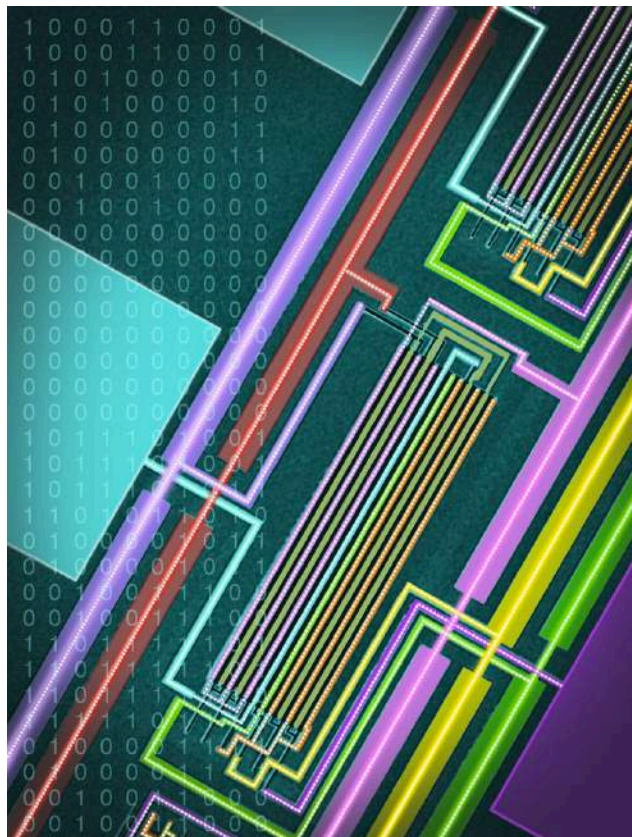# eHealth in Sweden

Interview with Patrik Sundström, Swedish Association of Local Authorities and Regions

Stockholm, Sweden

By Sofia Widén
ACCESS Health Sweden

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they live, have a right to access high quality
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About Patrik Sundström

Patrik Sundström holds a Master of Laws degree from Uppsala University, Sweden. He also holds a degree in Business and Economics from the same university. After graduation, Mr. Sundström worked for ten years as a lawyer in the public sector. Since May 2014, he has been the program manager for eHealth at the Swedish Association of Local Authorities and Regions.

Introduction

What follows is an interview with Patrik Sundström about his thoughts on eHealth in Sweden.

The national focus on eHealth is an initiative of the Swedish government. The initiative is a part of a national digitization agenda, with the goal of Sweden becoming the most prominent digital user in the world. The aim of eHealth is to improve the health, participation, and independence of patients in Swedish society. Individuals should be able to take control of their own health. Patients should also be able to make informed decisions and take care of themselves.

The initiative also aims to contribute to proper working conditions for employees in healthcare and social care. The healthcare workforce needs access to the right information, at the right time, in the right place. Healthcare workers need solutions that provide substantial support in their daily work. The result for healthcare staff will be easier medical decisions and reduced administrative work. The eHealth initiative will also result in more time for personal interaction with patients and users.

Finally, the initiative provides policymakers with the opportunity to monitor healthcare performance. Leaders are then able to plan, run, and control the work, based on the need for continuous improvements.

The Swedish Association of Local Authorities and Regions governs the eHealth initiative. The Association represents and acts on the initiative of all municipalities, county councils, and regions in Sweden. The Association also collaborates with other independent actors in the area of eHealth. One example is Inera AB, a public eHealth development company.

Interview

Sofia Widén (SW): Tell me about your background.

Patrik Sundström (PS): I am a lawyer by training. I have worked both in the private and in the public sector. In the public sector, my main role was to support local governments on issues related to information management. For the past fifteen years, I have worked with various information management issues in the healthcare sector. I have worked for the Swedish Supervisory Authority[1] in the Data Protection Department.[2] I worked in government offices. I currently work at the Swedish Association of Local Authorities and Regions.[3] I am the program manager for eHealth at the Association. I am passionate about my work.

Much of my work revolves around relationships. Internal relations and relationships with the Swedish government and the state authorities are important. The Association is a membership organization. Interactions with our members, the local governments, are of great importance too.

eHealth is about information management. Legislation is the foundation of our work. Laws can restrict innovation in eHealth. Much effort goes into creating opportunities for local governments to digitize their operations. This is a big part of our mission. We want to lower the thresholds for local governments to succeed in the area of eHealth.

