

Summary

Health care was the most important political issue in the 2018 Swedish election⁶. While people recognise the health care system delivers good results in an international perspective, they are very frustrated when it comes to access. Their frustration is shared by the health care personnel who find their work situation untenable.

A factor contributing to their frustration is the dysfunctional management of information in the health and care sectors. Being spread across thousands of incompatible systems, the information is not available when and where it is needed. Some of the consequences are unnecessary extra work, high system costs, unequal care, and in the worst case, risks of patient injuries. Furthermore, researchers have great difficulties accessing and using the information which slows down progress in the medical field. A better and more comprehensive management of health- and care-related information would create radically better conditions for healthcare, as well as for research, and we could go from reactive treatment of illnesses to proactive care.

The problems with information management in the health and care sectors can be summarised in five points. The information is: a) fragmented, b) partial, c) unstructured, d) not well protected, and e) costly.

Three structures – the institutional set-up, the IT-legacy, and the legal framework – together tie a knot that has made it very difficult to achieve the type of information management that individuals and care professionals expect today.

Having the responsibility for information management spread over 20 county councils and 290 counties and municipalities has, in the absence of central government leadership, led to the information

⁶ Novus (2018). <https://novus.se/valjaropinionen/viktigaste-politiska-fragan-och-basta-parti/viktigaste-politiska-fragan/>

being spread and locked up in thousands of IT silos. And, the attempts at co-ordination under the stewardship of the Swedish Association of Local Authorities and Regions (SKL) have had very limited impact. When push comes shove, the different county councils have chosen to go their own way or, at best, to collaborate with a few other county councils, efforts that, however, often have come to naught.

Coordinated information sharing between counties has never really been on the agenda.

The legislation regulating the processing of personal data is also spread between a number of silos. One of the reasons is the presumption upon which the legislation is founded: that it is institutional actors that generate and store information about individuals. As a consequence, every time a new agency or function is created, legislation governing their operations must include paragraphs on the processing of personal data. Just with the realm of the Ministry for Social Affairs there are 47 laws and regulations that include paragraphs on the matter.

A clear trend around the world is creating personal health accounts to solve similar problems. The US, Estonia, Finland, and Australia are some countries that have done this or are in the process of doing so. Through these accounts, individuals have access to certain information generated about them in and by the health care system. And, in certain cases, these accounts include facilities to combine this information with own-generated data.

This report addresses three questions:

1. How do we manage information management in the health and care sectors so that all data that is relevant in a care and research perspective is available in generic, structured format when and where it is need?
2. What problems and opportunities do the General Data Protection Regulation (GDPR), and the Swedish national legislation adapted to it, create for personal health accounts?
3. How should a legal framework for person-centred storage be designed?

The Swedish Government and the Swedish Association of Local Authorities and Regions (SKL) have formulated a vision that

Sweden, in 2025, shall be ranked first in the world in using the possibilities opened up by digitalisation and e-health – so as to achieve good and equal health and social care.

The starting point for this report is that a precondition for this to be achieved is that the information is: a) directly accessible, b) comprehensive, c) traceable, d) structured according to the same principle, and that the processing of it is: e) secure, f) compatible with the GDPR and Swedish law, and cost-effective.

The report argues that this, in practice, requires that the information is stored in personal health account rather than as today in institution-centred systems alone. The linchpin in the more advanced type of personal health accounts that is advocated here is that all relevant health and care information – not just excerpts of it – is stored in and accessed from one common, person-centred, distributed service held together by one semantic principle and one way of storing the information.

The potential benefits to society of such health accounts are likely to be very large.

By better access to logically unified, complete information for anyone needing it in their day-to-day clinical work, the quality of healthcare could be improved, and the problem of care-induced complications and injuries reduced. The personal integrity of patients could be better protected than in the present patchwork of systems. The possibilities of monitoring and evaluating healthcare and social care services could increase and thereby improve the possibility of proactively spreading best practice and achieving more equal care. The costs of IT-systems in healthcare and social care could be drastically reduced when all systems interact with the same information platform. Small IT start-ups could compete with the big dominant suppliers by developing innovative, bespoke solutions for different actors in the health, healthcare and social care sectors. And, research institutions would have access to a rich source of anonymised information.

