Health data – at your service!

Three key actions to transform health data into patient benefits

2024 Agenda for Health and Prosperity report

Thanks to medical and health science research, we now have better opportunities to prevent diseases, make earlier and more accurate diagnoses, and provide more effective treatments. The pace of development is rapid, not least due to improved capabilities in analyzing and utilizing health data.

To enhance the benefits of health data in Sweden, we need robust technology and supportive legislation. But for health data to truly strengthen quality-driven healthcare and the nation's competitiveness, the involvement of professionals and their organizations must also evolve. Numerous processes must function effectively at both national and regional levels for this to happen.

Research!Sweden and the members of "Agenda for Health and Prosperity" share the goal of strengthening quality-driven healthcare and national competitiveness by maximizing the benefits of health data linked to Sweden's unique personal identification system. We have thus developed a shared analysis of current challenges and identified priority processes needed to achieve this goal.

Our ambition is not to preempt ongoing development efforts at both regional and national levels or to create new organizations or redundant work that could drain limited resources. On the contrary, our proposals aim to leverage existing successful activities and propose processes that coordinate and prioritize for improved efficiency and quality. This includes creating clear responsibilities and follow-up measures. Our proposals focus on:

1. how clinical research can be strengthened, and how healthcare can be more involved in developing and utilizing the knowledge created,
2. how regions and other actors can be provided with clear guidelines for managing and using health data,
3. how knowledge management and implementation processes can be made more efficient.
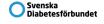
Agenda för hälsa och välstånd – ett samarbete mellan FORSKA SVERIGE FÖR HÄLSA OCH VÄLSTÅND och:

Summary of proposed measures

1. A national function with a mandate to coordinate infrastructures for clinical research

A primary purpose of clinical research is to translate medical advancements into healthcare benefits. In Sweden, the system is fragmented across the various components needed to create strong medical research that ultimately benefits patients. This is evident in the distribution of funding and responsibilities among ministries, agencies, government and regions, particularly affecting clinical research. To strengthen clinical research and healthcare's capacity to develop and use the knowledge produced, we propose the government establish a national entity similar to the National Institute for Health and Care Research (NIHR), which should have mandates in four key areas:

a) Funding high-quality research that benefits healthcare.

b) Investing in world-class expertise, facilities, and skilled personnel to translate discoveries into improved treatments and services.

c) Collaborating with patients, users, healthcare staff, and society to enhance the relevance, quality, and outcomes of research.

d) Partnering with other public funders, charities, and industry to help create a cohesive and competitive clinical research system.

2. A national framework with guidelines for managing and using health data linked via personal identification numbers

The purpose of a national framework is to develop guidelines and procedures to improve the use of health data linked to personal identification numbers for research and quality-driven healthcare. To offer our population the best possible equal, high-quality care, we need to connect different types of health data. To enhance data management, quality, and utilization, we propose the government ensures the establishment of a national, dynamic, and applicable framework that includes guidelines and routines for:

a) Structured health data, to ensure common coding systems for both primary and secondary use.

b) Quality standards, to support effective secondary use of data.

c) Health data usage, to efficiently spread knowledge about standards, specifications, technical platforms, and applications.

d) Partnerships, allowing more actors to contribute to the collection, use, and sharing of data.

e) Integrity, to protect sensitive personal information while enabling health data-based research.

3. A national knowledge-based governance and monitoring system

Governance through knowledge aims to achieve knowledge-based, equal, and resource-efficient healthcare of high quality, both in routine operations and during crises. Several inquiries have highlighted deficiencies in the current system. Knowledge-based governance must be more efficient. We propose that it be conducted at a national level, with the mandate to develop knowledge bases, guidelines for implementation, and monitoring. The processes should include, among other measures:

a) Purposefully composed expert groups that are not limited to regional employees.

b) Governance through knowledge and dissemination efforts should be linked to Health Technology Assessment organizations, existing quality registers, patient organizations, and professional associations.

c) Knowledge bases should be made digitally accessible to healthcare staff in a way that allows them to be used effectively during patient meetings.