SW: Are the barriers to success high?

PS: There are many basic thresholds. We need to communicate and package the message of digitization and eHealth properly. We must move our focus from information technology to operational issues. We should focus on strategic operational development with the help of digital technology. The technology is the tool, not the final objective.

Strategic operational development imposes high requirements for our membership organizations, such as the local governments. The introduction of new information technology systems is not the key. Change is the key. We need to find new ways of working. Work with the profession and with the legal system. Work with finance and business models.

SW: With whom in the municipalities and the county councils do you work?

PS: I work at the Association. I work with representatives from the municipalities and the county councils. We manage a number of networks at the Association. We gather county council directors, healthcare directors, and politicians. We are a point of contact for representatives from local governments.

Regional representatives from the Association work in different parts of Sweden. There are 290 municipalities. The Association is unable to work closely with every municipality. Regional municipal eHealth coordinators serve as links between the local and national level.

There are twenty one county councils in Sweden. We collaborate with all the county council directors. The leaders in the county councils are connected through networks. The county councils own Inera, a public eHealth development company. Inera is independent of the Association. The Association and Inera collaborate closely in the area of eHealth.

SW: How large is Inera?

PS: I do not know how large the workforce of Inera is. However, the county councils provide four hundred million Swedish kronor (fifty million US dollars) in funding to Inera annually. I believe that Inera owns a portfolio of somewhere around six hundred million Swedish kronor (seventy five million US dollars).[4]

SW: Can you define eHealth?

PS: There is no definition of eHealth. I think that individuals view eHealth differently. For me, eHealth is about developing operations with the help of digital technology. eHealth should be something that contributes to the benefit of patients, employees, and policymakers.

"In the future, the "e" in eHealth will be irrelevant. We are not talking about eCarpenters just because they use a drill that runs on electricity. We have used eHealth to shed light on the importance of digital technology in healthcare. In the future, we will only talk about healthcare with implicit references to technology."

I believe we are at a turning point in eHealth. For a number of years, eHealth as a concept has been very important. We relied on the concept of eHealth to break

new ground in Sweden. In the future, the "e" in eHealth will be irrelevant. We are not talking about eCarpenters just because they use a drill that runs on electricity. We have used eHealth to shed light on the importance of digital technology in healthcare. In the future, we will only talk about healthcare with implicit references to technology.

SW: What is the difference between information technology and eHealth?

PS: Today, it is difficult to improve healthcare without the help of new and older technology. Technology is a central part of operations development. We need to understand the importance of technology. Technology is only one part of innovation and healthcare development. We are starting to understand this. We also need policies, architecture, and infrastructure.

We observe a rapid development in eHealth, especially in the area of welfare technology.[5] eHealth aims to provide individuals with digital solutions. The objective is increased data security, autonomy, and patient participation. Digital technology enables individuals to monitor their health, to make informed decisions, and to stay healthier longer. Healthcare professionals monitor patients´ health remotely to avoid unnecessary hospitalization. Remote monitoring will help us reach out to patients instead of waiting until they seek healthcare.

We begin by focusing on health promotion and prevention. Digitization is a key. We have an aging population. Our population suffers an increased risk of chronic disease. Digitization plays a central role in managing chronic diseases. Kry, the first digital primary healthcare clinic, recently opened in Sweden. This is one example of how we can develop healthcare with technology.

SW: What do you think about digital primary care clinics?

PS: I think digital clinics are complementary to traditional clinics. A digital health clinic is not a full service primary healthcare clinic. Digital clinics can help patients with certain diagnoses. A doctor/patient video meeting increases the availability of healthcare. Online healthcare access may allow you to visit your physician during your lunch break instead of taking half a day off to visit your doctor. I believe that we will see many online clinics in the future.

SW: How do we increase access to healthcare?

PS: We need to solve the barriers to technology adoption, including technology financing, implementation, and legal frameworks. We run many projects in eHealth. However, we seem unable to integrate new solutions in our operations. There are several reasons why we fail to integrate digital solutions. We need to invest in the architecture of eHealth. We need to build our infrastructure in Sweden. We also need to work with standardization of eHealth terminology. Finally, we need to develop a coherent regulatory framework. Standardization and regulation will create direction for suppliers and the healthcare providers

We want to avoid introducing new technology that is incompatible with our operational systems. Individuals who use private healthcare applications and devices cannot send information to healthcare professionals. The information may be expressed in a language impossible for the doctors to understand. The information may be of poor quality. We need to improve our systems to allow this information exchange. If I can prescribe a healthcare mobile application to a patient I must be sure that the application is of high quality. Ultimately, eHealth applications should meet regulatory standards. We must build secure data systems. We also must build a system that can transfer data from mobile applications into medical records.