Besides a technical solution, person-centred storage also requires a legal framework, which is the focus of this report.

A thorough review of the General Data Protection Regulation (GDPR) in this report leads me to the conclusion that it creates the necessary legal conditions for person-centred storage.

What opens up for storage is article 15 in the GDPR regarding “*Right of access by the data subject*”. Unless explicit restrictions in Union or national law prohibit it, the article gives the individual the right to request and receive all information that concerns him or her.

A corresponding review of the Swedish legislation that has been adapted to GDPR comes to the same conclusion: it makes possible person-centred storage.

While the GDPR creates the necessary legal conditions for person-centred information storage, it needs to be supplemented – in Union or Swedish law – by a person-centred equivalent of the Swedish Data Protection Law. The fundamental premise of such a law should be that an individual has full control of his or her personal data – unless that control is explicitly restricted in another Union or Swedish law.

The law must be concrete and in detail regulate the rights and obligations of all actors in relation to the information in the accounts. And it must be possible to technically implement in the platform. This can be done by structuring the legal framework in seven dimensions: a) purpose, b) legal basis, c) type of processing, d) type of data, e) user role, f) individual, and g) time.

The specific rights and obligations would be defined in the intersections of these dimensions. The rights and obligations should either be specified in law, in agreements between two or several parties, or unilaterally by the concerned individual or the institutional actor. In the law or in a regulation it should be specified who “owns” the rights and obligations in the relevant intersections.

The implementation of personal health accounts will have to be done in steps. In a pilot, individuals should be offered the possibility to freely use the facility to fill it with data by requesting that information that has been generated about them by health and care providers be continuously transferred to his or her account in the storage facility.

After rigorous testing, it should, however, become compulsory for all care providers to directly store all person-related information in the personal health accounts. The text in the Swedish Health Data Act (Chapter 3 § 1) presently stipulating that “*When caring for patients, a patient journal shall be kept*” should then be replaced by: “*All patient-related information shall be stored in a structured format in the patient’s personal health account*”.

It should, furthermore, be stipulated in law that the individual shall have the right to store, via apps or other equipment, own-generated health- and care-related information and to fetch and store in the personal account any other information that may be relevant from a health perspective – such as his or her own genome and socio-economic and environmental information. This information the individual would have full control over including to be able to share it with whomever he or she would want to, including health and social care providers and researchers, on conditions that he or she would stipulate.

A storage facility for personal health accounts should be looked upon as societal infrastructure in the same way as roads, railroad, the electricity grid, and broadband. It thus behoves Central Government to finance the building of this infrastructure.

This can be done in different ways, for example:

1. The Swedish eHealth Agency is given budgetary funds and the authority to commit funds for conducting an “innovation procurement process” forming, for example, a partnership with the independent, government research institute RISE⁷. The advantage of the innovation procurement modality is that it can be used to develop things or services that don’t exist but that meet obvious needs. Furthermore, funds can be made available in batches against delivery of clearly specified benchmarks.
2. The Government makes earmarked budgetary funds available to Sweden’s Innovation Agency (Vinnova) to finance the development of the platform. In this case the resources can also be made available against specified deliverables.
3. The Government makes earmarked funds available to the newly formed Digitalization Agency in order to finance the development the platform as part of a broad programme to digitalize public services.

Central Government or any other politically run institution should, however, not run the platform. Neither should it be run by a commercial actor. Even if it is possible to design the platform so that the information is not accessible to the body operating it, it is of

⁷ <https://www.ri.se/sv>

outmost importance that the public fully trusts that the information is safe. A foundation to run it could therefore be an option.

In parallel with the development of the platform, a study should be initiated to review and propose how such a non-public-non-commercial body should be set up, how it should be governed, which tasks and responsibilities it should have, what resources and competencies it would need, and how it should be financed.

The Government should furthermore initiate a process that should lead to a generic law regulating the management of personal data generated in the interaction between the individual and public bodies and which is stored in person-centred accounts.