Healthcare Data
– High Time for Action

Foreword

There is intense debate concerning what should be done to deal with shortcomings and challenges in healthcare. Many voices are calling for structural reform, believing that gradual interventions changing the current system are no longer sufficient. One crucial issue is healthcare data.

Swedish and British research shows that Sweden has unique opportunities for creating knowledge, and improving healthcare with healthcare data. For instance, we currently have very good cardiology care, thanks to work with quality and follow-up via the Swedeheart register. Mortality rates 30 days after a heart attack were almost 30 per cent lower in Sweden than in England.[1]

In the wake of the Cambridge Analytica and Swedish Transport Agency scandals, there is concern that the general public won't want to share personal data for reasons of integrity. These concerns are unfounded. The share of people willing to share healthcare data has actually increased somewhat. In a recent SIFO survey, 95 per cent of the population said they would consent to sharing their healthcare data, for one or more of the below purposes:

- Promoting medical research (87 per cent)

- Improving patient healthcare (71 per cent)

- Supporting authorities' work with developing general health among the population, and with communicable disease control, etc. (61 per cent)

- increasing own participation, and, in the long term, gaining more knowledge of own health (57 per cent)[2]

Integrity issues are absolutely crucial when it comes to healthcare data. New data protection regulations, based on the EU's General Data Protection Regulation (GDPR), come into force on the 25th of May, 2018. That gives us the tools to be ready for digitisation, and it protects individuals' integrity, while making it easier for healthcare providers to comply with the Patient Act. When it comes to healthcare data, this includes the right to have your data utilised, getting the most efficacious treatment, and not suffering iatrogenic injuries.

Each year, 110,000 patients suffer iatrogenic injuries in Swedish hospitals, according to a report from the Swedish Association of Local Authorities and Regions (SALAR)[3]. That's 8 per cent of the healthcare cases included in the survey. Time spent receiving healthcare treatment is almost twice as long for patients who suffer iatrogenic injuries as for other patients. The cost for this extra healthcare is almost 9 billion SEK per year, which is 13 – 14 per cent of the total cost for hospital care.

[1] Chung S-C., Gedeborg R., Nicholas O. (2014) *Acute myocardial infarction: a comparison of short-term survival in national outcome registries in Sweden and the UK*, The Lancet, vol 383, nr. 9925, s.1305-1312
[2] Forska!Sverige (2018) *Opinionsundersökning*
[3] The Swedish Association of Local Authorities and Regions (2018) *Skador i vården, 2013 – första halvåret 2017*

By collecting, utilising and sharing healthcare data in real time, we can create better conditions for avoiding mistakes, and also identify and change inefficacious treatment methods.

Iatrogenic injuries are just one example. There are a number of important goals that can be achieved if we have a national structure for interoperability that facilitates the collection, utilisation and sharing of data. We can:

- increase healthcare quality

- reduce the number of iatrogenic injuries

- achieve more equal healthcare

- reduce the burden of administration in healthcare

- improve integrity protection

- increase patient safety

- increase patient participation

- get more efficacious diagnoses and treatments

Many countries are now investing in the synchronisation of healthcare data. At the same time, knowledge is developing rapidly, and big technical leaps are being made in biomedical research. Sweden should be at the forefront of both processes and their integration.

Thanks to new, large-scale methods, such as for analysis of the genome, we find ourselves at the beginning of a diagnostic revolution. This can fundamentally improve healthcare, as a greater number of patients get precise, individual diagnoses on a molecular level. This gives a new understanding of disease mechanisms, and will, in the near future, bring completely new opportunities for tailored treatments, so-called precision medicine.

Sweden's conditions for tackling healthcare problems with the help of digitisation, and thus to meet the population's expectations that their healthcare data will lead to better healthcare, are very good.

In our view, however, there are a number of different factors that cause the great potential of collected healthcare data to not be fully utilised in Sweden:

- There are a number of healthcare data systems that don't communicate with each other.

- There are shortcomings when it comes to standards for the construction of healthcare data.

- Joint, national tools and methods for handling data are lacking.

- Relevant healthcare data isn't registered to the desired extent.

- Documentation differs between different healthcare professions, which makes the transfer of information to the next step of the care chain harder.

- Legislation surrounding healthcare data is complex and difficult to get an overview of, which, among other things, leads to healthcare staff feeling insecure as to how the legislation should be interpreted, and therefore choosing not to act.

Patients, healthcare providers, researchers and businesses must get better opportunities for contributing to the collection, utilisation and sharing of relevant data, and it must be done in an ethical, safe, and structured manner.

A number of national level initiatives within the framework of the Vision for eHealth 2025, a col-

laboration between SALAR and the Government, are ongoing.

The county councils hold the main responsibility for healthcare. A number of county councils are working hard with the issue of healthcare data, but in general, there is, according to several reports, a lack of standardisation of healthcare information, which creates poorer conditions for good and equal healthcare in Sweden. We are very concerned that development in healthcare is too slow due to a lack of governance and resources. The process of collecting, utilising and sharing healthcare data according to national standards must be hurried along. This requires a number of political interventions. The 33 organisations involved in Agenda for Health and Prosperity have jointly, and with the purpose of hurrying the process along, developed a number of concrete intervention proposals aimed at the Government, authorities and county councils.*

To create basic conditions for removing the bottlenecks when it comes to synchronised healthcare data in the country, we propose, among other things, that the Government:

- Strengthens investment into medical research and development, and its application in healthcare, which includes national level infrastructure supporting regional level work.

- Ensures that all healthcare providers are required to, and compensated for, collecting, utilising and sharing healthcare data according to national requirement specifications.

The three government ministers for health, research, and enterprise want to invest more in digitisation. In an opinion piece in Dagens Medicin from February, 2018, they write that 'Sweden doesn't have a choice other than to increase investments and the pace of innovation if we are to tackle the health challenges of the future, and maintain a competitive life science sector".

This is in line with Research!Sweden's request that public investment into medical research for health should, in the long term, be doubled, and equal 0.04 SEK per 1 SEK of healthcare spending.

Sweden can't stay at the forefront of neither research, enterprise, nor healthcare if we can't utilise the collected healthcare data. Many processes are already up and running, but they are far too slow, and need to be strengthened. Therefore, it's of the utmost importance that decision makers realise that great investments are needed to transform healthcare so that it can realise the population's expectations, not just today, but in the future too.

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"Agenda för hälsa och välstånd"

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* The Dental and Pharmaceutical Benefits Agency and many county councils participate in the work within Research!Sweden's Agenda Group, and individuals from these organisations contribute with knowledge and perspectives. The Dental and Pharmaceutical Benefits Agency and the county councils do not, however, express opinions on concrete investment proposals formulated by the Agenda Group.

Agenda for Health and Prosperity - a collaboration between **FORSKA SVERIGE** *FÖR HÄLSA OCH VÄLSTÅND* and:

Sveriges läkarförbund · region västerbotten · janssen · Sveriges Ingenjörer · Apotekarsocieteten

Arthur D Little · Cancerfonden · Linköpings Universitet · Medtronic *Further.Together* · diabetes organisationen

Hjärt Lungfonden · Lunds Universitet · MSD · Sahlgrenska Universitetssjukhuset · IQVIA · Pfizer

Region Stockholm · Svenska Läkaresällskapet · Göteborgs Universitet · Region Kalmar län · Riksförbundet HjärtLung

Reumatiker förbundet · Natursvenska · Uppsala Universitet · Capio · Friskare liv · Nätverket mot Cancer

LIF · Karolinska Institutet · TLV · Region Östergötland · Umeå Universitet · Farmaceuter

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Proposal Summary

Below is a summary of our intervention proposals for getting rid of the bottlenecks for synchronised healthcare data, and for reaching the goals of more equal healthcare, more efficacious diagnoses and treatments, as well as improved quality and patient participation. The proposals are described in more detail in the report.

Overall Intervention Proposals

We propose that the Government:

- Strengthens investment into medical research and development, and its application in healthcare, which includes national level infrastructure supporting regional level work.
- Ensures that all healthcare providers are required to, and compensated for, collecting, utilising and sharing healthcare data according to national requirement specifications.
- Reviews the possibilities of increased collaboration between healthcare, academia, and trade and industry, which could contribute with investments and competence for the development of health-care.

We propose that the county councils:

- Review and increase the share of the total county council budget that is used for research and de-velopment in healthcare.

Intervention Proposal for Bottleneck 'There is no cohesive strategy for healthcare information'

On a national level, we propose that:

- The Government makes a decision concerning a national administration organisation for joint, na-tional specifications.
- The National Board of Health and Welfare strengthens work with developing standardised codes, and develops requirement specifications for input and output in collaboration with Inera, the Swe-dish eHealth Agency, and Forumet för Standardisering inom eHälsa (the Forum for Standardisation in eHealth).

- The National Board of Health and Welfare follows up healthcare providers' delivery of healthcare data, which includes ongoing results reports concerning both production, medical results, and the utilisation of well-working viewing tools.
- the Swedish eHealth Agency uses its work with creating a technical infrastructure for a cohesive system in the shape of Nationella LäkemedelsListan, NLL (the National Medications List) as a starting point to develop a similar system in the areas that have objective variables that can be agreed upon.
- The Government ensures that all healthcare education programmes include a course in registering and handling healthcare data, which is uniform across professions.
- SALAR ensures that the following issues are included within the framework of recently begun work with a national system for knowledge-driving:
    - Hurrying up work with the continued development of Vården i Siffror (Healthcare in Numbers) so that areas that currently lack data can be included.
    - Collaborating with the Swedish eHealth Agency and the National Board of Health and Welfare in the work with showing the value of utilising healthcare data nationally.
    - Strengthening competence: more access to and utilisation of data, combined with the need for evidence, requires new competence.

We propose that the county councils:

- Ensure that there is a person who has overall responsibility for the collection, handling and delivery of healthcare information, including governance, coordination and training.
- Ensure that the people with overall responsibility are involved in development work for a support function for structured healthcare information, which will be initiated by SALAR in 2018.
- Develop a time-bound plan with a budget for joint development work.
- Ensure that the medical record systems are compatible with the national standard that is being established.
- Continuously provide information to their staff and patients concerning the value of collected data, and how this contributes to new knowledge, the development of healthcare, and improved material from which to make decisions in the meeting between healthcare provider and patient.

Intervention Proposal for Bottleneck: 'There is uncertainty concerning legislation and policy'

We propose that SALAR:

- Develops a joint code of conduct that shows how GDPR can be complied with.

We propose that the county councils ensure:

- That they implement SALAR's ten point programme and code of conduct.
- That a data protection organisation is established, and that the division of responsibility for interpretation and implementation of legislation concerning healthcare data is clarified.
- That the data protection organisation inspects, adapts and ensures implementation.
- That information concerning the data protection organisation is disseminated according to a communication plan so that all staff know who is responsible for legislative issues surrounding healthcare data.
- That staff are trained in what data can and should be saved, as well as how, where, and by whom data should be handled.
- That the procedure for complying with related legislation, such as legislation concerning registers, is also reviewed.

Intervention Proposals for Goals that Can Be Achieved with the Help of Synchronised Healthcare Data

The goal: More equal healthcare

On a national level, we propose that:

- The National Board of Health and Welfare requires healthcare providers to take improvement measures so they achieve healthcare that is as good as other healthcare providers' if their healthcare is below the national average in any area.
- The National Board of Health and Welfare adjusts the instructions for the Health and Medical Services Act so that the mission of collaborating and disseminating knowledge between healthcare providers financed by county councils, and between healthcare, academia, and businesses, is clarified.
- The Government initiates regulated on-the-job training for healthcare staff, which would improve patient safety.
- The National Board of Health and Welfare establishes a national registration database to strengthen patients' right to register with a doctor in primary healthcare.

The goal: More efficacious diagnoses and treatments

On a national level, we propose that:

- The Government initiates investments into the development of indicators to enable more efficient evaluation and utilisation of research progress in healthcare.

We propose that the county councils:

- Create incentives for healthcare providers, regardless of responsible authority, to introduce clear career progression for healthcare staff working in research and development.
- Ensure that they have a certain capacity to develop new indicators and evaluate innovations.
- Clarify the innovation mission and how it relates to knowledge-driving.

The goal: Increased efficacy, quality and patient involvement

We propose that SALAR:

- Ensures that the issue of eHealth solutions is included in the recently begun work with a national system for knowledge-driving.
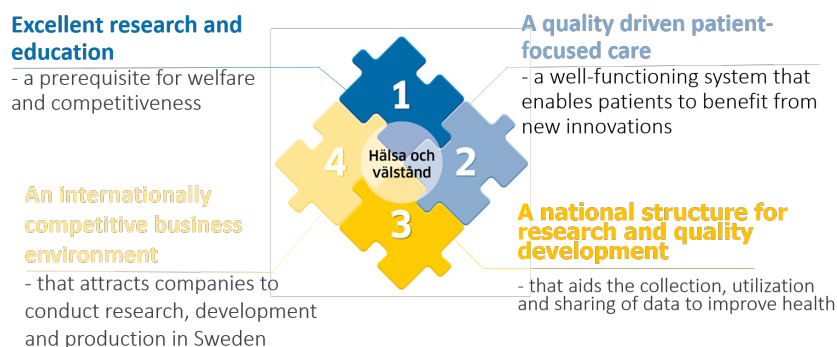
Introduction

Public spending on healthcare continues to increase, and reached 402 billion SEK in 2016. Over 80 per cent of healthcare spending is thought to be related to chronic diseases, which mainly affect the elderly. The over-80s are expected to be twice as many in number just 23 years from now.[4][5][6] This development means that we have to continuously improve preventative work, and focus on healthcare that has been clearly proven to be beneficial.

To achieve goals such as improved quality and efficacy in healthcare, in parallel with increased equality and patient participation, there has to be an efficient and safe system for collected healthcare data. Research!Sweden's member organisation Agenda for Health and Prosperity believes it to be of the utmost importance that healthcare data is utilised to a greater extent.

Research based on healthcare data creates a lot of valuable knowledge. Research is needed both to introduce new treatments and ways of preventing diseases, and to evaluate existing treatments independently. This includes phasing out inefficacious treatment methods.

Research needs healthcare data, and healthcare needs research that is based on healthcare's data, and that becomes useful for patients and healthcare staff. Therefore, data has to be made available to healthcare providers and patients, but also to other parties that develop knowledge further, based on healthcare data. It's very important that investments into research connected to healthcare data increase, and that various data sources, such as medical record systems and quality registers, are made interoperable and accessible.

In the report, we focus on the collection, utilisation, and sharing of healthcare data, but we are also aware that there are other aspects that are important for improving healthcare. We have previously presented intervention proposals within the framework of four areas which all contribute to increased health and prosperity.[7]

Excellent research and education
- a prerequisite for welfare and competitiveness

A quality driven patient-focused care
- a well-functioning system that enables patients to benefit from new innovations

An internationally competitive business environment
- that attracts companies to conduct research, development and production in Sweden

A national structure for research and quality development
- that aids the collection, utilization and sharing of data to improve health

1 2 3 4 Hälsa och välstånd

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[4] Statistics Sweden (2018) *Hälsoräkenskaper*

[5] The Swedish Agency for Health and Care Services Analysis (2014) *VIP i vården – Om utmaningar i vården av personer med kronisk sjukdom*

[6] Statistics Sweden (2017) *Sveriges framtida befolkning 2017–2060*

[7] Research!Sweden (2017) *Agenda för hälsa och välstånd – 14 konkreta åtgärdsförslag med handlingsplaner*

The third area focusses on Sweden's need for a national structure for interoperability that facilitates the collection, utilisation and sharing of data to improve health. We are currently worried, as we feel that developments in healthcare – when it comes to handling healthcare data – are far too slow. To create an increased sense of urgency, and to constructively contribute to the processes speeding up, we have chosen to focus on the issue of healthcare data in this report.