The opportunities for technological development are great. New technological solutions need a solid foundation. Suppliers and healthcare providers develop new solutions in isolation. These new solutions depend on internet coverage and a mobile connection. All areas in Sweden do not have access to internet and mobile coverage. The gaps in Sweden are small. In other countries, like the US, the gaps are much bigger.

SW: How can these gaps prevent access to healthcare?

PS: We need to ensure that all individuals have access to the internet. Our networks need to be robust and of high quality. These need to work perfectly at all times if we are to create reliable digital health services. In the future, applications will monitor my health. Applications will send out an alert if my health is at risk. If the internet suddenly stops working, my life may be in danger. Today, our networks are unreliable. A reliable internet connection is crucial for the healthcare sector, as well as in most parts of the welfare sector. The quality of the internet connection varies across Sweden. These quality variations prevent us from using technological solutions in healthcare.

SW: If you were given unlimited resources tomorrow to lower the thresholds. Would you begin with the legal questions or the technological issues?

PS: We need to work in different areas. The Association needs to initiate conversations with the municipalities, the county councils, and the government. We must develop a united vision. Sweden needs a strategy with an action plan. We have many unanswered questions. How do we finance the development process in the long run? Who is responsible for what? We seek answers in the legal system, in the information structure, and in the business models.

We need to take several aspects into consideration. Reimbursement for a primary care doctor is higher if the doctor meets with the patient. If we give the service through a digital service online, the doctor obtains no reimbursement. This is a barrier for technological development and adoption.

SW: You adopted a national eHealth strategy in 2010. What has happened since? What does the government think?

PS: We are in need of an updated and more cohesive strategy. The current strategy played an important role for a number of years. We need to combine several strategies in the digital arena. We do not need to solve every problem from scratch in every welfare sector. We can find shared solutions for different sectors. eHealth may benefit from digital solutions in the educational system. Society needs a fundamental digital infrastructure to develop an eHealth system.

SW: Do you have the support of the national government?

PS: In the beginning, the new government devoted a lot of effort to eHealth and to technology. The new government spent time establishing relationships with the important actors in this area. I think that we have worked well together. We engage in discussions on how to reach a long term agreements on development of eHealth. The Minister of Health, Gabriel Wikström, expressed a desire to reform the legal framework and to launch new efforts in eHealth to deliver more equal patient centered healthcare.

SW: County councils work in different ways. Uppsala County Council introduced My Patient Record Online.[6] My Patient Record Online offers online access to patient records. Can you take the Uppsala model and spread it to other regions?

PS: Some regions have implemented patient records online. Many counties are starting to provide medical records online. The implementation process is different in every county. All counties need to codevelop a set of fundamental regulations that govern online patient records to enable all individuals to receive the same information. We travel across the country. We should receive the same

information regardless or where we are in Sweden. The care professionals should have access to my patient information regardless of where in the country they work.

Skåne and Västra Götaland regions finished their implementation process for online patient records. Stockholm and Norrbotten counties are working to increase the accessibility of online medical records. In a few years, every county council will be up and running in this area.

SW: Can we store medical records online? If the cloud is good enough for banking, the cloud should be good enough for healthcare. What legal aspects must we take into account?

PS: The cloud could be a solution. In my opinion, you cannot say if the cloud is good enough for banking, it is good enough for healthcare. Banking information is incredibly sensitive. However, health related information is even more sensitive. Medical records contain personal information. They describe our medical history. We must ensure that the information is handled in a safe way. Patients need to be able to trust us. Patients do not know where their personal data may end up. People need to feel secure using our systems. Individuals who feel insecure may hide important information from their healthcare professionals. We need to invest in and increase our information security. Investment is essential to embrace fully the digital possibilities.

There is another difference between banking and healthcare information: Individual information should not be accessible to other banks. A bank where I am not registered as a customer cannot access my banking information. The information is exclusive to the bank that registered the data. Healthcare providers need to exchange information.

