

**Call to action:** let's start connecting  
Swedish health data today to bring success  
to Swedish Life Science tomorrow



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## ■ Introduction

Sweden has a unique resource: comprehensive healthcare data. Data is available from electronic medical records (EMRs), healthcare databases and disease registries. This data is known around the world as being rich in content, granular in detail and extends over many years (longitudinal data). The personal identification number enables linkage across databases on an individual level; this feature is unique to the Nordic countries and allows the creation of an unparalleled patient insight.

From an international perspective, the whole of the Nordic region has outstanding opportunities in real-world data (RWD) due to our well-structured healthcare systems and structured health information. There have been national and population-based health registries in the region since the 1950s. Also there are strong academic hubs in the region.

If we combine and integrate all healthcare data to give easy access, Sweden will be a very attractive hot-spot for life science development, research and investments. This would take innovation with health data into the next generation - simultaneously creating a new life science paradigm and improving the health outcomes of the Swedish citizens.

Put simply, Sweden has the most fantastic deposits of health data gold. Unfortunately, we have major shortcomings in accessing and extracting the gold. Other countries have gold deposits too, but those are rarely as large nor of the high quality found in Sweden and the rest of the Nordics. Recently, some of these countries have decided -- at a national level -- to focus on finding gold and are investing heavily to do so. Sweden needs to do the same, or else other countries will be the winners in the new gold rush.<sup>1</sup>

The sense of urgency in integrating the health data has been expressed by Helene Hellmark Knutsson, minister of research and higher education, and Jenni Nordberg, head of the new Office of Life Sciences. Both have indicated that integrating the health data

should be a top priority. It is essential to act quickly to realize the opportunity for Sweden. This whitepaper showcases the importance of RWD and the opportunities for Sweden to become a world-leading life science nation.

*This is why AmCham Sweden Life Science passionately wants to push for a fast healthcare data connection in Sweden. We want the companies we represent to keep, and increase, the investments in Swedish Life Science and improve healthcare in Sweden.*

## Healthcare challenges

Sweden is struggling to finance the growing healthcare costs associated with an aging population, chronic health challenges and the introduction of new effective, but often costly interventions. In the future, gene- and cell therapy will revolutionize disease outcomes and health practice. Increased demands for healthcare, and the rising costs associated with it, require healthcare systems to be more efficient. This efficiency can be achieved by implementing better tools to evaluate the benefits of new drugs and healthcare interventions. One of the tools to optimize and evaluate health outcomes is real-world evidence (RWE). Costs of new drugs can be justified if they reduce the total cost to society, for example reducing sick-leave, raising quality-of-life, increasing life expectancy and/or improving general health. RWE plays a central role in the evaluation of treatments and other healthcare interventions, such as staffing and health process changes.

Healthcare systems must demonstrate a therapeutic value in the real-world setting by collecting and interpreting RWD in an accurate and publicly accessible way. RWD represent a huge opportunity to improve the health of the citizens of Sweden, but is also of global value.

## Benefitting from real-world data today

Today, the use of RWD is a natural and integrated part of drug development. RWD is used to demonstrate unmet medical needs, as a complement to randomised clinical trials (RCTs) by comparing research results from RCTs with real-world clinical observations, and to evaluate the effectiveness of drugs among unselected patients as compared to the highly selected RCT patients.

Globally, RWD is used by many stakeholders (for example, pharmaceutical companies, health authorities, providers, payers and academic research organizations) as the basis for a wide-range of significant decisions:

- The healthcare authorities are using RWD to support reimbursement decisions, and to develop guidelines and decision-support tools for use in clinical practice.

- Medical product developers are using RWD to design clinical trials (for example, large simple trials, pragmatic trials) and observational studies to generate innovative, new treatment approaches ([www.FDA.gov](http://www.FDA.gov)).
- Life science is using RWD increasingly to provide personalized healthcare, and to evaluate the value of innovative drugs and new medical interventions including diagnostics.