The purpose of this report is to:

- identify and describe the bottlenecks experienced by businesses, healthcare professionals, patients and researchers when it comes to the collection, utilisation and sharing of healthcare data.
- Identify and describe existing initiatives that are expected to contribute to the removal of these bottlenecks.[8]
- Present intervention proposals that contribute to driving the process forward at the fast pace required for patients in Sweden.

In the report, we summarise the current situation based on results from various investigations and reports, as well as the Agenda Group's own experiences. In addition, we have spoken to a number of involved authorities and a legal expert. Based on this, we have identified the following bottlenecks:

- The resources for research and development within healthcare are insufficient.
- There is no cohesive strategy for healthcare information.
- There is uncertainty concerning legislation and policy.

Based on a joint analysis, the Agenda Group has developed concrete intervention proposals that we believe that county council politicians need to implement for healthcare in the whole country to be able to benefit from new technology for handling healthcare data, thus increasing quality and equality. Different county councils can be expected to take on different roles and responsibilities depending on their capacity, and on whether or not they are home to a university hospital.

In work with developing the intervention proposals for county council politicians, we have also identified and included proposals for which responsibility is on a national level, meaning that they are aimed at the Government and authorities.

In the report, we have limited ourselves to data that is generated or integrated via healthcare financed by county councils, regardless of the provider, and regardless of whether the data is created within healthcare or reported to healthcare via tools used at home by patients, such as blood sugar monitors for diabetics (examples of how patients get better healthcare via digitisation projects can be found in appendix 2).

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[8] We don't claim to be able to give a full picture of this highly complex system, and the vast amount of currently ongoing projects. The Swedish eHealth Agency has, however, been tasked with developing a map of the eHealth world, which is to be presented in 2018.

Municipal welfare operations encompass 10 – 15 per cent of healthcare. We have not been able to include these operations in the report, but our starting point is that data from welfare should be able to integrate with healthcare data, not least to improve patient safety.

The interventions we propose:

- Are patient-focussed (improve patients' opportunities for participation).
- Are disease-focussed (improve the handling of chronic diseases).
- Are treatment-focussed (improve the opportunities for precision medicine, for instance).
- Address efficacy (such as safety, quality, and minimisation of duplication).
- Address social issues (equal healthcare).

Our view is that there are many good initiatives going on, on several levels, and in different organisations, which we show through a number of examples in this report. But we also feel that there is a lack of resources and governance, which makes the processes too slow, and leads to benefits of collaboration not being utilised to a large enough extent.

Brief introduction to Vision for eHealth 2025 and its background

- In 2005, the Ministry of Health and Social Affairs presented an initial, national IT strategy for healthcare and welfare, to meet the challenges of the future. The strategy was supposed to provide support for operational development on local and regional levels, and constituted the first stage of achieving deeper, national collaboration on these issues.[9]

- The strategy was updated in 2010, now with a focus on the introduction, usage and benefit of technology, with the purpose of underlining that IT is a natural part of the operational development of healthcare and social services.[10]

- In 2016, the Government and the Swedish Association of Local Authorities and Regions (SALAR) presented Vision for eHealth 2025.[11] It stated: 'In 2025, Sweden will be the best in the world at using the opportunities offered by digitisation and eHealth to make it easier for people to achieve good and equal health and welfare, and to develop and strengthen their own resources for increased independence and participation in the life of society.' The vision document replaced the earlier strategy, but is built on its thoughts and efforts.

- In 2017, the vision was followed by an action plan.[12] The Action Plan for eHealth outlines how responsibilities are divided, perspectives, principles, target groups, and the overall initiatives in standardisation, follow-up and external monitoring (see appendix 1).

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[9] Ministry of Health and Social Affairs (2005) *Nationell IT-strategi för vård och omsorg (Skr. 2005/06:139)*

[10] Ministry of Health and Social Affairs (2010) *Nationell eHälsa - strategin för tillgänglig och säker information inom vård och omsorg*

[11] The Government and the Swedish Association of Local Authorities and Regions (2016) *Vision e-hälsa 2025 – gemensamma utgångspunkter för digitalisering i socialtjänst och hälso- och sjukvård*

[12] The Government and the Swedish Association of Local Authorities and Regions (2017) *Handlingsplan för samverkan vid genomförande av Vision e-hälsa 2025 2017–2019*

Vision and Goals

Agenda's Vision 2025 – Healthcare Data

Sweden is a pioneering country when it comes to healthcare, thanks to competence being translated into practice. Healthcare's coordinating mission to document relevant information contributes to a national platform for research and quality development. Researchers and businesses come to Sweden as a leading nation for point of care studies.

(Excerpt from Agenda for Health and Prosperity's vision for 2025, see the complete vision on the back of the report.)

Overall Goals

Sweden has synchronised and relevant healthcare data within the framework of current legislation. Thus, we have taken pole position in ensuring individuals' integrity while simultaneously benefitting from and developing healthcare data further in order to achieve and maintain improved health, which has increased equality, patient participation and quality in healthcare. It has also created scope for more efficacious diagnoses and treatments.

Goals Concerning Real Time Data

All county councils have introduced real time updates of patient data as part of the healthcare mission for healthcare providers, public and private ones alike. The systems that are used are interoperable throughout the country, and there is no data duplication.

The focus is on output, i.e. continuous results reports concerning both production and medical results in accordance with national requirement specifications. This is how all healthcare providers that are financed by county councils report whether or not they have reached the stated result goals. Healthcare staff and patients have access to well-working, simple viewing tools with which they can collect relevant data easily and in real time, for an individual or a group, to interpret the current situation and trends. Patients feel safe in the knowledge that all healthcare providers hold up-to-date, correct information, and handle details in a way that ensures integrity.

Bottlenecks for Synchro-nised Healthcare Data

In this chapter, we focus on bottlenecks, and contribute concrete intervention proposals to eliminate these obstacles and to be able to reach the goals of more equal healthcare, more efficacious diagnoses and treatments, as well as increased quality and patient participation.

Overall Conditions

We have to create certain basic conditions to find solutions for the bottlenecks that obstruct the synchronisation of healthcare data in the country. Strong development work in healthcare is a requirement. In general though, development operations in healthcare are very limited compared to in other industries.[13] Only seven of Sweden's 21 county councils invested over two per cent of their total healthcare spending in research and development (R&D) in 2016. Most county councils invest between 0 and 0.75 per cent (see appendix 3). Investments into digitisation are ongoing, however, in around half the county councils, which is not yet visible in the R&D statistics. But we can still confidently state that resources for work with collecting, utilising and sharing data for healthcare development and quality are insufficient.

SALAR says in a position paper that 'Patients need research to get the best possible healthcare – not just today, but tomorrow too,' and they present good intervention proposals to improve the situation.[14] It is, however, unclear whether the interventions are being implemented, and one obstacle could be that the county councils, according to SALAR, are facing financial strain. SALAR believes that the municipalities' and county councils' work with changing and developing the operations must be intensified, and that the state has to help make it easier for the sector to become more efficient.[15]

Investments into digitisation increase costs initially, but make up for it through increased efficacy and improved health. In a scenario where digital technology is fully utilised by 2025, McKinsey estimates that the annual gross unit cost for healthcare will be 25 per cent lower than if no investments are made into eHealth, and if the development continues as it has done so far. For the year 2025, that equals 180 billion SEK.[16]

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[13] I Radar Eco´s rapport IT-radar 2017 says that the average scope for development and innovation in Sweden across all industries was around 25 per cent in 2016. This can be compared to details from an article from Dagens Samhälle (Torbjörn Carlbom, Dagens Samhälle, no. 5, 2017) in which it is stated that the scope for development and innovation in the county council sector is around 11 per cent, i.e. significantly lower than for other industries in Sweden.
[14] The Swedish Association of Local Authorities and Regions (2016) *Patienter behöver forskning för att få bästa möjliga vård – inte bara idag utan även imorgon, SKL:s positionspapper om klinisk forskning*
[15] The Swedish Association of Local Authorities and Regions (2017) *Ekonomirapporten, oktober 2017, om kommunernas och landstingens ekonomi*
[16] McKinsey & Company (2016) *Värdet av digital teknik i den svenska vården*

So there is a risk that insufficient resources for research and development in healthcare will mean that Sweden won't be able to reach the goal of being the best in the world at eHealth by 2025.

Against this background, certain basic conditions for dealing with the bottlenecks that prevent synchronised healthcare data in Sweden have to be created.

We propose that the Government:
- Strengthens investment into medical R&D and its application, which includes national level infrastructure supporting regional level work.
- Ensures that all healthcare providers are required to, and compensated for, collecting, utilising and sharing healthcare data according to national requirement specifications.
- Reviews the possibilities of increased collaboration between healthcare, academia, and trade and industry, which could contribute with investments and competence for the development of healthcare.

We propose that the county councils:
- Review and increase the share of the total county council budget used for research and development.

There Is No Cohesive Strategy for Healthcare Information

In Sweden, we have a number of systems for healthcare information that can't communicate with each other. This has become a bottleneck for synchronised healthcare data. We need to nationally mobilise work with a cohesive strategy for healthcare information in order to lessen the administrative burden in healthcare, while also increasing patient safety and healthcare quality. **Patients, healthcare providers, researchers and businesses have to get better opportunities to contribute to the collection, utilisation and sharing of data, and this must be done in an ethical, safe, and structured way.** This would lead to increased quality, equality and safety in healthcare. This development, with improved healthcare data, is ongoing in a number of countries across the world, and there are also projects running in the OECD and the EU, for instance, to support countries' processes in this transformation (see appendix 4).

Every year, around 110,000 patients in Sweden suffer iatrogenic injuries, leading to suffering for the affected patient, and high costs for society. The cost of the extra healthcare is almost 9 billion SEK per year if the average cost of 24 hours spent in healthcare is 10,000 SEK. That's around 13 –14 per cent of the annual cost of healthcare, excluding psychiatry.[17]

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[17] The Swedish Association of Local Authorities and Regions (2017) *Skador i vården, 2013-2016 - På nationell, regional- och landstingsnivå. Markörbaserad journalgranskning.*

To reduce the number of iatrogenic injuries, there is a very great need for staff to be able to follow trends in real time, and identify whether an injury happened by chance or if it's part of a trend. If it turns out to be a trend, this trend must be broken so that similar iatrogenic injuries can be avoided in the future. But looking into the past isn't enough – we also need to look forward. Healthcare providers must be able to follow real time data, and have the competence and methods to make the forward-looking analyses required for them to take the necessary steps to avoid unwanted incidents, and to drive development and quality forward.

In a report on national quality registers by Mona Boström (2016), three main problems appear:

- Usage of the registers is too low in the operations' improvement work.
- The technology still leads to duplication, and isn't cost effective.
- National quality registers and their whole organisation is located outside the regular healthcare system to too great an extent.

Boström establishes that the Vision for eHealth 2025 is an important piece of the puzzle, and that the more long-term goal is for healthcare information systems to develop so that data can be collected straight from them for follow-up of all healthcare and welfare.[18]

In our view, there are a number of reasons why the large knowledge potential of collected healthcare data isn't being fully utilised:

- There are a number of systems for healthcare data in Sweden that don't communicate with each other.
- There are shortcomings when it comes to standards for the construction of healthcare information, including which codes should be used as alternatives to free text in the respective disease area or operational area. Work with addressing this is ongoing, but better coordination and a faster pace are needed.
- Joint tools and methods for handling data, i.e. set interfaces enabling everyone to get comparable data, are also lacking. The reason is that there are no requirement specifications, which in turn is due to a lack of coordination and follow-up goals.
- Relevant healthcare data isn't registered to the desired extent, as those who could register it don't always know why it's important, and what the data should be used for.
- Healthcare staff from different profession do documentation in different ways, which makes the transfer of information to the next step in the healthcare chain harder.

(Detailed status reports on the IT infrastructure within healthcare and the development in the county councils can be found in appendices 5 and 6.)

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[18] Boström M. (2016) *Nationella kvalitetsregister 2017 och framåt*

The Swedish eHealth Agency writes that 'the lack of standardisation of information within health-care and welfare has many consequences, depending on the perspective. For patients and users, the fact that information is based on different foundations tends to create uncertainty, making them feel unsafe. For healthcare staff, it can become an unnecessarily time-consuming and inefficient hunt for, and duplication of, information concerning patients and users. Put together, this risks creating poorer conditions for equal healthcare.'[19]

There are a number of ongoing, future, and past initiatives, run by various parties, that aim to support the application of standards, and the development and implementation of specifications in different ways (see appendix 7). One example is Stockholm County Council (SLL), which has initiated the Framti-dens Vårdinformationsmiljö SLL (The Healthcare Information Environment of the Future, SLL) project, with the goal of establishing technical solutions that make it possible to increase patient participation, and create conditions for operational development within healthcare (see appendix 8).

The Swedish eHealth Agency believes that a national administration organisation for joint, national specifications is one of the most crucial prerequisites for reaching the interoperability aspired to on a national level, as well as the goals of Vision for eHealth 2025. The purpose of such a national adminis-tration organisation would be to:

* Constitute a competence centre that provides support and advice in standardisation issues,
* Enable a point of contact for collaboration and exchanging experiences.
* Make joint, national specifications accessible.

The Swedish eHealth Agency thinks that this would give the users, especially the responsible authoriti-es, increased opportunities to focus on developing and applying specifications through the state taking responsibility for a long-term administration mission (see appendix 9).

On a national level, we propose that:
* The Government makes a decision concerning a national administration organisation for joint, na-tional specifications.
* The National Board of Health and Welfare strengthens its work with developing standardised co-des, and develops requirement specifications of input and output in collaboration with Inera, the Swedish eHealth Agency, and Forumet för Standardisering inom eHälsa (the Forum for Standardi-sation in eHealth). Work should focus on achieving a one-stop shop where all data is available (as opposed to separate medical registers and other registers) and connected to international system Snomed CT[20] when it comes to codes.
  Examples of issues to address:

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[19]The Swedish eHealth Agency (2018) *Nationellt stöd för utveckling och förvaltning av gemensamma, nationella specifikatio-ner*

[20] Snomed CT (Systermatized Nomenclature of Medicine) is an international system of terms that has been translated into Swedish. It is used to express, in detail, information such as symptoms, diseases, anatomical localisation, examination fin-dings, diagnostic methods, treatment methods, etc. in clinical information systems. This enables a uniform way of descri-bing, indexing, storing, searching for, and collating medical information jointly for different medical specialisms and healt-hcare units. The system can also help to organise the content of patients' medical records, reduce the variability in how information is registered, collected, coded and used in healthcare and research. The National Board of Health and Welfare is working for Snomed CT to be introduced and used in Sweden's healthcare and social services.

