EDITORIAL

This issue of the Nordic Journal of Health Economics presents a new type of contribution, a Commentary. While the journal maintains a focus on original research papers, it has from the beginning also welcomed other types of contributions to the academic dialogue. The specific format of the contribution will of course depend on the issue and objective of the paper. The journal welcomes reviews, shorter contributions, comments, and discussions on developments in health economics and health policy reforms.

In his Commentary “Health care information: gold mine or mine field? Collection, protection and utilization in Denmark’s primary health care system”, Justin C. Matus, associate professor of the Wilkes University, PA, USA gives the initiated outsider’s perspective on health data and health system. While Denmark is the scene as Matus recently spent his sabbatical at Syddansk University in Odense, many of the points raised are equally valid in Finland, Sweden, Norway and Iceland. Although Nordic researchers are sometimes briskly reminded of differences health systems and organization of data in our five countries, these differences remain by and large manageable. Key features of the Nordic health care systems remain sufficiently similar to allow for great research initiatives with potential to address important knowledge gaps including the economic perspective on health and health care. Two recent special issues in this journal show examples of the ongoing research activities among Nordic researchers: Nordic performance comparisons and Health care the Nordic way.

In his commentary in this issue of the journal, Matus addresses both the beauty of the richness of health data availability for different stakeholders but also the challenges inherent in any system that collects substantial amounts of more or less sensitive individual-level data. Matus reminds us that health information has become an asset with values beyond those at the micro-level patient-physician interaction. Modern technologies enable improved understanding of health in the population and the effectiveness of alternative treatment strategies when applied in clinical practice. Nevertheless, collection and utilization of health data warrant careful address of health information protection.

Across the Öresund straight from Denmark, in the southern Swedish province Skåne, the health care region is currently spending 1.3 billion Swedish kronor on a complete makeover of the current health data system. The current system for patient data, or rather forest of isolated data systems with limited or no interaction, has been criticized for being unwieldy and inefficient, and often causing patient risks. Features include multiple logins and denied access to vital information on the patient from other parts of the system. For instance, hospital specialists have relied on patient reported information on medication prescribed in primary care as they, as a rule, have not been granted access to the primary care database. The new system in Skåne minimizes barriers and make registered patient data available for professionals and for the patient himself. Matus’ point is that while health data from registers is a gold mine for learning about health in the population, use of health care resources and treatment outcomes, it may also be a mine field. Health information is an asset, and as any information collected in a systematic way, it can be used for purposes that unintentionally, or even intentionally, harm people.

The duality of interests of health information is not new. Health care has been collecting information to follow-up on treatment of patients for centuries since doctors started to take notes on their patients. The difference is that in the 21st century, technological development allows us to store unprecedented amounts of data at low cost, and the collection of data may even be automated from treatment devices assisting people in the
daily management of chronic disease. True, health data is in that respect no different from other information assets in the economy. Information collection and storing has become cheap.

The Nordic countries have rigorous legal frameworks in place for safeguarding health information that is managed within the health system. This has served well in most cases, and Nordic researchers in health economics and other areas have gained global recognition for innovative analyses and game changing findings.

The new challenge is that new stakeholders are entering the market that offers citizens tools that store health information and activities that may be related to health. The current legal framework was developed for a different era when health data in the Nordic countries could be monopolized by the national and regional health system itself. This is no longer the case. Data stored by other stakeholders may be as important and as sensitive. The new European General Data Protection Regulation, GDPR, is in place since May 2018. The work to implement GDPR into daily routines and understanding of the power of information at all levels in society in years to come, has just begun. Individuals may choose to share information at one point in time, but is it possible to understand the wide range of potential use such data may have? As citizens of societies possessing gold mines of health information, it may not the time to relax and conclude that we now know what there is to know of how data may be used in the future. The GDPR is a necessary tool for protection of health information but the legal framework is not sufficient in itself. Stakeholders need to feel responsible for its beneficial implementation. As always, the democratic society will require of its citizens to be active, engaged and willing to take responsibility in their various roles. Matus describe five groups of stakeholders regarding health information: government, medical community, patients, payers and health service researchers. As individual citizens, we may find ourselves in several stakeholder categories at the same time or at least at different points in life. This provides a good starting point for mutual understanding and resolving of issues that may arise around health information.

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