## RWD can improve healthcare in Sweden

Compared to other countries, for example the USA, Sweden is not utilizing its own RWD efficiently to improve its healthcare system, nor is it using RWD effectively by allowing others to access it for research and development purposes. Because of that, Sweden risks losing its position as a global leader to other countries (for example, Finland, Denmark, Estonia) that are rapidly improving the quality of and the access to their healthcare data.

Forska!Sverige recently released a report highlighting the lack of an overall strategy for Swedish health information, and included a proposal on how to create an integrated healthcare data system and how to utilize data better to improve healthcare.<sup>2</sup>

## Other countries are catching up

The health registries in Sweden contain a huge amount of clinically relevant information, but the time taken to access this data is too long and many of the registries are incomplete in areas such as primary care diagnosis and hospital administered drugs. Other countries are investing strategically in terms of RWE availability. The newly established Danish Office of Life Sciences and the Danish Government plan to invest approximately 30 million DKK each year to make Denmark a leading life science nation by 2021. Approximately 40% of that money is earmarked to increase Denmark's global competitiveness in life science.<sup>3</sup>

The Danish "Plan for Life Science" shows a high level of ambition, for example:



- Establish a national organization to promote clinical trials in Denmark.
- Promote collaboration between private and public organisations in the health care sector to “ensure that the industry can get feedback on the effect and side-effects of the usage of medication”.
- Create a digital hub for a better environment for digital growth.

Finland is also making huge strides to become an RWD nation and has recently created a “one-stop-shop” for extracting health data:

- Biobanks and the innovation-friendly biobank legislation
- Comprehensive healthcare registers
- Comprehensive electronic medical records

These features ensure that Finland can “offer outstanding opportunities for drug target discovery, clinical research and Real World Evidence”.<sup>4</sup>

In the future, we should develop a greater pan-Nordic collaboration than we have today. Specifically, studies in rare diseases would benefit from a larger patient population. However, there is an obvious risk of a slower process linked to this expansion, and it is crucial to keep up the speed in this work.

### Data inaccessibility is a problem in Sweden

Pharmaceutical companies, health authorities, academic research organizations and patient organizations are using Swedish healthcare data, but the process to access it is long, complex and imbalanced (depending on who tries to access the data). Therefore, some of those organisations will look for data in other countries.

Healthcare data is underutilised in Sweden; we are not taking advantage of the opportunities to improve the healthcare system and evaluate the efficiency of innovative drugs and interventions. The main reasons for the underutilisation of healthcare data are:

- **Data are difficult to access:**
  - There are many different data sources, but no single point of contact.

- The lack of national mandate for quality registry utilization means we see big differences in regional coverage in various quality registries, which leads to many outcomes which cannot be assessed robustly for Sweden.

- **Technical infrastructure and manpower is lacking:**

- Data extraction has not been automated systematically and still requires an excessive amount of manual work. This is not sustainable in the long-run.
- It takes too long to link data between Swedish healthcare registries (sometimes up to 12 months), so organisations look to other countries for RWD. Statistics Sweden (SCB) and National Board of Health and Welfare (NBHW) need to have sufficient resources, most importantly staff, to be able to meet the increased demand for data.

- **Legal and ethical aspects:**

- The legal and regulatory framework for healthcare data is complex, and that makes it difficult to obtain a clear overview. The key to getting the overview is good governance of information, and Sweden is already good at that. The new GDPR legislation, in effect from May 25th 2018, will further ensure the protection of an individual’s privacy. The Swedish government, in alliance with many others, have worked hard (and succeeded) to get an exception from GDPR rules for data used for research. However, it is critical that the interpretation and implementation of rules and regulations is consistent, correct and not arbitrary.

We recommend that common guidelines on the legal and regulatory use of RWD are developed. These guidelines will be used by all Swedish County Councils when they use and interpret RWD, and by the designated persons (expert legal counsel) when they advise on the legal and regulatory aspects of RWD use. Data security must be robust and resilient if we are to fully realise opportunities using RWD.