  - The introduction of structured, interoperable systems of data – improve the ability to
    deal with input and output.

  - Access to, and deeper knowledge of, analyses and real-time follow-up.

  - Coordination of objective data (medications, lab results, operation codes, diagnosis
    codes, image banks) so that separate medical records and interpretations don't need
    to be unified.

  - Utilisation of healthcare data, including handling various interested parties' (healthcare
    staff, researchers, patients, those responsible for budgets, etc.) varying data needs.

  - Dissemination of knowledge.

  - Development of indicators for the evaluation of innovations.

- The National Board of Health and Welfare follows up healthcare providers' delivery of healthcare data, which includes continuous results reports concerning both production, medical results, and the utilisation of well-working viewing tools.

- The Swedish eHealth Agency uses its work with creating a technical infrastructure for a cohesive system in the shape of Nationella LäkemedelsListan, NLL (the National Medications List) as a starting point to develop a similar system within the areas where there are objective variables that can be agreed upon[21]. Other areas that this may be appropriate for are lab, operation codes, diagnosis codes, and image banks. Collaboration with the National Board of Health and Welfare, which already runs relevant work in these areas should take place. Ongoing work with developing codes in various areas should also be utilised within the National Board of Health and Welfare's project Patientens Väg genom Vården (The Patient's Road through Healthcare).

- The Government ensures that education for all healthcare professions includes a course in registering and handling healthcare data, which is uniform across professions.[22] The National Board of Health and Welfare's administration and development work within the area means that this authority should participate in the creation of the courses.

- SALAR ensures that the following issues are included in the framework for recently begun work with a national system for knowledge-driving:

  - Hurrying up the ongoing development so that areas that currently lack data can be in
    cluded in Vården i Siffror (Healthcare in Numbers) – SALAR's service at www that
    shows indicators and measurements concerning healthcare.

  - Collaborating with the Swedish eHealth Agency and the National Board of Health and
    Welfare in the work with showing the value of utilising healthcare data nationally. This

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[21] A law concerning a national medications list will come into force on the 1st of June, 2020, but will not cover requirements of healthcare parties or disclosure responsibility. The law shall give all authorised healthcare staff access to view which medications have been prescribed to a patient, regardless of who has prescribed them. These regulations are proposed to come into force on the 1st of June, 2022. The new law should give scope for creating national initiatives in other areas. The Government (2018), *Lagrådsremiss – Nationell läkemedelslista.*

[22] In Canada, independent, non-profit organisation Infoway, which works to hurry up the development, implementation, and efficient usage of digital healthcare solutions, has involved national faculties over the past six years for the education of clinical information competence. Among these faculties can be found the Canadian Association of Schools of Nursing, the Association of Faculties of Pharmacy of Canada, and the Association of Faculties of Medicine of Canada. From a presentation by Green M., Sepa S. (2018) Advancing Digital Health in Canada, at the HIMSS conference, the 6th of March.

includes developing indicators, and thus showing the value in similar ways as has been done within the areas of rheumatism, prostate and HIV, for instance, where outcome measures have been developed.

- Strengthening competence: More access to and utilisation of data, paired with the need for evidence, requires new competence. New roles, such as professional health-care data analyst, are needed, in combination with competence development for healthcare staff.

We propose that the county councils:

- Ensure that there is a person who takes overall responsibility for the collection, handling and de-livery of healthcare information, including governance, coordination and training. It would clarify responsibilities, and improve leadership. It's important that the appointed persons in each county council collaborate across county council and region borders, for instance regarding internal gover-ning documents, leadership support when it comes to training staff in why registration of health-care data is necessary, and development work based on healthcare data in general.

- Ensure that the people with overall responsibility are involved in the development work for a sup-port function for structured healthcare information that SALAR will begin in 2018.[23] The purpose of the support function is to contribute knowledge, coordination, method development, and expe-rience exchanges in the area of structured information. In the long term, there are plans to add a lo-cally and regionally anchored collaboration structure as a clear part of county councils' and regions' cohesive system for knowledge-driving to the central support function.

- Develop a time-bound plan and a budget for joint development work. The county councils also need to budget for new roles, such as logisticians and data analysts, who will make work with benefitting more from healthcare data easier. This includes giving healthcare staff an easy to understand real time interface so they can influence healthcare decisions. The interface should be the same, regard-less of what part of healthcare, or what part of the country they work in.

- ensure that the medical record systems are compatible with the national standard that is being es-tablished, with the purpose of enabling synchronised healthcare data in Sweden. It shall be possible to input and output data, not just on a local level, but on a national level too. It is, quite simply, a requirement for cohesive handling of healthcare information across all publically financed healthca-re, regardless of responsible authority. Continued work within the framework of MedTech4Health's project Gemensamt Ramverk av Standarder för Interoperabilitet och Förändringsledning (Joint framework of Standards for Interoperability and Transformation Leadership) is important, not least as connected to the issue of international standardisation initiatives with the purpose of preventing individual national solutions.

- continuously provide information to their staff and patients concerning the value of collected data, and how this contributes to new knowledge, the development of healthcare, and improved mate-rial from which to make decisions in the meeting between healthcare provider and patient.

[23] Swedish Association of Local Authorities and Regions (2018) *Strukturerad vårdinformation*
https://skl.se/halsasjukvard/ehalsa/standardiseradinformationsforsorjning/struktureradvardinformation.15030.html

Knowledge-Driving

A national collaboration group for knowledge-driving (NSK) was initiated in 2008. To create knowledge-driving on different levels of healthcare that is more effective and suited to its purpose, county councils and regions are now (2018), with support from SALAR, establishing a national system for knowledge-driving.

The purpose is to make it easier to coordinate knowledge support that is used in healthcare, that the support is developed in relevant areas, and designed to be easy to use in meetings with patients. Aside from knowledge support, support for follow-up and analysis, support for operational development, and for leadership, are also included in the system for knowledge-driving.

National Information Structure 2017

The National Board of Health and Welfare is working, as per given instructions, with a joint information structure for healthcare and welfare, and this is included as a prioritised intervention area in the Action Plan for eHealth.

The instructions are to create and provide uniform terms and classifications, as well as a cohesive information structure within the operational area of healthcare and welfare. The purpose is to support and contribute to the goal of having structured documentation in healthcare and social services that is suited to its purpose. The joint information structure includes a national information structure (NI) and national nomenclature.

NI is a tool for achieving semantic interoperability within and between these different parties. Interoperability is defined as the ability of systems, organisations or operational processes to work together and communicate with each other as agreed upon rules are adhered to.

Structuring and Coding Information for Electronic Handling

The National Board of Health and Welfare has been tasked with developing method support that is mainly aimed at operational developers and informaticians, and provides support in the work with structuring and coding information that is to be exchanged electronically within healthcare and welfare.[24]

In May, 2018, the National Board of Health and Welfare is going to publish an update on the development of eHealth, based, among other things, on interviews with several county councils and regions.

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[24] This is part of the mission of better utilisation of resources in healthcare (S2017/01565/FS).

Working Groups within Work with eHealth

- More uniform use of terms: For information to be reused and shared between different systems without losing meaning or context, agreements concerning a joint, underlying information structure, and unambiguous terms, codes and classifications, are needed. The working group works to create a uniform structure and unambiguous documentation content.[25]

- Standards: With the help of standards for information transfer, more effective working processes are created for staff, the flow of patients becomes safer, and patients get increased participation in their own health. The working group works to achieve well-working information transfer within and between operations' digital systems, through improving the use of standards.[26]

Activity proposals for 2018 – 2019 have been developed within the framework of a joint plan for more uniform term usage and standards:[27]

- Establish processes for national collaboration to support the uniform usage of standards, information structures, terms, classifications and sets of codes (ultimately responsible: the Swedish eHealth Agency).

- Establish a national support function for structured healthcare information (ultimately responsible: SALAR).

- Investigate how applied standards, information structures, terms, classifications and sets of codes can be made digitally accessible (ultimately responsible: Inera).

- Strengthen the knowledge area through education (ultimately responsible: the National Board of Health and Welfare and SALAR). Education at universities as well as in regions, county councils and municipalities to reduce the lack of competence that exists today.

- Plan for communication interventions – target group politicians and leaders in municipalities and county councils (ultimately responsible: the Coordination Office at the Swedish eHealth Agency).

- Establish processes for handling reference architecture (details as yet undecided).

New Digitisation Authority

Special investigator Bengt Kjellson has been tasked by the Government with preparing and implementing the formation of a new authority for digitisation of the public sector. The new authority shall develop, coordinate and support the digitisation of state authorities, as well as administration in municipalities and county councils. It will be up and running in Sundsvall by the 1st of September, 2018.[28]

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[25] eHealth 2025 (2017) *Arbetsgruppen för enhetligare begreppsanvändning*
https://ehalsa2025.se/gemensam-organisation-samverkan/arbetsgrupp-enhetligare-begreppsanvandning/
[26] eHealth 2025 (2017) *Arbetsgruppen för standarder*
https://ehalsa2025.se/gemensam-organisation-samverkan/arbetsgrupp-for-standarder/
[27] The Swedish eHealth Agency (2018) *Viktiga steg i visionsarbetet under 2018*, 21 feb.
https://ehalsomyndigheten.solidtango.com/video/11-00-viktiga-steg-i-visionsarbetet-under-2018/
[28] The Government (2017) *Ny myndighet för digitalisering av den offentliga sektorn till Sundsvall*
http://www.regeringen.se/pressmeddelanden/2017/12/ny-myndighet-for-digitalisering-av-den-offentliga-sektorn-till-sundsvall/

There Is Uncertainty Concerning Legislation and Policy

Legislation surrounding healthcare data is complex and difficult to get an overview of. Uncertainty concerning how healthcare staff should interpret legislation has become a bottleneck for synchronised healthcare data.

Special investigator Cecilia Magnusson Sjöberg has mapped and analysed the legislation that makes digital development and collaboration within public administration harder unnecessarily: 'One reflection on the result of the mapping is that the legislation that in a wide sense encompasses law, regulations and directions, can hinder or inhibit digital development within administration in many ways; through obvious legal obstacles, legal uncertainty, or through a lack of regulation.'

There are many interesting proposals in the investigation. One is that the Government should appoint a legal preparation body that, over the next few years, would be tasked with continuously developing preparation material for adapting the law in force for case-handling, supported by existing as well as new forms of digital information supply.[29]

Personal integrity protection is a human right. A new data protection regulation, based on the EU's General Data Protection Regulation (GDPR) comes into force on the 25th of May, 2018, to create a 'digital single market' which is to enable data flows within Europe.[30] GDPR exists to create trust. When it comes to healthcare data, it's about the right to:

- Say no.
- Not have your data misused.
- Have your data used.
- Get the most efficacious treatment.
- Not suffer iatrogenic injuries.

GDPR comes with a number of requirements directly connected to the handling of healthcare information, so it is of the utmost importance that all county councils are well prepared. Overall, the impression of GDPR is that we should do more tomorrow than we do today. At the same time, GDPR really gives us the tools to be prepared for digitisation, which, in our opinion, increases the likelihood that we'll be able to comply with the Patient Act.

It has previously been unclear to county council management groups to what extent healthcare data, and the legislation surrounding it, affect day-to-day work in healthcare, and development opportunities in the operation. Today, the issue is on the county council management groups' agenda, which was rarely the case three years ago, when it was more likely dealt with by the director of IT. It's only when you see the extent of the possibilities that a sense of urgency arises about helping operations to interpret and comply with the new legislation.

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[29] Ministry of Finance (2018) *Juridik som stöd för förvaltningens digitalisering SOU 2018:25*
[30] GDPR Portal https://www.eugdpr.org/

Knowledge concerning the importance of the issue has increased, as have the investments, but there seems to be a disconnect between management and staff who, on different levels and in different areas, still don't know how to interpret legislation or who to turn to in order to find out what they can and can't do. There is a lack of knowledge, and the division of responsibility is not clear.

The result could be that staff make mistakes, which could have legal consequences. Alternatively, the result could be that staff refrain from taking action, and important development concerning the handling of healthcare data risks falling behind, which affects patients. **We see GDPR as an opportunity. It's important to not just handle GDPR through adjustments to the current legislative framework, but to really seize the opportunity to optimise data handling within the framework of the new rules.**

To facilitate the adaption to GDPR, SALAR is working actively with interpreting what this legislative change will mean practically for municipalities, county councils and regions. SALAR has developed a ten point programme about what the members need to do to meet the requirements. [31]

We propose that the Government:
- gives high priority to a rapid process when it comes to handling and making decisions on the proposals included in the investigation on digital development.

We propose that SALAR:
- Develops a code of conduct[32] that shows how GDPR can be complied with, as a development of the ten point programme. The code of conduct shall make the application of the regulation more efficient, and include handling of healthcare data within the framework of healthcare's mission, including research and education.[33] A code of conduct with guidance could, for instance, include guidelines on:[34]

    - Legitimate and transparent handling of personal details.

    - Justified interest from those responsible for personal details in certain contexts.

    - The collection of personal details.

    - Pseudonymisation of personal details.

    - Information for the public and those registered.

    - The exercising of the rights of those registered.

    - The handling of children's details.

    - Technical and organisational safety interventions.
    - Incident reporting.

    - Built-in data protection and data protection as standard.

    - The transfer of personal details to third countries and international organisations.

    - Extrajudicial processes and other dispute resolution processes for the resolution of

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[31] Ministry of Finance (2018) *Juridik som stöd för förvaltningens digitalisering SOU 2018:25*
[32] Codes of behaviour are guidelines for how a certain operation or industry should handle personal details in accordance with the requirements of GDPR. The code of conduct should also include regulations to ensure that the code is complied with.
[33] Ministry of Justice (2017) *Så stärker vi den personliga integriteten (SOU 2017:52)*
[34] Olstedt Carlström C. (2018) *Det Europeiska dataskyddet – presentation för Forska!Sverige den 23 januari*

disputes.

- Internal infrastructure points/issues – information and education.

Developing a legislative framework to show how to use GDPR, not least in connection with patient data, makes clear how SALAR's members interpret and are going to apply the law. If such a code is developed, and collaboration with the Swedish Data Protection Authority is initiated after the 25th of May, 2018, they are obliged to handle the code. If it is approved, there is a safe tool to rest against, and accusations of carelessness can be avoided. With the introduction of GDPR, all organisations must be able to show that they take responsibility, at all stages, which requires them to introduce structures and processes. If they don't, they lack the ability to show how they work and comply with the legislative framework.

We propose that the county councils ensure:

- That they implement SALAR's ten point programme and code of conduct.

- That there is a data protection organisation, and that responsibilities for interpretation and implementation of legislation concerning healthcare data are clarified (how data should and can be used, including for research and development).

- That the data protection organisation develops protocols for upgrading and adapting systems to be able to handle GDPR.

- That the data protection organisation inspects, adapts, and ensures the implementation (data security classification of all systems, including databases and everything else that is searchable).

- That information concerning the data protection organisation is disseminated in accordance with the communication plan so that all staff know who is responsible for legal issues concerning healthcare data (utilise policy and education documents developed by SALAR).

- That staff are trained in what data may and should be saved, as well as how, where, and by whom data is handled.