SW: What are the advantages of digital records?

PS: There are some risks with digital records. I believe that we can manage these risks. In the digital world, many people can access the information. All users of the system have potential access. In the manual world, this number is lower. I believe the digital world is better. You increase the traceability when you store information digitally, compared to hard copies. You cannot trace who reads the information. You can detect unauthorized data intrusion with digital records.

We need to find smart solutions to gain patients' trust. Information travels faster than the individual. This is a critical aspect of healthcare delivery. A primary

healthcare clinic is unaware of who will need help on a certain day. Patients should receive the same quality of care regardless of where they seek help. The health center must be able to access information about all potential patients from different sources.

SW: Sometimes, the quality of data collected at home is of suboptimal standard. Is this a problem?

PS: Data quality can be a problem.

SW: Sweden managed to improve the quality of the data with the Patient's Own Reporting.[7] The Patient's Own Reporting is an eHealth tool for patients who suffer from neurological diseases. The information goes into a separate data system. A doctor must approve the patient's data before the data is registered in the medical record.

PS: I am unable to comment on this specific example. In my opinion, you are describing a general problem. We provide monitoring devices to patients. Patients wear these devices. Data from the devices is transmitted automatically to the operational systems of the healthcare providers.

"Data incompatibility is a greater problem that data quality."

The problem is not the data but the product. Patients often purchase consumer products independent of the doctor. Consumer products deliver data that are incompatible with the information technologies in healthcare. Our systems prevent the information to register. Data incompatibility is a greater problem that data quality.

SW: Do we gather too much data in healthcare?

PS: Maybe. Some individuals want to monitor their vital organs. This adds up to a large body of data. Our systems are not designed to process this much data. Data processing is costly. We can use our resources more efficiently.

We need to design our systems carefully. We need to define what type of data we need. We need to engage in a dialogue with doctors who treat patients. The doctors can tell us what data they need. We need to ask patients about what data matters for them. Our eHealth products need to correspond to the needs of

patients. Sweden needs a national framework and specific product requirements. There is a large consumer market for health applications. The problem is that we lack a national framework for compatibility. Suppliers do not build applications that fulfill healthcare regulations. Suppliers build consumer products, which we are unable to link to digital patients records and treatment methods. Many other countries struggle with the same problem.

SW: We have developed many digital applications in Sweden. What other countries do you consider when you look for inspiration?

PS: The digital inventions must to be designed to match the demand in the healthcare sector. Healthcare delivery differs across countries. In Sweden, the county councils are responsible for healthcare delivery. Not all countries have county councils. Instead of comparing digital development in different countries, we should focus on the outcomes. Increasing investments in eHealth and other digital solutions must contribute to the patients' overall health.

Countries that we look to for inspiration are the Netherlands, the United States, Denmark, and several Spanish regions. The United States has shown remarkable results in digital technology. In the United States, the healthcare sector uses systems that increase digital accessibility for patients and healthcare professionals.

SW: Why are some countries more successful than others in eHealth development?

PS: In Sweden, the county councils invest approximately three percent of total income in information technology. In the United States, some healthcare providers invest around ten percent. Americans understand the importance of eHealth technology. Sweden spends a fraction of what the United States spends on eHealth infrastructure. It is difficult to compare countries. Since the United States spends so much on eHealth technology, they have progressed quickly in some areas. Healthcare systems like Kaiser Permanente, Intermountain Healthcare, and the Mayo Clinic use advanced healthcare technologies.

"When we invest in technology, we invest in patient outcomes and better health."

Technology affects how we deliver care when we meet patients. I need eHealth tools that support my workflow, that provide key information, that provide treatment recommendations, and that contain up to date medical information. When we invest in technology, we invest in patient outcomes and better health. Regional healthcare providers and county councils need to invest in technology. We also need to pool resources and make joint investments.

SW: What are you most proud of with your work here at the Association?

PS: We are driving the development forward. We spread the message about the many uses of technology. We support good practice and help those who lag behind to catch up.

SW: We have a National eHealth Day in Sweden

PS: Yes. We have had a National eHealth Day for several years.

SW: Has it always been called the National eHealth Day?