## CASE STUDY 1

### ASSESSING TREATMENT EFFECTIVENESS FOR PATIENTS WITH SCHIZOPHRENIA

#### CHALLENGE:

The study of the comparative effectiveness of antipsychotic treatment for patients with schizophrenia has posed a challenge because core aspects of the disease and its treatment are an obstacle to inclusion and retention of these patients in RCTs and observational studies, which severely limits generalizability to real-world populations.

#### RESEARCH:

An RWD analysis of nearly 30,000 Swedish patients with schizophrenia followed during 7.5 years was conducted by Professor Jari Tiihonen at Karolinska Institutet, using register-based Swedish data.<sup>7,8</sup>

#### OUTCOMES:

These nationwide register-based cohort studies aimed to study the comparative real-world effectiveness of antipsychotic treatments for patients with schizophrenia. The outcomes examined were overall mortality, risk of rehospitalization, treatment failure (defined as psychiatric rehospitalization, suicide attempt, discontinuation or medication switch, or death).

#### These studies found:

- Mortality among patients with schizophrenia is over 40% lower during those time periods when the patients use antipsychotics than when they do not.
- Long-acting injectable antipsychotic medications use is associated with an approximately 30% lower risk of death compared with the oral use of the same substance.
- Within the study population, the lowest mortality was detected among the patient group treated with second-generation long-acting injectables.
- 44% of the study population was rehospitalized during the study period
- The risk of rehospitalization was 22% lower for the patients treated with long-acting injectables compared to patients treated with oral medication
- The risk of rehospitalization was 32% lower for newly diagnosed patients treated with long-acting injectables compared to newly diagnosed patients treated with oral treatment.

#### WHAT DOES THIS MEAN?

This RWD analysis has provided a critical evidence base for the use of long-acting injectables to decrease deaths, re-hospitalizations and treatment failure among patients with schizophrenia. The nationwide health registers allowed for selecting essentially all patients diagnosed with schizophrenia within Sweden, and allowed for a thorough assessment regarding the critical variables of interest, without the limiting aspects of selection bias that have been present in previous RCTs and observational studies. This demonstrates clearly the critical importance and value of secondary data sources to biomedical research, to ensure that patients receive the best possible care.

Most patients with schizophrenia are not eligible for inclusion in RCTs because of refusal, substance abuse, suicidal or antisocial behavior, or mental or physical comorbidities. Furthermore, patients that have the lowest adherence are those that would benefit most from long-acting injectables, yet these patients are least likely to be included in RCTs; this prevents an accurate assessment of the comparative effectiveness of oral antipsychotic medications versus long-acting injections of antipsychotic medications.

## We need to connect healthcare data now

The Swedish government appointed the NBHW to be responsible for RWD and align the Swedish RWD landscape. Several "Vision e-health 2025" initiatives will improve the current situation regarding access to healthcare data (for example overview and adaption of rules and legislation, a common terminology, standardization of technologies and processes). However, all these initiatives need to be delivered much sooner; the Office of Life Science, healthcare regions, academia and industry must start focusing on RWD now and collaborate. 2025 may only be 7 years away, but it is too far into the future in terms of improving access to existing healthcare data. We need that to change now. For the patients, for society, for the healthcare system and for Sweden as a life science nation.

## ■ Real-world data – Sweden's unique opportunities

### Real-world data and real-world evidence

Healthcare data in electronic medical records (EMRs) and in national and quality registers are RWD; when captured and analysed, RWD produces Real-World Evidence (RWE). RWE can be the foundation of an economic case to show that we are using innovative medicines or new interventions in the most cost-effective way. Moreover, RWE can replace expensive randomised clinical trials and make clinical development much cheaper and faster, leading to faster access to new and more cost-effective treatments for patients around the world, possibly at a lower price. In fact, if we do not make RWD more available, patients may die earlier or suffer longer with diseases for which we have a growing pipeline of innovative treatments. RWD saves lives.