- That the procedure for complying with related legislation, such as the legislation concerning registers, is also reviewed.

GDPR

The data protection regulation, which is based on the EU's General Data Protection Regulation (GDPR) is law in all of the EU's member states from the 25th of May, 2018. The regulation brings a fair amount of changes to those who handle personal details, and enhanced rights for individuals when it comes to personal integrity. [35] The regulation means that the Personal Data Act (PuL), which applies to the handling of personal details, ceases to apply.[36] The Ministry of Health and Social Affairs commissioned a public investigation because of GDPR: *Dataskydd inom Socialdepartementets verksamhetsområde – en anpassning till EU:s dataskyddsförordning* (SOU 2017:66) (Data protection in the operational area of the Ministry of Health and Social Affairs – an adaption to the EU's data protection regulation SOU 2017:66).

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[35] The Swedish Data Protection Authority (2018) *Dataskyddsref*
[36] The Employers' Alliance (2018) *Rådgivning GDPR - personuppgifter*

Data Protection Act (Prop. 2017/18:105)

The Government proposes that the Personal Data Act is abolished, and that a new law with regulations to act as complements to the EU's data protection regulation is introduced. The changes to the legislation are proposed to come into force on the 25th of May, 2018.

The Patient Data Act

The Patient Data Act (PDL), has been in force since 2008, and regulates how personal details are handled within healthcare. PDL applies both to public and private healthcare providers. PDL also includes regulations concerning giving out details and documents, as well as some disclosure obligations, regulations concerning national and regional quality registers, patients' right to access their medical records, correction of details, destruction of patient's medical records, information for patients, taking custody of patients' medical records and returning them (private healthcare).[37]

The Swedish Data Protection Authority Will Be Called Integritetsskyddsmyndigheten (the Integrity Protection Authority)

In a press release from the 15th of December, 2017, the Government proposed that the Swedish Data Protection Authority should change its name to Integritetsskyddsmyndigheten (the Integrity Protection Authority). Furthermore, the authority's mission should be changed so that its supportive and advisory role becomes clearer. The transformation will take place bit by bit over the course of 2018. To strengthen work with personal integrity, the Government will supply the Swedish Data Protection Authority with 30 million SEK.[38]

Working Groups Working with the Vision for eHealth

Working groups are working to achieve a legislative framework that is suited to its purpose, and that looks after individuals' integrity, and promotes digital development. Their starting point is that the laws, regulations and directions that govern the operations have the purpose of satisfying individuals' various needs. But the laws must also be able to handle the specific issues that digital development comes with. Digitisation of information-handling has to be secure and protected from unauthorised access, for instance through encryption and secure identification of users, so that details aren't given to unauthorised persons.

Digital, Pedagogical Support with a Focus on Law

In 2016, the National Board of Health and Welfare was tasked with developing and making accessible digital, pedagogical support for change and development work, with the help of eHealth solutions. In January, 2018, the National Board of Health and Welfare presented a website that included a list of 32 points, including summarising texts about important terms from the legal perspective of working with eHealth. The legal support describes the legislative framework surrounding information-handling and documentation, based on current law. The support is aimed at those who work in healthcare or social services.

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[37] The Swedish Data Protection Authority (2008) *Patientdatalagen och den personliga integriteten*
[38] The Government (2017*) Datainspektionen blir Integritetsskyddsmyndigheten*, 15 dec
http://www.regeringen.se/pressmeddelanden/2017/12/datainspektionen-blir-integritetsskyddsmyndigheten/
[39] Ministry of Health and Social Affairs (2016) *Uppdrag angående utbildning kring förändrings- och utvecklingsarbete med stöd av e-hälsa.*

Goals that Can Be Achieved with the Help of Synchronised Healthcare

We have already described how synchronised healthcare data would contribute to reducing the administrative burden in healthcare, while simultaneously increasing both patient safety and healthcare quality, as well as reduce the number of iatrogenic injuries. In this chapter, we explore three goals in more detail, and contribute proposals of how they can be reached.

More Equal Healthcare

The population is, to an increasing degree, asking for services made possible by the digitisation of data – such as easy-to-access information and participation – in healthcare as well. All county councils and regions are now connected to e-service Journalen (the Medical Record), which gives all inhabitants in Sweden access to selected parts of their medical record information, regardless of where in Sweden they sought healthcare. The goal is to make it possible for patients to access all their health and healthcare information through Journalen, but it is unclear when this goal can be reached.[40]

Nationella PatientÖversikten, NPÖ (the National Patient Review) makes it possible for authorised healhcare staff to access medical record information registered with other county councils, municipalities or private healthcare providers, with the patient's consent, but this potential hasn't been fully realised.

The lack of equal healthcare in Sweden is a great challenge, and the divided healthcare structure with 21 county councils is often highlighted as one of the reasons for that. **With joint standards for storage and exchange of data, it becomes possible to follow and analyse healthcare provided to patients in a uniform way across the country, to adjust deviations, and thus increase equality in healthcare.**

It is often said that the county councils don't cooperate to the desired extent. That makes it even more important that best practice is standardised for quality assurance, and that new knowledge is efficiently disseminated so that citizens don't suffer because they live in a certain county council. The county councils and regions have created a joint system for knowledge-driving (see appendix 11) which aims to:

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[40] Inera (2018) *Nu har hela Sverige tillgång till e-tjänsten Journalen*
https://www.inera.se/aktuellt/nyheter/2018/journalen/nu-har-hela-sverige-tillgang-till-e-tjansten-journalen/

- Give patients access to the best possible healthcare, regardless of where in the country they live.
- Give healthcare access to the latest and best knowledge for every patient meeting.
- Give the regions the opportunity to utilise healthcare's national resources efficiently.

It is a special challenge to disseminate new knowledge to primary healthcare at a desirable pace. Insufficient dissemination leads to great variation in healthcare quality. This means, for instance, that patients run unnecessary risks of suffering iatrogenic injuries. To meet this challenge, SALAR and the county councils have developed joint knowledge support for primary healthcare in 300 – 400 areas, as well as an IT structure, *Nationellt Kliniskt Kunskapsstöd* (National Clinical Knowledge Support), to make knowledge accessible everywhere.

Knowledge dissemination is also lacking between different parties – academia, healthcare, businesses, patients – and the resources aren't coordinated effectively. One example is that the industry, since 2015, is no longer allowed to finance half of travel and accommodation costs for healthcare staff when it comes to on-the-job training at international congresses.[41]

One reason for the insufficient dissemination is that there are no structures, methods or tools for disseminating and implementing new knowledge.[42] That is in turn due to the fact that requirements and compensation for collaboration between parties concerning knowledge dissemination aren't developed enough, and that this isn't included in the Health and Medical Services Act.

SALAR has begun work with knowledge dissemination, and according to Avtal om Läkarutbildning och Forskning, ALF (Agreement on Medical Training and Research), university healthcare should supply their results to other healthcare providers.[43] Both processes are important, but the issue is urgent from the perspective of the patient.

Patients expect correct collection, usage and sharing of healthcare data, and the county councils have to live up to that. The Patient Act aims to strengthen and clarify the patient's position, and to promote the patient's integrity, self-determination and participation. The Swedish Agency for Health and Care Services Analysis does, however, comment: '*In conclusion, patients' actual position has not been improved since the introduction of the Patient Act, but rather weakened in the areas that concern accessibility, information and participation. The purpose of the act has therefore yet to be realised.*'[44]

With increased help from correctly used digital tools, many of the legal requirements can be met more efficiently, contributing to increased quality and equality.

[41] The Swedish Association of Local Authorities and Regions, LIF, Swedish Labtech, Swedish Medtech (2013) *Överenskommelse om samverkansregler*

[42] Ministry of Health and Social Affairs (2017) *Kunskapsbaserad och jämlik vård. Förutsättningar för en lärande hälso- och sjukvård (SOU 2017:48)*

[43] According to the ALF agreement of 2014, the tasks of university healthcare are, among other things, to monitor international research, education and healthcare, and to transfer their own and others' research results, to evaluate methods, and supply their results to other healthcare providers. According to the ALF agreement, the evaluation of university healthcare shall be performed every four years, with the purpose of supporting university healthcare's development. The National Board of Health and Welfare's evaluation of university healthcare was presented in March, 2018.

[44] The Swedish Agency for Health and Care Services Analysis (2017) *Lag utan genomslag.*

On a national level, we propose that:

- The National Board of Health and Welfare adjusts the instructions for the Health and Medical Services Act so that the mission of collaborating and disseminating knowledge between healthcare providers financed by county councils, and between healthcare, academia and businesses, is clarified.

- The National Board of Health and Welfare requires healthcare providers to take improvement measures to achieve healthcare that is as good as that supplied by other healthcare providers if their healthcare, in any area, is below the national average. The result is what should be measured, regardless of what party supplies the healthcare. The National Board of Health and Welfare's reports concerning quality should be used to identify the providers whose performance is the worst, and the Swedish Agency for Health and Care Services Analysis should be tasked with following and evaluating them and their improvement work. The healthcare providers who don't improve their quality should no longer receive compensation for healthcare provided.

- The National Board of Health and Welfare establishes a national listing database to strengthen patients' right to register with a doctor in primary healthcare. Patients already have a legal right to do so, but the structure is lacking. Norway already has a national database for this purpose, and can be used as an example.

- The Government initiates regulated on-the-job training for healthcare staff, which would improve patient safety.

More Efficacious Diagnoses and Treatments

Investments into synchronisation of healthcare data that are currently being made in many countries run in parallel with a rapid knowledge development and large technological leaps in biomedical research. Sweden should be at the forefront of both processes and their integration. Thanks to new, large-scale methods, such as for analysis of the genome, we are currently at the beginning of a diagnostic revolution that is in the process of changing clinical medicine drastically, by soon giving a larger number of patients precise, individual diagnoses on a molecular level. **This gives a new understanding of disease mechanisms, and will, in the near future, bring completely new opportunities for tailored treatment, so-called precision medicine.**

There are, however, a number of challenges when it comes to benefitting from new knowledge.

One challenge is about evaluation. New indicators that are needed to evaluate research findings and innovations have not been developed to the required extent. The reason is a combination of lacking competence, limited resources, and that the development in research has been very rapid. Therefore, more work is needed with identifying what can and should be measured. Better opportunities for collaboration across vocations, specialisms, competences and technology areas are also needed, which the Agenda Group has addressed with previous intervention proposals.[45] If healthcare staff don't have up-to-date knowledge, they can't evaluate new innovations.

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[45] Research!Sweden (2017) *Agenda för hälsa och välstånd – 14 konkreta åtgärdsförslag med handlingsplaner 2017*

Another challenge is that incentives for working with development and change are often lacking.

One example of the importance of connecting collected healthcare data with new research findings can be found in rheumatology and neuroimmunology (care for those suffering from MS). There, the need for evaluation of new therapies has been great over the past few years, and Sweden has been far forward in this development. Crucial factors in the construction of the evaluation systems that have allowed quick and efficient introduction of new medications for rheumatism patients and MS patients have been usage of digital, country-wide registers, and the option of using these registers in day-to-day healthcare, as well as to evaluate effects and side effects of new medications. In rheumatism and MS healthcare, tools such as quality registers, new sample-taking systems and patient-focussed digital aids have been used both in healthcare and research.[46]

On a national level, we propose that:

- The Government initiates an investment into the development of indicators for healthcare to more efficiently evaluate and benefit from progress in research. Sweden has the potential to become a leader in the area, thanks to the investments made into SciLifeLab for instance. To get added value from research in the shape of better diagnostics and treatments, we require dedicated and long-term resources for the development of indicators. Sweden needs a nationally coordinating expert unit that can perform/ensure that patients get access to future tests.

We propose that the county councils:

- Create incentives for healthcare providers to, regardless of responsible authority, introduce clear career progression for healthcare staff who work in research and development, and ensure that staff who spend some of their working hours on R&D have time set aside for collaboration with academia and businesses to bring competences together.

- Ensure that there is a certain capacity for developing new indicators and evaluating innovations. Conditions for this vary between the county councils. A structuring of levels is needed, i.e. certain things must be done by all county councils, but in certain cases, it may be enough for smaller county councils to connect with larger county councils. This is also in line with the Government's law proposal concerning nationally highly specialised healthcare.[47] The important thing, to achieve more equal healthcare, is that all county councils must be part of a context that ensures a certain level.[48] This requires all county councils to reach a certain basic level.

- Clarify the innovation mission (at least for university healthcare), and how it relates to knowledge-driving. Patients who come to university healthcare should feel safe in the knowledge that research and development takes place there, and that it's a test bed for new innovations.

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[46] Personal communication with professor Lars Klareskog, Karolinska Institutet, Karolinska Institutet

[47] The Government (2017) *En ny beslutsprocess för den högspecialiserade vården* (proposition 2017/18:40)

[48] The term 'a certain level' could be described through an example from the area of medications: A minimum level could, for instance, mean ensuring equal and good access to a new, innovative medication, approved by the Medical Products Agency, for which decisions concerning price and subsidy have been made by the Dental and Pharmaceutical Benefits Agency.

Increased Quality and Patient Participation

In a report from the Swedish Agency for Health and Care Services Analysis about quality registers, it is established that a lot of information is collected, but that it isn't comprehensive enough, of high enough quality, and not structured in a way that promotes usage. Many registers are highly comprehensive and have high quality, but variation between registers is great. Almost half of the holders of quality registers stated that support for decision-making in healthcare was a primary area of usage for the register. **. Around three quarters believed that there is a need for the ability to use the information in the quality registers to develop support for decision-making that can be used in individual meetings between patients and healthcare staff.**

The Swedish Agency for Health and Care Services Analysis writes: *'It's hard for healthcare staff to analyse and use the information in the registers for local improvement work. Well developed clinical quality information is also still lacking for large parts of healthcare and welfare.'* [49] (Read more about the Swedish Agency for Health and Care Services Analysis' status report in appendix 10.)

The Swedish Agency for Health and Care Services Analysis believes that digital health details must be permeated by six guiding principles:[50]

- The details shall be utilised.
- The details shall be protected.
- The details shall be correct.
- Patients shall be offered access and information.
- Patients' wishes shall be met to as great an extent as possible.
- Patients shall not be disadvantaged because they don't want to or can't make decisions.

The lack of synchronised data means that the value, and thus the usage, of advanced analysis tools isn't as great now as it will be in the future, when we really have an aggregated system. Even so, we believe that it's important to work with the issue of using analysis tools, and that the process for learning how to use them should run in parallel with the work of synchronising healthcare data.

There are, for instance, viewing tools that mean that you can easily, and in real time, collect individual level and group level (current situation and trend) data. Such tools reduce the input of duplicate data, and increase healthcare staff's motivation to register data early, at the patient meeting, as they know why this is done. There are also clinical decision support tools that give healthcare staff access to plenty of relevant data when diagnosing and treating specific patients, which creates increased patient safety.

