including good health and well-being, gender equality and reduced inequalities. Even though Sweden has come a long way in achieving the SDG goals, we still have gaps to fill. We need to continue working on tackling non-communicable diseases and guarantee equal access to quality healthcare across the country, especially for vulnerable groups such as people with substance abuse and mental health problems who are less likely to receive treatment for their somatic diseases and more likely to fall out of the labor market. We need to leave no one behind. Luckily, we possess a lot of data to guide us, but we must work on implementation.

Where do you hope to see the Swedish healthcare system in the next three to five years?

I wish to see this transition towards a stronger primary care sector. Research shows that investing in primary care is the best way to achieve a more inclusive healthcare system. I also would like us to be better at harnessing the power of all the data we have to address stubborn inequalities.

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