The ability to link different data sources using the personal identification number (a unique, life-long number given to each citizen in the Nordic countries), offers the possibility to generate longitudinal cohorts

with extremely rich healthcare data covering many years. This enables us to follow the patient journey, natural history, drug effectiveness and more. Mandatory and long-term recording of national health and disease-specific registries – and the possibility to also enrich this with EMR data – gives increased granularity and insight into hospital-administered drugs such as cancer therapies. When all this information is linked together, it gives a detailed insight into the patient's condition and the disease progression; that, in turn, enables us to draw conclusions about a patient's response to treatment and the factors that affect the treatment outcome. It is not possible to find this information elsewhere.

RWE studies improve the understanding of the effect and quality of treatment – especially early treatment where data is scarce – as well as disease progression, and that presents opportunities to review current management approaches with the goal of achieving more efficient, evidence-based treatment practice. Professor Johan Hansson at Karolinska University Hospital explains the benefits of a RWE study in malignant melanoma in Stockholm:<sup>5,6</sup>

"We can now tell how many patients have been treated according to guidelines and where improvements are needed. By revealing waiting times and other bottlenecks in the healthcare system, this RWE study has provided extremely useful input for work that is ongoing at a national level to develop structured care processes for a number of diagnoses, as well offering guidance for resource planning." This knowledge can also lead to a more personalized approach to the treatment of cancers such as melanoma.<sup>5,6</sup>

In recent years, life science has been transformed by the move towards personalized healthcare and the shift from volume-based to value-based payment or reimbursement models. The use of RWE to evaluate the value of drugs and interventions has increased markedly. Today, RWE is used by many different stakeholders as the basis for significant

## CASE STUDY 2

### RAPID DATA FEEDBACK ON QUALITY OF CARE FOR PROSTATE CANCER

#### CHALLENGE:

Cancer care should be constantly improving. Information collected from the quality cancer registries is a key factor of care improvement since it has the potential to facilitate monitoring of quality of care. Quality cancer registries hold a breadth of information on cancer patients and their treatment. Nevertheless, the dissemination of information collected has been traditionally slow and restricted to an annual report released in Portable Document Format (PDF).

One example is the National Prostate Cancer Register (NPCR) of Sweden, and it holds data of 98% of patients diagnosed with prostate cancer since 1998 (181,660 incidence cases in March 2018). NPCR provides real-world data to professionals involved in patient-care. However, as with many quality registries, an annual PDF report has been the main source of information.<sup>9</sup>

#### RESEARCH:

An online interactive reporting system was created based on data collected by the NPCR. This online report is posted in April following the most recent year of diagnosis.

In detail, the interactive system was created using the module SHINY in the "R" software package and is available in Swedish and English. Apart from a short description of the report, the system has different tabs, which include 53 variables in the areas of capture, diagnostic evaluation, primary treatment, and waiting times. These variables allow the user to select the source population, year(s) of diagnosis, patient's age, prostate cancer risk category, and level of aggregation (i.e. national, regional, county- or hospital-level). Furthermore, ten and nine variables have been selected by the

Swedish National Prostate Cancer Guidelines and the NPCR steering group as quality indicators for urological and oncological care, respectively. Thus, the user can create a customised report based on their needs and the question at hand.

#### OUTCOMES:

By using this interactive online reporting system, it is possible for everyone to rapidly obtain and assess information on different aspects of prostate cancer care.

#### For Example:

- The Swedish Prostate Cancer Association, a patient interest group, has been using the system to gather information on the quality of care by all healthcare providers.
- Data is used by healthcare organisations and decision-makers with the aim to improve prostate cancer care and ensure equal access to best treatment practices.
- Patients can use the system to understand and evaluate clinical outcomes. In fact, the patients contribute to the system themselves before seeing the physician.

#### WHAT DOES THIS MEAN?

The data driven, interactive system allows for rapid and transparent outcomes assessments and reporting. The great overview offered by the system means that less time is required by the physician for preparation before meeting a patient while the meeting between patient and physician are of higher quality. Moreover, by examining clinical and patient outcomes and providing this feedback to multiple stakeholder groups, it facilitates improvements and equity in prostate cancer care.