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[49] The Swedish Agency for Health and Care Services Analysis (2017) *Lapptäcke med otillräcklig täckning - slututvärdering av satsningen på nationella kvalitetsregister*
[50] The Swedish Agency for Health and Care Services Analysis (2017) *För säkerhets skull - Befolkningens inställning till nytta och risker med digitala hälsouppgifter*

The tools aren't used to the desired extent because the profession doesn't have enough access to them. This is in turn due to the lack of aggregated data, and difficulties navigating and choosing from the many available solutions. In many cases, clear governance around what eHealth solutions should be implemented in healthcare is lacking. It's worth exploring and being inspired by the national standards for decision support that have been developed in the US.[51]

We propose that SALAR:

- Ensures that the issue of eHealth solutions is included in the recently begun work with a national system for knowledge-driving, and that the following aspects are dealt with, among others:

    - Reviewing how decision support can be implemented within the framework of GDPR in the most suitable way.

    - Ensuring that solutions and agreements around them are flexible, and can be revised over time.

    - Developing requirements for interfaces and sets of codes for eHealth solutions so that everyone follows international standards (but no requirements for which solutions are to be used, as this would limit development and innovation).

    - Evaluating the concrete value of various eHealth solutions, as well as looking at which ones are the most suitable on a national and regional level respectively. This includes handling the issue of how eHealth solution evidence, as well as collected data, should be assessed. It's important to be careful with interpretation, analysis and conclusions of data, as special competence provided by analysts is required.

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[51] Office of the National Coordinator for Health Information Technology (ONC)
https://searchhealthit.techtarget.com/definition/ONC

Conclusion

We welcome the fact that Sweden's three ministers of health, research and enterprise want to invest more into digitisation. In an opinion piece from February, 2018, they write:

'Today's digital technologies create completely new opportunities for diagnosing conditions, and proposing individually adapted treatments. With the help of artificial intelligence, we can develop decision support for healthcare staff that rests on a larger amount of data than any doctor can accumulate throughout their professional career. Such decision support can make healthcare and welfare safer and more equal.'[52]

Both organisations and individuals have to prepare for handling big data. Our ability to handle data and use algorithms for better decision support will, in the future, be even more dependent on aggregated data to benefit from AI solutions. It must be possible to aggregate healthcare data that is generated via healthcare financed by county councils, regardless of provider, not just nationally, but internationally as well.

This requires healthcare to use the existing standardised interfaces and sets of codes. It will also require handling and integration of data that isn't generated in healthcare, but largely by the individual, which is often called health data. The latter is an issue that we haven't had the scope to include within the framework of this report, but that we believe should be prioritised.

Finally, we'd like to point out that none of the proposals in this report can be implemented well enough if it isn't done in collaboration with patients, patient networks and patient organisations. Unfortunately, there are no clear and systematic working methods for this, so it's a job that must take place in parallel. There are some initiatives that work with this issue, of which Spetspatienter (Forefront Patients) is one, but a lot of work remains.

Sweden has very good conditions for increasing quality and equality in healthcare with the help of digitisation, but political intervention is required, both at a governmental level and on a county council level. We hope that the collected information and proposals that we have presented in this report can contribute to driving the process forward at the rapid pace that is required with consideration for patients, and for Sweden to be competitive in healthcare, research and enterprise.

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[52] Damberg M, Hellmark Knutsson H., Strandhäll A. (2018) Regeringen tar ett helhetsgrepp om life science, Dagens Medicin, 2nd of February

Method

In January and February, 2018, two full-day workshops were held with the members of Agenda for Health and Prosperity. Between and since them, work has continued via phone and email conversations. The varied experiences of the different professions have been utilised, and the parties have been able to agree on goals and prioritised interventions.

Research!Sweden has written this report, based on the results of the aforementioned workshops and extensive reference material. We'd like to thank all members for their generous contributions of time and knowledge, both in workshops, and in the subsequent process surrounding the report.

The issues that the Agenda Group has worked with are complex, but the respect, openness and dedication that the members have shown has made it possible to develop concrete proposals. We'd also like to thank Arthur D. Little, who facilitated the two workshops, in his role as Research!Sweden's pro bono donor.

Throughout the process, we have also discussed the proposals with various affected parties, in addition to the members of the Agenda Group. We thank representatives of many affected authorities, as well as individual experts for valuable views on the report.

We'd like to thank the committee of Agenda for Health and Prosperity, and the committee of Research!Sweden for their continuous dedication to health and prosperity in Sweden.

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Definitioner

eHealth: Using digital tools and exchanging information digitally to achieve and maintain health.

Interoperability: The ability of systems, organisations or operational processes to work together, and to communicate with each other through adhering to agreed upon rules.

Equal Healthcare: *'Equal healthcare means that everyone should be offered healthcare based on their needs, on the same terms, and that everyone should be treated well, regardless of gender, gender identity, gender expression, sexual orientation, ethnicity, religion or other beliefs, functional impairment, age, where they live, their education and finances. That women and men, girls and boys should have equal access to good health, being offered healthcare and welfare on the same terms, is one of the part goals of the equality policy, and an extension of the overall equality policy goal of men and women having the same power to shape society and their own lives.'*[53]

Semantic Interoperability: Information can be handled and interpreted in similar ways when exchanged between systems.

Technical Interoperability: Systems can efficiently send and receive information regardless of where and by whom it has been created.

Healthcare Data: Data generated within the framework of the operations of healthcare providers.

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[53] The Government (2017) *Budgetpropositionen för 2018, utgiftsområde 9 Hälsovård, sjukvård och social omsorg*

Appendices

Appendix 1: Vision for eHealth 2025

Excerpt from: *Handlingsplan för samverkan vid genomförande av Vision eHälsa 2025, Ministry of Health and Social Affairs and the Swedish Association of Local Authorities and Regions (2017)*

When it comes to the division of responsibilities in general, municipalities and county councils hold the main responsibility for social services and healthcare. This responsibility includes organising, leading, planning, developing, assuring the quality of, and financing the operations. The state's responsibility is mainly concerned with legislation, supervision, equalising systems and subsidy. There is also a general responsibility, both for setting goals and requirements when it comes to the quality of and access to public operations such as social services and healthcare, and for following up on them.

The parties intend to work for a clearer division of responsibilities between the state and the municipalities and county councils. The general division of responsibilities has been described above, and also applies to the area of eHealth. Today, there are operations in the eHealth area where several different parties work in parallel. The ambition is for upcoming work to clarify who does what, and to ensure that coordination takes place. Furthermore, the parties' ambition is that new interventions and proposals shall, when possible, considering current responsibilities, be analysed based on the perspective that the organisation(s) or party(ies) that is/are best suited to deal with the intervention should take responsibility for it. Interventions should focus on creating basic conditions and forms of governance that are needed for the possibilities of digitisation to be realised, and for national interests concerning equal service across the country to be ensured.

Perspectives, Principles and Target Groups

Work with the vision shall rest on a number of basic perspectives and principles that are based on the laws and other regulations that regulate the operations, etc. Equality is a starting point for social services and healthcare. Among other things, this is about people living in varying socio-economic conditions having equal access to support based on their needs, and being met in a way that suits their circumstances. By providing tools that support interventions that are adapted to the users', clients', and patients' individual needs, digitisation can make it easier for operations to work for increased equality. Digitisation also improves opportunities for follow-up and analysis of unmotivated differences in the results of different operations.

The work with digitisation and eHealth shall be developed from an equality perspective to ensure equal service, resource allocation and influence between girls and boys, women and men. Work should also take into account individuals' protection against encroachments on personal integrity, the need for confidential handling of access to personal details, and issues of consent.

Efficacy is another starting point for social services and healthcare. Increased efficacy that enables long-term sustainable healthcare and social services is necessary for dealing with the challenges of an aging population and increased expectations.

In addition to the aforementioned perspectives, work shall also be done based on a number of basic principles such as accessibility, usability and digital participation, as well as integrity protection and information security. Digital services shall, to the greatest extent possible, be universally designed based on the idea of design for everyone, i.e. IT support should be accessible to and usable for all people, regardless of age, functional impairment, skill level, etc. without the need for adaptation or special design.

The eHealth strategy of 2010 pointed out three main target groups: individuals, healthcare and welfare staff, and decision makers. In work with the vision, emphasis should be on the first two groups, but they should also be expanded to include not just healthcare and welfare, but all of social services, all healthcare, and applicable parts of dental care. Furthermore, there should be a children's and young people's perspective in the work, as this is a group whose position can be strengthened with the help of different kinds of IT support. In the strategy of 2010, the developmental power of other parties, such as private and non-profit entrepreneurs and the research community, was affirmed. These parties shall, as in the previous strategy, be involved in upcoming work with concretising the vision.

For the vision to be achieved, it is important that staff have support so they can offer social services and healthcare of high quality. On a general level, this is about creating a digital work environment that supports the processes that staff work in. Digitisation also contributes to the development of new career routes when other, new types of needs or services appear, which could be attractive for long-term competence supply. Digitisation can also contribute to a better working environment for the women and men who work within the operations. A basic condition for achieving this is access to well-working tools for documentation, as well as knowledge and decision support that ensure high quality and safety while facilitating day-to-day work.

One basic condition for IT support to be fully utilised is the availability of competence to handle it on all levels of the operations. As foundation for the work, the affected decision makers need to create the necessary conditions for social services and healthcare to be able to use the opportunities of digitisation, both in day-to-day work, and in long-term improvement and development work. This could include ensuring personal or operational resources, legislation, or other types of regulations or division of responsibility between different parties.

Action Plan

The state and SALAR have, in the continuing work, agreed to implement initiatives, interventions and undertakings in the respective intervention areas, and overall initiatives within the areas of standardisation, follow-up and external monitoring. The starting point is that the governance and collaboration organisation should handle initiatives and related interventions and undertakings that are described in the action plan above, as well as any further initiatives that may be added during the action plan period.

Legislative Framework

The laws, regulations and instructions that govern operations shall ensure individuals' various rights and interests, but must also be able to handle the specific issues brought by digital development. Therefore, interventions aim to achieve legislative frameworks that are suited to their purpose, and that look after individuals' integrity and safety, while also contributing to the promotion of digital development. It's about balancing rights, such as protection for personal integrity, with healthcare that is equal, safe for patients, and accessible. The possibilities afforded by digitisation when it comes to handling today's legislative framework, concerning managing authorisation for instance, should be utilised.

The state and SALAR should jointly and continuously identify, and, where possible or called for, perform, interventions that become necessary as digital development progresses. When it comes to the division of responsibility in the intervention area of legislative frameworks, the vision emphasises that the responsibility for standard-setting lies with the state, while SALAR shall work to support the responsible authorities' work concerning compliance with existing legislation, and to bring new or changed legislation into operations.

Goals and Planned Initiatives

The goals for work with legislative frameworks within the action plan are:

Creating legislative frameworks that are suited to their purpose, and that look after individuals' integrity and safety, promote digital development, and facilitate the application and introduction of legislative frameworks in affected operations.

The state and SALAR shall therefore:

- Determine a process for joint identification and capture of information concerning existing rules or upcoming changes there of,
- create conditions for a safer process when it comes to medications.
- Look after interests, disseminate knowledge concerning initiatives, and, when needed, develop national guidance concerning collaboration with the EU.

More Uniform Usage of Terms

When information is allowed to be shared and used for different purposes, the quality and safety of the operations can improve. Inhabitants, patients, users, and next of kin also get opportunities for better knowledge and a better overview of their own situation, and thus an opportunity for greater participation and influence. This facilitates work for more equal and equitable social services and healthcare, and contributes to giving staff a better digital working environment and simpler administration. Furthermore, more uniform usage of terms brings better conditions for using information for research, innovation, operational development, quality assurance, follow-up and evaluation. More uniform usage of terms is also a basic condition for affected operations to benefit from the technological standardisation described below.

Because healthcare and social service operations procure new or adjust existing systems based on local and regional needs, strengthened national coordination that, to as great an extent as possible, ensures uniform application when it comes to issues of so-called semantic interoperability, and thus contributes to well-working information transfer within and between operations, is required.

The vision emphasises that the Government should work to provide the responsible authorities with national support in their work. SALAR shall work for the responsible authorities, where called for, to collaborate with each other and with affected state parties, in the work with applying joint terms, classifications or structures in operations.

Goals and Planned Initiatives

The goal of the work with more uniform term usage within the framework of the action plan is for:
terms and classifications that are necessary for the operations to be uniformly handled and similarly interpreted when exchanged between systems or operations, and for the pace of introduction of joint terms and classifications into the operations' IT support to be hurried up.
Therefore, the state and SALAR shall:

• Openly report, and, when necessary, clarify which state, regional or local parties or organisations should supply terms and classification in different areas.

• Establish a national collaboration method that handles the selection, prioritisation, application and development of joint terms and classifications.

• Define and categorise operational needs in such a way that different operations measure and mean the same thing by the same terms and classifications.

• Further develop the support for application on regional and local levels based on national specifications or guidelines.

Standards

Technical standards for information-handling need to be implemented in a similar way to enable technical interoperability. Continuous development and systematic work with standards for interoperability aims to enable the efficient exchange and sharing of information, regardless of which organisation or system the information was created in. The area is complex, and just pointing to which standards should be used is rarely enough. Unity around how standards should actually be applied in different situations is often needed, for instance through the development of national specifications.

Standardisation work is ongoing on many different levels, and a lot is happening in the EU. It's important in upcoming work to consider the processes and initiatives that international and European standardisation organisations are involved in – in and out of the country – that could have a bearing on standards in the eHealth area. Where possible, joint transborder solutions should be promoted to prevent individual, national solutions.

When it comes to the division of responsibilities in the intervention area of standards, the vision emphasises that the Government should primarily work to ensure that national and international standardisation work with connections to social services and healthcare is easy to apply, and that SALAR should work to ensure that the responsible authorities introduce agreed-upon standards in their systems.

Goals and Planned Initiatives

The goal of work with standards within the framework of the action plan is for:
the operations' information and communication systems to be able to send and receive relevant amounts of information in a way that is suited to the purpose, without a need for extra interventions.
Therefore, the state and SALAR shall:

- Establish a national process whereby application and development takes place based on a joint framework of standards for interoperability.

- Develop a reference architecture, i.e. descriptions, models, and guiding examples that facilitate the design of technical solutions, and support the development of healthcare and social services that can be provided regardless of the user's geographical proximity to the operations.

- Support the implementation of standards and joint, national specifications.

- Ensure a long-term administration of a joint framework of standards for interoperability.

- Increase involvement in international standardisation work, and connect this more clearly to regional and local needs, as well as to research and enterprise.

Overall Interventions

Better coordination and deeper collaboration concerning standardisation in the eHealth area.

The purpose of the initiative is to increase the pace of the development of technical and semantic interoperability, standards, and their application. The initiative is limited primarily to eHealth and digi-

tisation issues within social services and healthcare, with a focus on national, regional and local interventions. There is plenty of previously done national level work to draw on. The work should include existing or established structures and parties in the standardisation area, such as relevant standardisation bodies and bodies within the Swedish Standardisation Federation, so that the competence and knowledge that already exists concerning standardisation processes is utilised in the best way. The state and SALAR shall also work to ensure that there are structures for following up and ensuring that agreed and decided upon standards within the eHealth area are adhered to and developed.

National Forum for Standardisation in eHealth

As one step in the implementation of the initiative, the state and SALAR have established a national forum for standardisation in eHealth. The forum shall constitute an arena for broad collaboration that is characterised by clarity, openness, joint processes and long-term sustainability in the area of eHealth.

Follow-up

Follow-up in the eHealth area has to improve. There is a large number of different investigations, ongoing as well as temporary, that all give a certain or limited image of the eHealth area. Frameworks for follow-up to give the affected parties access to the information needed to ensure that interventions are made based on the right foundations are needed. The state and SALAR agree that both authorities, county councils and municipalities need to develop tools and methods for showing how digitisation progresses towards the vision, and how the benefits of digitisation are realised. A requirement for measuring the realisation of the vision's goals is a system that also includes international comparison. From an individual perspective, open comparisons are currently provided, in healthcare and social services for instance. Where it is suited to the purpose, similar comparisons should be made in the area of eHealth.

External Monitoring

The pace of digitisation in society is high, and will affect social services and healthcare at large. The state and SALAR have agreed to develop a joint process and model for coordinated external monitoring. It's important to find a method that enables the collection and compilation of the external monitoring performed by different parties, to benefit them all. This work should also include an international perspective.

Governance and Collaboration Organisation

Through this action plan, the state and SALAR form a joint governance and collaboration organisation. The starting points, principles, directions and intervention areas, etc. that have been outlined in the action plan provide the foundation for upcoming work in the organisation.

The purpose of the organisation is to strengthen collaboration so that the parties, together and individually, within their respective responsibilities and undertakings, contribute to the vision in the best possible way. The organisation constitutes the joint arena for governance, collaboration, coordination and

follow-up of the implementation of the action plan. As a whole, the work should balance, coordinate, and – to the greatest extent possible – unite interests to contribute to the development of a joint vision of goals and priorities in the implementation of the action plan.

Appendix 2: Good Examples of Digitisation

Excerpt from: *Vägen mot världsklass – så får vi en bättre vård för personer med långvariga sjukdomar, Astma- och Allergiförbundet (the Asthma and Allergy Federation), Neuroförbundet (the Neuro Federation), the Swedish Rheumatism Association, the Swedish Heart and Lung Association, Diabetesorganisationen i Sverige (the Diabetes Organisation in Sweden), and Storstockholm's Diabetesförening (Greater Stockholm's Diabetes Association)* (2018)

Handling Referrals of Rheumatism Patients

The Karolinska University Hospital is at the front edge when it comes to rheumatism healthcare. One new project is called Patientens Egen Provtagning, PEP (the Patient's Own Testing). Patients with rheumatic diseases can, with the help of PEP, handle their own testing referrals. The eHealth service makes it possible for patients to generate their own referrals and book tests when it suits them best. The test results go directly to the patient, while simultaneously entering their medical records. Via PEP, patients participate more in their own healthcare chain, and patient safety increases as patients are active participants throughout medical treatment. At the same time, healthcare resources are freed up. PEP is part of national service 1177, and can be expanded to more areas. The structure is ready, and could not only be used for rheumatics across the country, but for many other groups too. Administrating your own testing creates completely new opportunities for participation in one's own treatment, and increased control over one's condition.

Home Test for Young Asthma Patients

At Astrid Lindgren's children's hospital, a special app has been developed for young asthma patients. The app comes with a mobile spirometer, which measures lung function, and is wirelessly connected via Bluetooth to the patient's mobile phone. This gives patients access to an objective measuring tool between their doctor's appointments. The technology can be extremely valuable for parents who have to treat children who aren't always able to describe their symptoms. Everyone is different, and this applies to how well the asthma medicines work as well. In spite of this, almost everyone gets more or less the same kind of treatment, though in different doses. One result is that only half the patients are made completely symptom-free by today's medication. Measuring lung function between doctor's appointments creates conditions for a much more individualised treatment. Asthmatuner is one of many examples of how new tools can help patients to follow their own condition and treatment.

COPD Healthcare at Home via Tablets

The Vård i hemmet av KOL-patienter (At home healthcare for COPD patients) project aims to offer patients the opportunity to have regular contact with their healthcare provider from home. Instead of going to a healthcare centre or to A&E, the idea is for the COPD patient to talk to a so-called healthcare operator through the tablet they have at home. The healthcare operator is a trained nurse, and is as a link between patient and doctor. The COPD patient has access to various meters and sensors at home, such as a blood pressure monitor and scales, and also regularly fills out a questionnaire about how they feel. All the information is then accessible to the healthcare operator as they give their advice. If necessary, the healthcare operator can connect the patient with the treating doctor in a video call, and include next of kin. The COPD project is an extensive national project that, on a base level, can be applied to many chronic diseases. It gives a sense of safety, and simpler meetings for the patient while also potentially saving resources for healthcare.

Self-Reported Health for Heart Failure Patients

In a pilot project in Norrtälje, within TioHundra, where digital tool Optilogg has been tested, hospital admissions of heart failure patients have been more than halved. In addition, the patients feel safer. The aid has two parts: scales and a tablet, consisting of a small screen. Patients weigh themselves every morning, and their weight is registered in Optilogg. Based on weight changes, which could indicate that the patient is binding fluid, they can be prescribed increased medication. Every five days, the patient inputs other details about how they feel, such as shortness of breath, tiredness and swelling. If there are signs of the patient getting worse, they are instructed to contact their healthcare provider. Heart failure admissions is the very area in primary healthcare where Sweden has the worst results in OECD's comparisons. This project also shows how much there is to be gained when patients get support to follow their own condition in everyday life. So the weaknesses found in questionnaires about this have a direct connection to tangible medical results. But better knowledge and control of one's condition and treatment also have a big influence on the sense of safety and quality of life in a wider sense.

Appendix 3: County Councils' Investment into R&D

County councils' investment into R&D concerning healthcare in 2016, as a share of their total health-care costs*
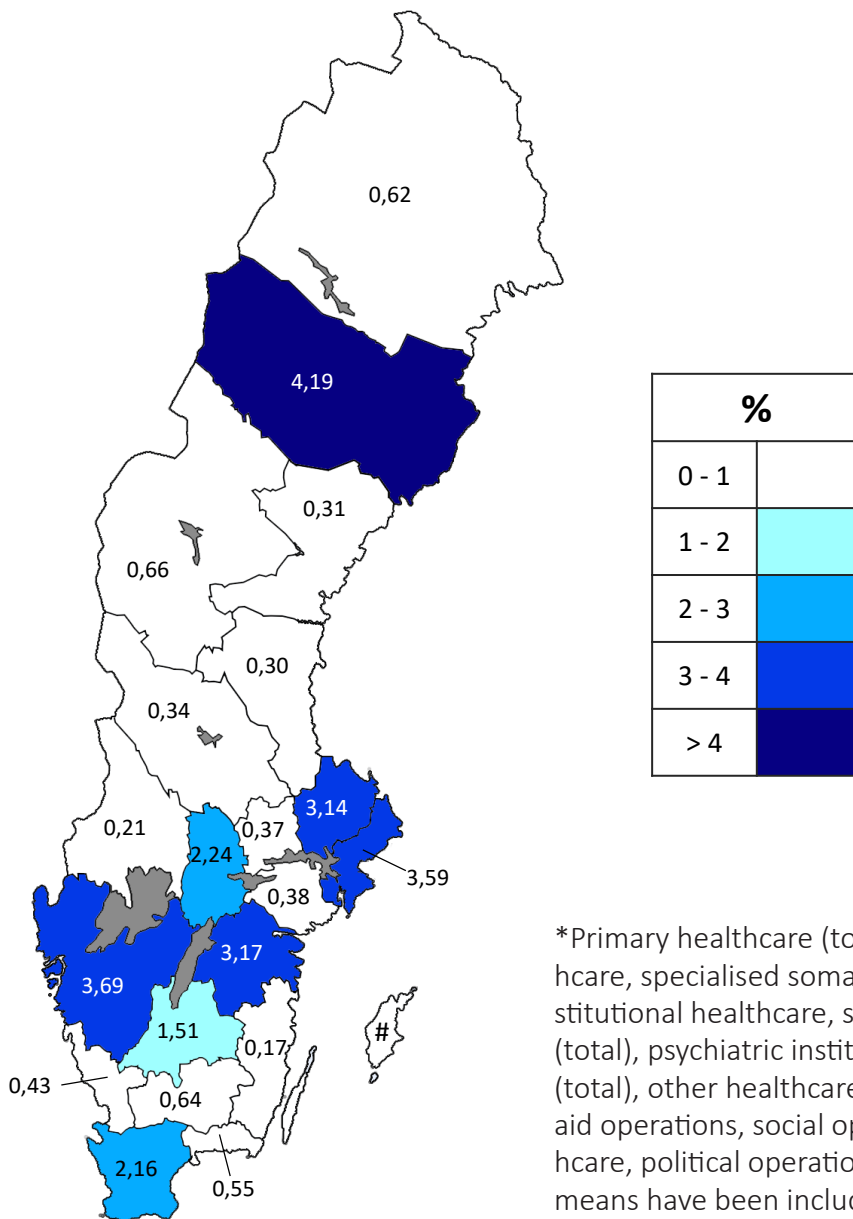
%	
0 - 1	
1 - 2	
2 - 3	
3 - 4	
> 4	

*Primary healthcare (total), institutional primary health-care, specialised somatic healthcare (total), somatic in-stitutional healthcare, specialised psychiatric healthcare (total), psychiatric institutional healthcare, dental care (total), other healthcare (total), functional impairments/aid operations, social operations, R&D as concerns health-care, political operations as concern healthcare. ALF means have been included.

#Gotland have not reported any figures, as they don't have an R&D unit. Statistics Sweden (2018) Investments into R&D

County councils that invest more than 1.7 per cent of their total healthcare spending* into healthcare R&D (2007 – 2016)
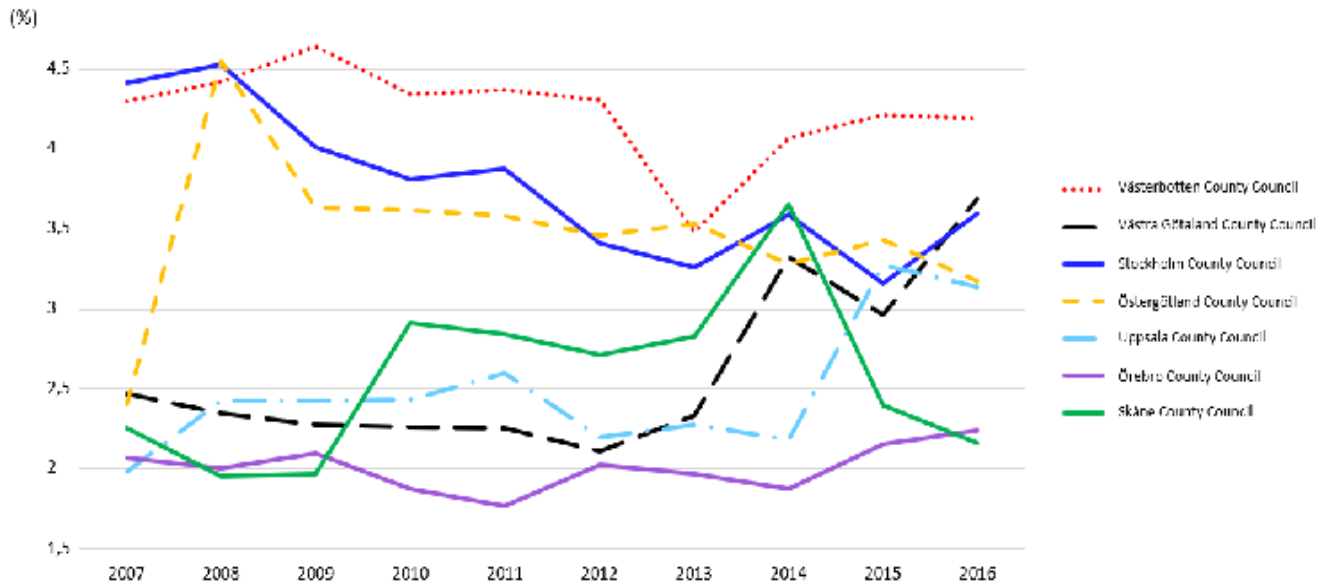
County councils that invest up to 1.7 per cent of their total healthcare spending* into healthcare R&D (2007 – 2016)
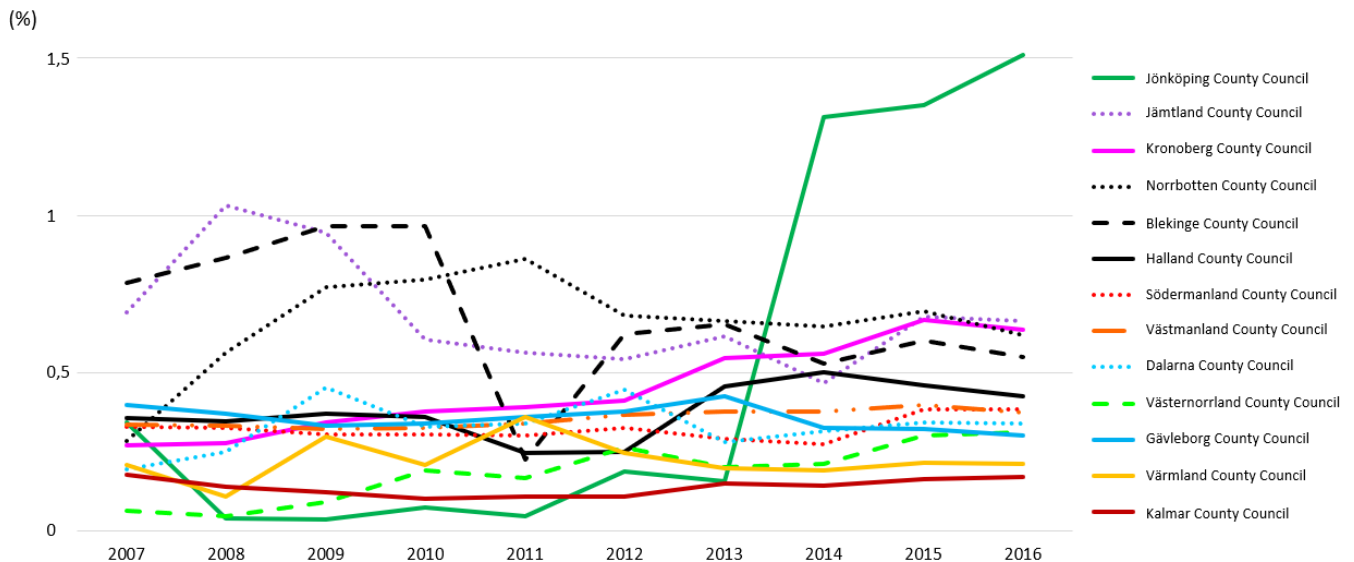
*Primary healthcare (total), institutional primary healthcare, specialised somatic healthcare (total), somatic institutional healthcare, specialised psychiatric healthcare (total), psychiatric institutional healthcare, dental care (total), other healthcare (total), functional impairments/aid operations, social operations, R&D as concerns healthcare, political operations as concern healthcare. ALF means have been included.

#Gotland have not reported any figures, as they don't have an R&D unit. Statistics Sweden (2018) Investments into R&D

Appendix 4: Recommendations for Decision Makers on how to Best Utilise Big Data in Health

Excerpt from: *Study on Big Data in Public Health, Telemedicine and Healthcare, European Commission (2016).*

The following ten recommendations offer guidance for decision makers and the citizens of the European Union alike on how to best to utilise Big Data in Health for the ultimate benefit of strengthening their health and improving the performance of MS's health systems.