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decisions. For example, health authorities such as the Medical Products Agency, the Food and the Drug Administration (in the US) and European Medicines Agency, use RWD and RWE to make regulatory decisions during post market surveillance (to monitor the safety of a pharmaceutical drug or a medical device after it has been released to the market).

### Randomised clinical trials and real-world evidence

A randomised clinical trial (RCT) obtains information about the safety and efficacy of treatment from carefully selected patients in a controlled environment. A real-world study collects RWD from health registries, healthcare databases and EMRs to evaluate the effectiveness of treatments in clinical practise. RCTs are used to get a drug or device to the market, but the true value is seen when the treatment is being used in real clinical setting on unselected patients. RWE creates new opportunities for follow-up and evaluation.

### Sweden as the land of choice for Life Science investments

Swedish RWD is world class. If we connect healthcare data and, hopefully, data from the biobanks of Sweden, we will soon be able to:

- Attract more companies to invest in clinical and post marketing trials in Sweden.
- Attract talented researchers to Sweden to conduct their clinical and RWE research. This will lead to more research and better education in the life sciences and the healthcare sector.
- Create better care for patients by introducing new and innovative treatments quickly in Sweden, and evaluating the safety and effectiveness of marketed products quickly and efficiently.
- Evaluate new drugs over time and have more than one decision point.
- Increase the quality and efficiency of the Swedish healthcare system by conducting frequent follow-up studies to give a better insight into our standard of care.
- Boost the life science sector of Sweden by increasing investment from global life science companies.

Ultimately, providing all stakeholders with easy access to RWD and linked healthcare data will help Sweden find solutions that improve patient outcomes, and deliver scientific and societal benefits.

### ■ Recommendations of AmCham Sweden

The EU has identified e-health as one of the strongest areas of growth in Europe. The Association of European Research Libraries has recommended the use of the FAIR data principles: a set of guiding principles to make data findable, accessible, interoperable and reusable.

## CASE STUDY 3

### IMPROVED CARE FOR CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

#### CHALLENGE:

- Chronic obstructive pulmonary disease (COPD) is characterized by a largely irreversible obstruction of the airways.<sup>10</sup> In Sweden, more than half a million people have COPD and nearly 3,000 die every year as a consequence of the disease.<sup>11</sup> This makes COPD a very common disease and with a large burden on society.<sup>12</sup>
- The importance of COPD primary care clinics run by a specialist nurse (together with the physician responsible) has been discussed during many years, but -- until now -- never been evaluated in a clinical study.
- The aim of the study was to understand the treatment practice of COPD patients during the last decade and the impact on patient health (number of exacerbations).

#### RESEARCH:

- Retrospective study including approximately 8% of the Swedish population from 1999 to 2009
- Study included 21,361 patients with COPD
- Information was received from electronic medical records, and national health registries. In total 3,500,000 contacts with primary care and 190,000 visits at hospital were analyzed<sup>13</sup>

#### OUTCOMES:

- The study demonstrated that access to an asthma/COPD specialist nurse in primary care was associated with an improvement in COPD management (COPD exacerbations and hospitalizations, and overall treatment costs)<sup>13</sup>
- Combination of budesonide/formoterol was shown to be more effective than fluticasone/salmeterol in preventing exacerbations in COPD<sup>14</sup>

#### WHAT DOES THIS MEAN?

- By making the relatively small investment of employing a COPD specialist nurse at primary care centres, one can ensure that patients will receive more accurate COPD-related care at an early stage leading to fewer COPD-related hospitalisations and increased patient health. This, in turn, will reduce hospitalizations and overall treatment costs to society.
- Evaluating the effect of pharmaceutical treatment among patients who are not part of a clinical trial will give a more realistic picture of the effectiveness of a drug, and that will be useful to ensure that each patient receives the best available treatment for their disease.