Recommendation 1 on Awareness Raising:

Develop and implement a communication strategy to increase the awareness of the added value of Big Data in Health and encourage a positive public mind set towards Big Data in Health.

Recommendation 2 on Education and Training:

Strengthen human capital with respect to the increasing need for a workforce that can utilize the potential of Big Data in Health.

Recommendation 3 on Data Sources:

Expand existing and explore new sources of Big Data in Health and secure their quality and safety.

Recommendation 4 on Open Data and Data Sharing:

Promote open use and sharing of Big Data in Health without compromising patients' rights to privacy and confidentiality.

Recommendation 5 on Applications and Purposes:

Increase target-oriented application of Big Data analysis in health based on the needs and interests of stakeholders including patients.

Recommendation 6 on Data Analysis:

Identify the potentials of Big Data analysis, improve analytical methods and facilitate the use of new and innovative analytical methods.

Recommendation 7 on Governance of Data Access and Use:

Implement governance mechanisms to ensure secure and fair access and use of Big Data for research in health.

Recommendation 8 on Standards:

Develop standards for Big Data in Health to enhance and simplify its application and **improve interoperability.**

Recommendation 9 on Funding and Financial Resources:

Ensure purposeful investment steered by the European Commission to warrant cost-effectiveness and sustainability.

Recommendation 10 on Legal Aspects and Privacy Regulations:

Clarify and align existing legal and privacy regulation of Big Data in Health.

Appendix 5: Status Report on the IT Architecture in Healthcare

Excerpt from: *Målarkitektur 2.0 3RFmv, Mannström M., Dahlin S. (2017)*

The current IT architecture in healthcare is based on the legislation and principles that existed before the Patient Data Act came into force in 2008. Information was then locked up in each system, and even in every clinic's and healthcare centre's 'own' database. Information was not to be communicated outside the clinic/healthcare centre (except via telephone, on paper, or via fax). This has led us to systems that don't enable information to be taken from or entered into the application in a simple way. For every amount of information that is to be transferred between two systems, development work that requires a lot of resources has to be done. This system structure has meant that relatively few reusable integrations have been built.

In summary, the current situation is that healthcare has many systems and IT services that, in most cases, don't work together. Loads of information is registered, but when it is needed most, the information is hard to find, or locked in a system where it can't be reached. This is largely due to insufficient interoperability between systems in healthcare, as well as many parallel systems and an unclear infor-

mation strategy. Quite simply, not enough systems make information accessible to other IT supports within the framework of the patient's flow in healthcare. The integrations that have been done are difficult to administrate because the existing systems are built to handle information locally, and not in joint collaboration. In some cases, the information can still be accessible, but because it's common that only a small part of the functionality of existing IT system is utilised, it can't be found. Administrative processes are, in many cases, not at all integrated with clinical processes, and are often handled separately, either in other IT support, or in other modules of clinical IT support.

Healthcare staff need lots of different IT supports in their day-to-day work, both to perform tasks in their processes, and to access the required information. This IT support often includes different interfaces, may have different information structures and separate logins, which creates a situation of low usability and time-consuming duplication.

Patients and healthcare don't have control of the flow between different healthcare providers and healthcare units. Most often, each individual unit works excellently, but when the patient and their information move elsewhere, problems arise. In many cases, the patient has to keep track of his/her own process, and be the one who carries information between different units.

The existing frameworks of legislation that are supposed to regulate the handling of electronic patient information are challenging to handle. The costs and amounts of work that go into adapting IT systems to laws and legislative frameworks can be enormous. It also gives healthcare staff extra administrative work, which means that a lot of their time has to be spent on that.

The complex system landscape is difficult to administrate, and one consequence is that several underlying technologies (software and hardware) that are used have passed end of life, and are unsupported by the supplier. Work with structuring and standardising terms and information has gone on for some time, but the steps taken in this development are far too small and uncoordinated. The more integrated our system landscape becomes, the greater the need for having a structured and standardised information structure will be. The further we get with adapting to a service-oriented architecture, where a system collects and leaves information, and uses functionality in other systems, the more structured the information will need to be. Development towards structuring information, and making it easier to understand on every level, has not, however, been prioritised in national work with architecture, for instance as related to the national service platform.

Appendix 6: Development in the County

Excerpt from: *eHälsa och IT i landstingen, SLIT – Landstingens IT-strateger/IT-chefer (County councils' IT strategists/heads of IT) (2017)*

The county councils in Sweden, 21 including Gotland, have worked with the development and introduction of IT support/eHealth for many years. Much has been done on the county council level, but also in collaboration between county councils, as well as through national collaboration via Inera. There is good collaboration with and between suppliers, such as via Swedish Medtech3 ICT. Over the past few years, collaboration between customers and suppliers (customer groups), and between Inera and the customer groups, increased significantly, and that is an important requirement for the implementation of the national Vision for eHealth. This type of collaboration is internationally unique.

The goals and prioritisations vary somewhat between different county councils, which means that the county councils haven't come as far as each other in some areas. This is also mirrored in the results of this inventory. There has been comprehensive work for increased consolidation and coordination, both when it comes to national services and other services within the county councils. The creation of Inera has led to a marked increase in coordination with national development over the past few years.

The introduction and usage of e-services for patients and inhabitants have increased significantly over the past few years. The goal is, among other things, to increase patients' access to and participation in healthcare. Many of the services have been established on a national level via Inera.

- For several years, the ambition has been to increase investments in the IT area. In reality, insignificant increases in means, relatively speaking, have been given to IT over the past ten years.
- Financial scope for new development and innovation is smaller in the county councils compared to other industries in Sweden.
- It's worth noting that adaption of systems, rules and routines, as well as some staff training, remains to be done to comply with the requirements of the Patient Data Act from 2008.
- 7 of 19 county councils that have provided information allow all operations to be part of consolidated medical record keeping. 12 county councils have chosen to exclude certain operations.
- The strategy of 13 of the 20 county councils that have provided information is to use a joint, overall system for healthcare documentation at hospitals, psychiatry and primary healthcare within their own county council. The strategy of 4 county councils is to use NPÖ, and 3 county councils use other solutions.
- A number of county councils/regions have initiated purchasing of new medical record systems, which will bring changes and affect system environments over the coming years.
- The view that healthcare has a wide variety of systems and suppliers for healthcare documenta-

tion is not correct. 4 systems/suppliers have 86 per cent of the market. There is, however, a lack of interoperability between systems. This is largely due to lacking standardisation of the informatics in the systems, and in how the systems are implemented.

- Most of the 20 county councils that have responded to the questionnaire require (17 county councils) or offer (1 county council) private healthcare providers who are included in Vårdvalet, LOV (the healthcare choice) to use the same medical record system as the county council.

- The introduction and usage of e-services for patients and inhabitants have increased significantly in 2016. Just over 3.6 million inhabitant accounts (2.7 million in 2015), which is 33 % of Sweden's population.

Appendix 7: Initiatives for Supporting the Application of Standards

Excerpt from: *Nationellt stöd för utveckling och förvaltning av gemensamma, nationella specifikationer, the Swedish eHealth Agency (2018)*

Below is a list of ongoing, future or finished initiatives run by different parties, which aim to support the application of standards, as well as the development and implementation of specifications in different ways.

- **The Swedish Association of Local Authorities and Regions (SALAR)** will, in 2018, establish a support function for structured healthcare information, with the intention that it will support and coordinate work with achieving increased structure and uniformity across system and healthcare provider borders. The idea is that the support function, together with county councils and regions, will constitute part of the work with contributing knowledge, and enabling coordination, method development, and experience exchange in the area. The imagined organisation seems to have many similarities with the 'production support organisation' that has been requested by users as per the above text.

- The **"Joint framework of standards for interoperability – part 2"** project was run by several parties in collaboration, and finished in 2017. The result included a work description for the implementation of user stories.

- The **"Joint framework of standards for interoperability – part 3"** project will begin in 2018. Running the project means going from theory to practice by trying different standards, combinations of standards, and different ways of working to apply standards. This happens through implementation of practical tests in the shape of proof-of-concepts that are based on the described implementa-

tions of user stories and work descriptions that were developed in the second part of the project. National support for development and administration of joint, national specifications.

- **Region Örebro** has a national mission of running a competence centre for informatics and quality registers. The centre is built according to a network principle where one central function is responsible for the development and administration of methods and models, coordinates training in the developed working method and coordinates practical informatics work for quality registers in Sweden.

- In **Region Uppsala** discussions are ongoing concerning the possibility of forming a national competence centre for informatics in laboratory medicine together with Region Örebro, Equalis, and some other parties. The competence centre would be organised in the same way as the existing competence centre in Region Örebro, i.e. as a network organisation. The new centre would be responsible for the necessary informatics work in the operational area of laboratory science, and would manage contact with experts.

- **The National Board of Health and Welfare's** strategic itinerary for 2017 – 2020 says that the authority shall make nomenclatorial selections for areas of healthcare where this is urgently needed. The authority also works with other applications that are based on the national information structure and national nomenclature, such as the information specifications for BBIC and IBIC.

- Several **regions and county councils** are working with initiatives to build competence in standardisation of information, and also to develop specification of different kinds to implement in their own information systems. This work is particularly urgent in the regions and county councils that are currently purchasing new systems.

Appendix 8: The Healthcare Information Environment of the Future, Stockholm

Excerpt from: *Framtidens vårdinformationsmiljö SLL,* Vårdgivarguiden (2018)
https://www.vardgivarguiden.se/utbildningutveckling/projekt/framtidens-vardinformationsmiljo-i-sll/Framtidens-vardinformationsmiljo/

The Framtidens VårdinformationsMiljö, SLL, FVM SLL (Healthcare Information Environment of the Future, Stockholm County Council) programme aims to introduce a healthcare information environment that creates conditions for efficient ways of working in Stockholm County Council's healthcare, as well as an ability to engage in regional network healthcare. Network healthcare means that it should be simple and safe to exchange information between organisations within and outside the public sector, with a focus on the health of the patient.

The programme is one of the county council's big investments into the development of healthcare. The overall goal is to give patients the opportunity to participate in their healthcare, and to enable new

ways of working that simplify work for healthcare staff, and make it more efficient.

Healthcare can be run in connected healthcare chains where different healthcare providers collaborate and share patient information with each other. The goal is to enable efficient leadership and governance of healthcare, and to make it easier for research to gain access to anonymised, relevant, quality assured and comprehensive data.

The Current Situation

The current IT and system landscape in the county council is complex, fragmented, and, in large parts, outdated, which leads to many great challenges. Many of the IT systems that are used by staff in healthcare today are slow, and don't share information with each other, which leads to time-consuming manual duplication, poor access to necessary patient information, and increased administration.

In turn, patients have limited opportunities to access information regarding their healthcare, and are often forced to carry their own patient information. The limited access to relevant data limits research and those who work with leading and developing healthcare with the purpose of developing new knowledge and new treatment methods.

Healthcare Information Should Follow the Patient

FVM SLL shall build the foundation of a new healthcare information environment. The ambition is that in the future, information should follow the patient on their journey through healthcare, a journey that very often cuts through different responsible authorities, healthcare providers, and IT systems.

Patients shall get increased access to information that concerns their own health and healthcare, and shall also be able to contribute information to healthcare.

The healthcare information environment shall simplify the exchange of patient information between healthcare providers, and give healthcare staff access to patients' healthcare data without needing to log into many different IT systems. Today's system for medical records is replaced with easier-to-use digital support with smooth, modern interfaces and intuitive functions. Staff can work on the go, and get quicker access to new research and knowledge through knowledge and decision support. Manual handling of patient information and paperwork are minimised.

Many Staff Participate in the Work

FVM SLL is planned to go on for several years, and will involve a large number of staff on all levels. Working together, we'll lay the foundation for the development of a new healthcare environment that better meets the needs and demands of patients, staff, researchers and managers to provide more efficacious and easily accessible healthcare.

In the spring of 2018, several hundred people from healthcare are going to help, making requests for the new healthcare information environment. Staff will participate in work with defining the joint ways of working, processes, informatics, and the technical functionality that is needed within healthcare in Stockholm County Council and Region Gotland.

The First Purchasing Process Has Begun

One important part of the healthcare information environment of the future is creating conditions to realise a cohesive healthcare information environment. Part of that is purchasing new IT systems that, in the long run, will replace many of the county council's current systems.

The first purchasing process has begun, and will take place through a so-called competitive dialogue procedure, in which a number of suppliers are invited to participate in a dialogue to discuss various proposals and solutions. This is to ensure that the purchase process demands the right things from the new systems, and that the demands that are made have matching functions in systems available in the market today.

Appendix 9: National Support for the Development and Administration of Specifications

Excerpt from: *Nationellt stöd för utveckling och förvaltning av gemensamma, nationella specifikationer,* the Swedish eHealth Agency (2018)

The Swedish eHealth Agency proposes two organisations that take responsibility for one role each: coordination and support for development, as well as administration and making it accessible. The goal is to create greater clarity for users as to who to contact when.

If both these organisations are established, there is great potential for the threshold to be lowered for users when it comes to understanding and taking on the standards and joint specifications that are developed, recommended and made accessible nationally.

The images on the next page describe the situation as it looks currently for those who want to apply standards and/or develop, collect or provide joint specifications, as well as an expected situation if the proposal is established.

- The top image describes the current situation where all the grey organisations supply, coordinate and create standards and/or joint specifications. Users have expressed that it's confusing and difficult to navigate who is responsible for what, and who can help.

- The bottom image describes the situation **when the proposed model exists,** where two organisations take responsibility for one role each: coordination and support for development, as well as administration and making it accessible. The goal is to create more clarity for users concerning who to contact when.
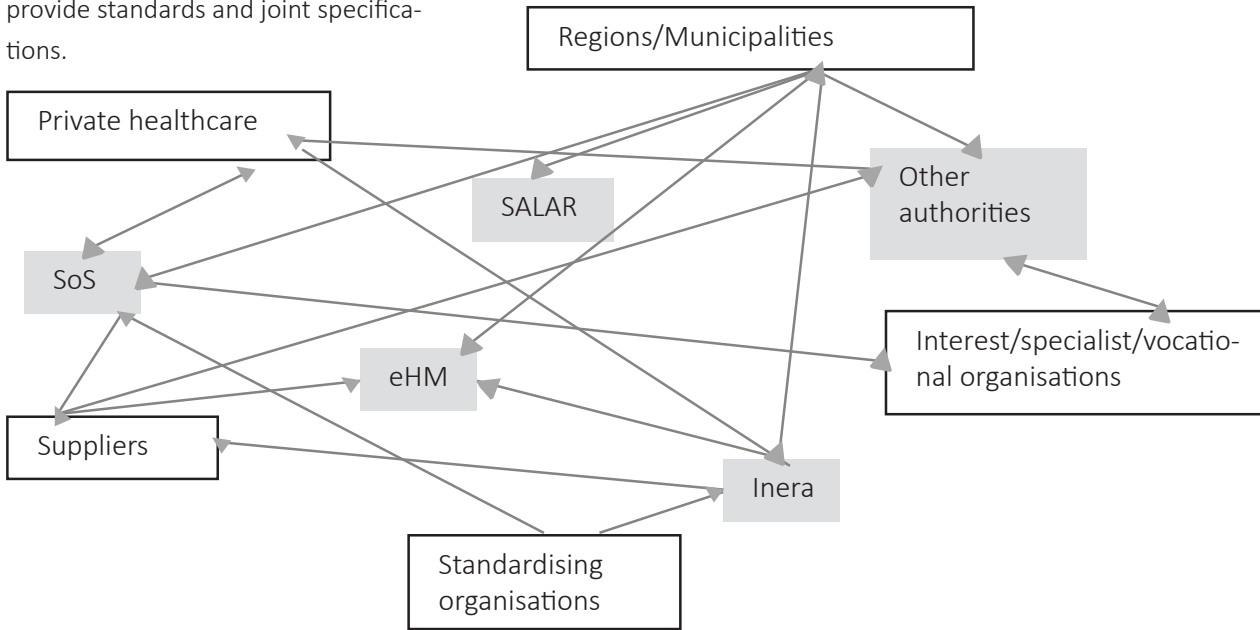
The arrows describe organisations that need to be contacted for those who, **in the current situation,** want to collect/provide standards and joint specifications.

Regions/Municipalities

Private healthcare

SALAR

Other authorities

SoS

Interest/specialist/vocational organisations

eHM

Suppliers

Inera

Standardising organisations

The arrows describe organisations that need to be contacted for those who, **following the implementation of the proposal,** want to collect/provide standards and joint specifications.

Interest/specialist/vocational organisations

Private healthcare

Regions/Municipalities

Suppliers

Inera

Authorities

Standardisation organisations

Administrationorg.
- Supplies
- Receives
- Coordinates visually

coordinates

Production org.
- Supports development
- Coordinates development
- Educates
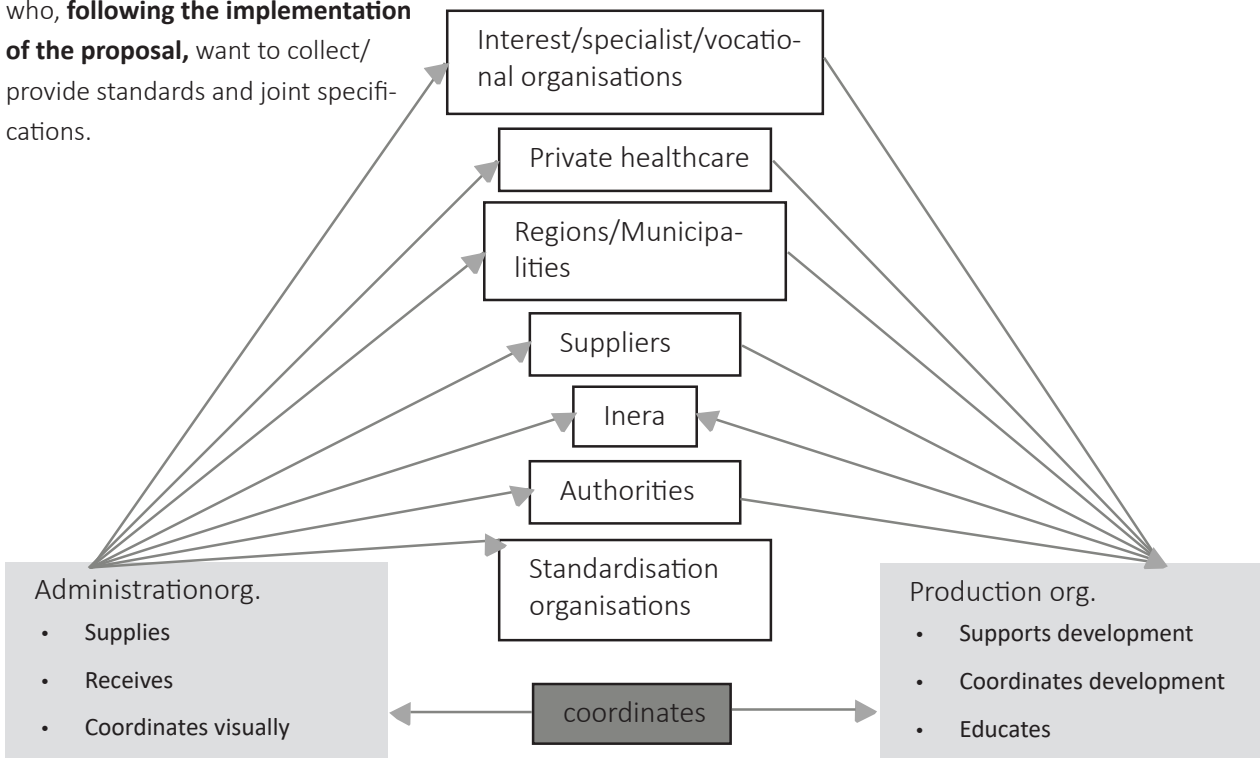
Appendix 10: Status Report on the Utilisation of Healthcare Data

Excerpt from: *Lapptäcke med otillräcklig täckning - slututvärdering av satsningen på nationella kvalitetsregister,* Swedish Agency for Health and Care Services Analysis (2017)

Our evaluation shows that the problems described prior to the investment into quality registers (Rosén, 2010) remain, in large parts. For instance, the quality registers' collection of data still requires a lot of resources,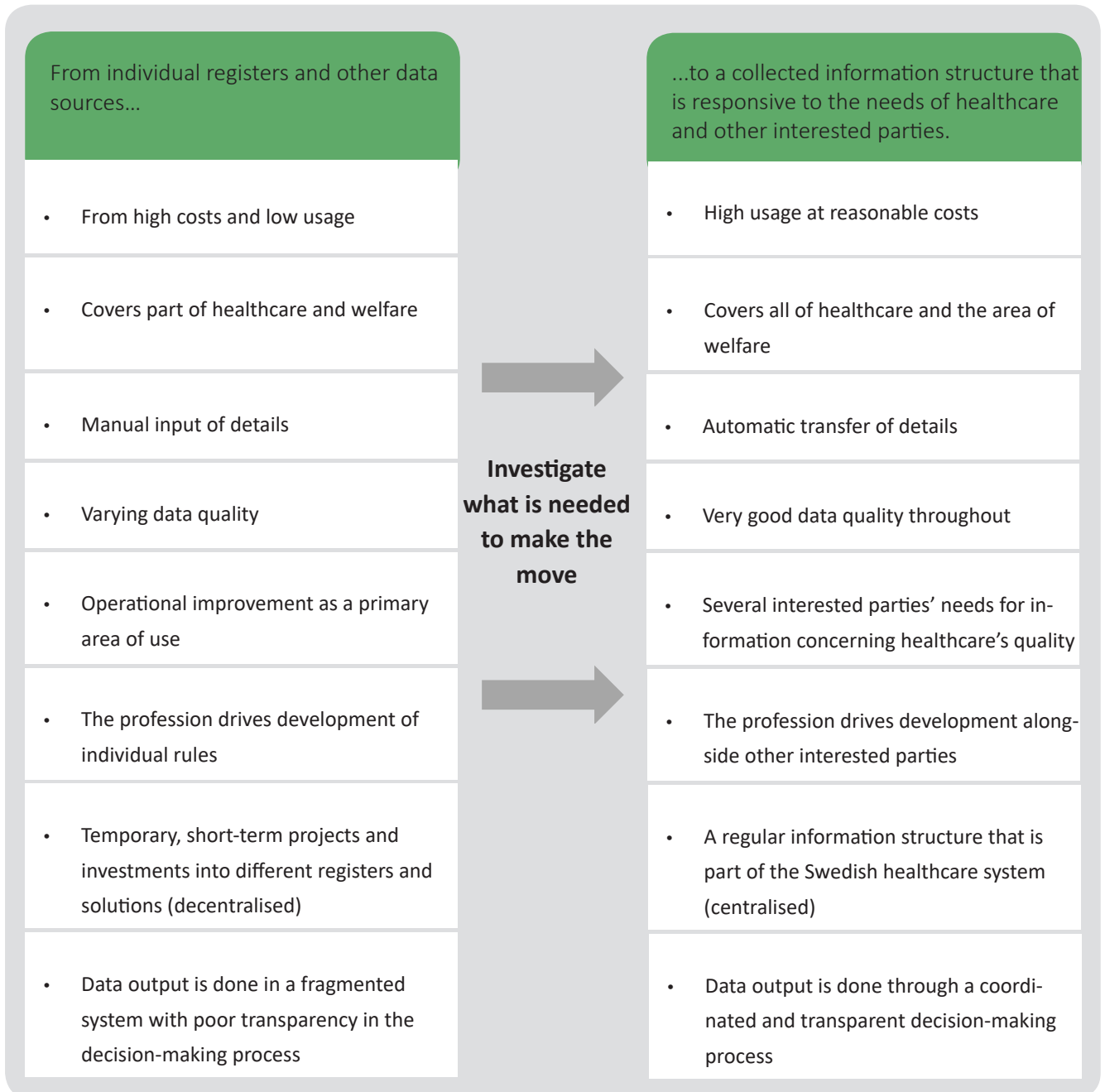 and it's hard for healthcare staff to analyse and use the information in the registers for local improvement work. Well developed clinical quality information is also still lacking in large parts of healthcare and welfare. Our joint assessment is therefore that the investment's emphasis on strengthening only one part of the heavily fragmented information structure in healthcare hasn't been enough to meet the ever-growing needs for information concerning the quality of healthcare that exists among operations, patients, researchers, businesses and authorities. Our overall needs analysis shows that the needs for information concerning the quality of healthcare are not met with today's complex information structure. A lot of information is collected, but the information isn't comprehensive enough, doesn't have a high enough quality, and is, in addition, not structured in a way that promotes usage.

The authorities responsible for healthcare and welfare should – regardless of which data source is the foundation – provide increased support for improvement work, and require the operations to follow and develop healthcare. Continuously securing and developing healthcare is part of the responsible authorities' mission. Regardless of which data source is used, such work should be prioritised and rewarded. Our evaluation shows that usage of national quality registers for improvement work has increased within healthcare operations, but that the conditions for running improvement work need to be improved regardless of what data source is used. Some factors highlighted by the operations are local competence in improvement work, time for such work, support from management, and easy-to-use IT support that works. Improving healthcare's and welfare's ability to develop operations is a priority, and such initiatives should be taken soon, regardless of the design of the information infrastructure.

The authorities responsible for healthcare and welfare should fulfil their responsibilities, and ensure that output of research data and the related assessments are harmonised, so that decisions are only made based on correct and objective foundations. The information that is stored in the national quality registers is very valuable for interested parties outside the operations of healthcare and welfare too. The information could be utilised more. Our assessment is that output of data from national quality registers should be harmonised between the authorities that are responsible for personal details and for the registers. Therefore, we recommend that these authorities develop a joint practice for this.

From individual registers and other data sources...		...to a collected information structure that is responsive to the needs of healthcare and other interested parties.
• From high costs and low usage		• High usage at reasonable costs
• Covers part of healthcare and welfare		• Covers all of healthcare and the area of welfare
• Manual input of details		• Automatic transfer of details
• Varying data quality	**Investigate what is needed to make the move**	• Very good data quality throughout
• Operational improvement as a primary area of use		• Several interested parties' needs for information concerning healthcare's quality
• The profession drives development of individual rules		• The profession drives development alongside other interested parties
• Temporary, short-term projects and investments into different registers and solutions (decentralised)		• A regular information structure that is part of the Swedish healthcare system (centralised)
• Data output is done in a fragmented system with poor transparency in the decision-making process		• Data output is done through a coordinated and transparent decision-making process

Appendix 11: County Councils' and Regions' Joint Systems for Knowledge-Driving

Excerpt from: *Nationella Samverkansgruppen för Kunskapsstyrning*, the Swedish Association of Local Authorities and Regions (2017)
https://skl.se/halsasjukvard/kunskapsstodvardochbehandling/systemforkunskapsstyrning/nationellaprogramomraden/samverkanforkunskapsstyrning.9686.html

A national collaboration group for knowledge-driving (NSK) was initiated in 2008. The purpose of *NSK* is to:

- Give patients access to the best possible healthcare, regardless of where in the country they live.

- Give healthcare access to the latest and best information at each patient meeting.

- Make it possible for the regions to utilise healthcare's national resources effectively.

Decisions made in NSK are not formally or legally binding, but are based in a joint responsibility to anchor decisions at home. NSK includes representatives from the six healthcare regions, representatives from nine authorities; the Swedish eHealth Agency, the Public Health Agency of Sweden, Forte, the Health and Social Care Inspectorate, the Medical Products Agency, the Swedish Agency for Participation, the National Board of Health and Welfare, the Swedish Agency for Health Technology Assessment and Assessment of Social Services, the Dental and Pharmaceutical Benefits Agency, as well as vocational associations the Swedish Doctors' Association and the Swedish Society of Nursing, alongside SALAR.

To create knowledge-driving that is more suited to its purpose and more efficacious on different levels of healthcare, county councils and regions, supported by SALAR, are now (2018) establishing a national system for knowledge-driving.

The purpose is to make it easier to coordinate the knowledge supports used in healthcare, to ensure that they are developed in relevant areas, and designed to be easy to use in patient meetings. Aside from knowledge supports, supports for follow-up and analysis are also included, as well as supports for operational development and for management of the system for knowledge-driving.

National collaboration groups are created for seven areas:

- Methods for knowledge support
- Quality registers
- Follow-up and analysis
- Medications and medical devices
- Research and life science
- Patient safety
- Temporary investments

While we wait for the new, joint system to be established, previously established national programme areas will continue their work for certain diagnoses (asthma/COPD, diabetes, stroke, ADHD, paediatric mental health, depression and anxiety, antibiotics resistance prevention work, biobanks, internet-based support and treatment, lifestyle work in healthcare). The national programme areas shall:

- Analyse and identify the gaps in healthcare and social services by mapping existing material, and identifying unwanted variations and needs for clinical research.
- Develop goals and indicators of healthcare quality.
- Identify and spread success factors.
- Develop and revise knowledge material such as national healthcare programmes, standardised healthcare plans and guidelines.
- Follow up and analyse knowledge development in healthcare practice.
- Contribute to consensus statements when scientific support is lacking.

18 national programme areas (joint for county councils/regions) with experts will be established, and they will, in turn, have national working groups within different diagnoses. Work will be led by a governance group for knowledge-driving in collaboration (SKS). County councils and regions adapt their regional and local knowledge organisation to this national structure. Only then will the effect reach all the way to the patient meeting.

This is our vision for life science 2025:

Sweden is a global key party in life science, attracting top talent

Strong and long-term investments into education and research give great scope for curiosity, drive, science and excellence.

Sweden is a leader in healthcare thanks to competence being put into practice

Interaction between academia, businesses, healthcare and the population creates attractive environments for research and innovation, and front-edge healthcare.

Healthcare's coordinating mission to document relevant information contributes to a unique national platform for research and quality development. Researchers and businesses want to come to Sweden as a leading nation for point-of-care studies.

Sweden is a magnet for life science investments

With its innovative and dynamic environment in combination with attractive conditions for trade and industry, Sweden is one of the most competitive life science nations in the world.

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