If Sweden is to maintain its position as one of the top countries to supply RWD and to attract finances for research and development activities, it must invest in the future. The AmCham Life Science Working Committee recommends that Sweden:

### **1. Reduce fragmentation of data using national and regional governance**

- Clearly identify the responsible persons/ organisations on national and regional level that own the responsibility to connect the health data in Sweden.
- Create a national guideline to align and link healthcare databases and reduce the fragmentation of healthcare data for use in RWE.
- Focus on increasing awareness of the value of RWD and RWE for treatment evaluation and healthcare interventions.
- Point the way forward to use RWD and RWE efficiently by developing best practises, raising awareness, and education.

### **2. Increase data accessibility by investing in technology and staff**

To attract investment for research and development, produce safer treatments and follow-up on existing treatments to improve patient healthcare, data must be made more accessible by investing in staff and technology.

- We need to increase investment to develop an integrated, national, health data system to benefit from RWD and RWE in the future. At the same time, we need to ensure that County Councils upgrade their systems and train staff to ensure the technology and skills required to work with RWD and RWE are developed and maintained.
- Data holders, for example NBHW, need to employ or allocate more staff to extract data from healthcare databases (registries) and combine data from different databases by linking.

*If Sweden is to maintain its position as one of the top countries to supply RWD and to attract finances for research and development activities, it must invest in the future.*

- Healthcare providers must prioritize better recording of patient data, either by putting more resources towards this or by applying a technical solution to do it. For example, follow-up and treatment information in quality-registries needs to be recorded to a much larger extent than it is today. To continuously upgrade and fund the national quality registers (also in the long run) is crucial. Also, there is a need to rapidly introduce a new EMR with more structured data – rather than free text – to minimize the influence of the individual who is recording the data and to make the information more standardized and readily available for research.
- There is also an enormous potential in creating an even more granular picture by also providing data storage of health data gathered by consumer products (this is associated with a wide range of complicated issues, but the value is potentially huge).
- Today there is a huge sense of ownership of many RWD sources by academia and a distrust of industry research. We need to increase collaboration between academia, healthcare authorities and industry to ensure that new, innovative drugs and medical interventions reach the patient.
- All County Councils should implement a single point-of-contact for collaborative work. A successful initiative by Stockholm County Council, SLL, and Karolinska Institutet (as the single point-of-

## CASE STUDY 4

### EARLIER DIAGNOSIS OF PSORIATIC ARTHRITIS (PSA)

#### CHALLENGE:

- Psoriatic arthritis (PsA) is a chronic inflammatory disease associated progressive joint destruction
- Diagnostic delay of 1-2 years from joint symptom onset is associated with worse radiographic and functional outcomes<sup>15,16</sup>
- In Sweden, PsA is diagnosed by a rheumatologist, following a referral from a Primary Care Physician (PCP)
- Despite screening tools to assist PCPs, the prevalence of undiagnosed PsA remains high and many patients are untreated today.<sup>17,18</sup>
- Insights into referral practices leading up to PsA diagnosis (including symptoms and time from symptom onset, and treatments received once diagnosis was made) were lacking

#### RESEARCH:

- This RWD study was led by Prof Ulla Lindqvist and Prof Jan Stålhammar at Uppsala University.<sup>19</sup>
- The study was set in Uppsala County Council and included 383 PsA patients; patients were diagnosed by rheumatologists between 2008-2013 using national and disease-specific registries and information from electronic medical records from primary care and hospitals.

#### OUTCOMES:

- The majority of PsA patients were referred to rheumatologists by PCPs; PCPs also diagnosed psoriasis and joint symptoms in most patients.
- Average delay from joint symptom onset to diagnosis was approximately 6.5 years; following consultation with a rheumatologist, patients were generally diagnosed with PsA within 2 months.

#### WHAT DOES THIS MEAN?

- Gaining insight into the care given in the real-world setting is important to be able to pinpoint the areas of care that need to be improved to ensure that every patient receives the best care possible.
- This example is a recent study in psoriasis arthritis (PsA) showing that it takes a very long time for patients to be referred to a specialist and receive the correct diagnosis.
- These findings have been used to inform Swedish PCPs on how best to detect the early signs of PsA and to ensure earlier referral to specialist -- so that patients can receive earlier care for their disease and thereby have a milder disease course.

contact) was implemented to support collaboration between external parties (including industry).

- Apply “Open Comparisons” to follow-up on the digital transformation in the healthcare system to ensure that there are measures in place to improve information exchange, that the use of health data is sufficient and that these meet the expectations of the citizens.

### **3. Utilize data-driven decision-making for a sustainable healthcare system**

Swedish authorities and healthcare providers should use real RWE in their decision-making:

- RWE is used to evaluate different treatment interventions, identify patient needs, describe patient populations over time, and compare treatments.
- Healthcare providers should use RWE to follow-up on quality of care to a much larger extent than today.
- RWE can improve patients’ quality of care and safety, increase efficiency and help build a sustainable healthcare system.

### **4. Use the law to promote digital development while ensuring individual integrity**

Vision E-health states that it will “... protect individual integrity and safety, support digital development and facilitate application and implementation of regulations.” The regulations shall promote digital development and secure the rights and interests of the individual, but they must also address the specific questions raised by digitalisation. To provide patients with safe and accessible healthcare:

- Create efficient and appropriate regulations that can adapt to and facilitate digital development, and ensure these regulations are interpreted and applied by all the County Councils.

- Assign an expert legal counsel who is knowledgeable in digitalisation and new technologies to interpret the regulations and advise on the legal, regulatory and ethical implications of their use, and who can identify the regulatory changes that are necessary to ensure digital development.

### **5. Time to act now**

In “Vision E-health 2025”, the government and SKL presents its plan to make Sweden a leading e-health nation and a timetable to create an integrated healthcare data system. However, AmCham’s Sweden life science working group believe it is extremely critical to shorten the timelines to attain the necessary efficiencies required in the healthcare system and, when viewed from an international perspective, remain an attractive life science nation.

- AmCham not only supports the “Vision E-health 2025” statement that “consistent use of terms” and “standardization” issues are “important”, but stresses that both issues should be given the highest priority for implementation by the County Councils.
- If necessary, government funding should be given to the County Councils to increase the pace.

### **6. Collaboration for better healthcare**

Collaboration and partnerships between healthcare providers, academia, patients and industry is critical to reach the vision of improving peoples’ health. It is the only solution to the challenges in the Swedish healthcare system.

Collaboration will strengthen Sweden’s global competitiveness and provide better healthcare. AmCham Sweden truly wants to collaborate for connected healthcare data in Sweden to attract investments from the companies we represent and to improve healthcare in Sweden.



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## ■ Abbreviations/Definitions

**COPD** Chronic obstructive pulmonary disease

**EMR** Electronic Medical Record

**NBHW** National Board of Health and Welfare  
(Socialstyrelsen)

**PsA** Psoriatic Arthritis: A disease of the joints often accompanied by joint pain and psoriasis

**RCT** Randomized Controlled Trial

**RWE** Real World Evidence

**RWD** Real World Data



### About AmCham Life Sciences Working Committee

In Sweden, health is a strategic and prioritized area, aligned with the government's agenda. Life science, more specifically, is becoming increasingly important and Sweden has a strong global track record from a performance perspective.

The American life science affiliates aim to contribute to Swedish healthcare by effectively providing solutions to improve patient outcomes, delivering scientific and societal value. To achieve this, we need to position Sweden as the global innovation hub for life science and health technology where all healthcare stakeholders, including patient organizations, academia, healthcare providers and industry, constructively collaborate.

It's the American life science affiliate's belief that continuous research and development drives treatment innovation, care provision and technology solutions that should be easily accessible to Swedish citizens as this is paramount to high quality healthcare.

Source: <https://www.amcham.se/lswc>

## Contact us

Phone: +46 8 506 126 10

info@amcham.se

### **AMERICAN CHAMBER OF COMMERCE IN SWEDEN**

Box 190

SE-101 23 Stockholm

Sweden

Twitter: @AmChamSweden

LinkedIn: [www.linkedin.com/company/american-chamber-of-commerce-in-sweden](http://www.linkedin.com/company/american-chamber-of-commerce-in-sweden)

Facebook: @amcham.se