PS: The day was originally called something else. For the past four years, it has been called National eHealth Day. We have a number of days throughout the year that focus on eHealth questions. We started a new conference in January of this year with Västerås stad and Vinnova, a state innovation funder. The conference is called Meeting Place Welfare Technology and eHealth. The day focuses on technology in the municipalities and in the elder care sector. Västerås was a founding member with us. We had over seven hundred conference participants and equally as many exhibitors. The conference was a success.

SW: I met your colleague Jeanna Thorslund from the Association. She gave a lecture about the legal aspects of welfare technology.

PS: This is a new legal area. This is about breaking new ground and being creative. Over time, the legal framework will develop as we analyze the implementation.

SW: The managers of elder care in Västerås asked their lawyer how to implement technology. They did not ask if they could implement technology.

PS: They had the right attitude. You must be determined and find solutions. Sometimes the technology will be costly and you will meet resistance. You can always find solutions.

SW: What are your priorities going forward?

PS: We have a number of priorities. We are prioritizing medical lists. We fail to keep track of all the medications that we prescribe to patients. The pharmacist has a better understanding of all the medications that we prescribe than the doctor. This is a risk for patients. It is also costly since we have a lot of complications related to patients. We need to improve in this area. We want a common medical prescription list that all healthcare providers can access. In the current system it is easy to prescribe medications that are harmful in combination. With the county councils, we are running a project in this area. The problem is that the laws prevent us from sharing this type of information among healthcare providers.

SW: What law prevents information exchange?

PS: The law about medical prescription lists. We may need to consider a number of laws. We will do so by highlighting the problem to our national politicians. We will explain that people must be able to feel safe when they obtain a prescription from their doctor.

We are also prioritizing information exchange more generally. Patients have the right to seek care all over Sweden. Therefore, it is important that healthcare providers exchange information. To allow such information exchange, we need to update our laws and develop new information technologies.

The most ill elderly, including patients who suffer from multiple diseases and require extensive services, often need a combination of homecare, primary care, specialist care, and inpatient care. The care coordination process must find a way to put the patient at the center of the care process. All providers must have access to relevant patient information. Healthcare providers must ensure information security. All patient information must be accessible to the healthcare provider. Patients' health may be at risk if healthcare providers fail to document and deliver patient information.

SW: Is National Patient Oversight[8] system a solution to this problem?

PS: Yes, National Patient Oversight is one example that could solve the problem with information security. This is a system that allows healthcare providers to exchange patient information. This solution demands a few resources. All healthcare providers must document all patient information in the records. This is essential for the records to be useful. The patient care records will not be

reliable if healthcare providers fail to document patient information. The providers must search for patient information elsewhere if they start to doubt the reliability of the care records. This would make the patient care records useless. One drawback is that adoption of National Patient Oversight has been slow in Sweden.

SW: How can we design technology in accordance with patients' needs?

PS: We can use technology to increase patient autonomy, patient safety, and patient participation in healthcare. Individuals can monitor their own health. Healthcare providers can deliver services depending on the wishes and the demands of patients. We can look at services that allow patients to feel safe at home. We must see how patients want to lead their lives. Placing the patient at the center of the care process is key. Which solutions can benefit the individuals the most? Patients should drive the development process.

The old systems were essentially papers in a box. Transforming the information from hard copies to digital information requires time. Technology can perform things humans cannot. Today, we use technology for things we can do manually. We must use technological solutions to transcend human limitations. Technology can process large quantities of information. Technology can link a symptom to a specific diagnosis. Technology can help healthcare professionals determine which medicine is suitable for a specific patient, based on his or hers patient information history. Technology can also determine the dosage of a certain medicine. Healthcare in Sweden would be more equal if we used all of the technological benefits available. Healthcare professionals across Sweden would receive the same treatment recommendations. Healthcare professionals can turn to technological systems in meetings with patients. Technology is valuable tool that can help the profession and increase quality of care.

SW: Can we finance this kind of technology?

PS: We cannot afford not to invest in healthcare technology. Healthcare professionals think that our current systems are complicated. Our current systems fail to provide the necessary patient information. The systems provide too much information. Healthcare professionals must search for relevant information. It is difficult for the professionals to determine what patient information is important. This is a problem. If we want to improve patient outcomes, we must use technological solutions more efficiently, going forward. In the long run, technology is an investment, not a cost.

SW: Do healthcare professionals consider eHealth to be an opportunity or an obstacle?

PS: I think healthcare professionals see the opportunities with eHealth. Healthcare professionals also experience the problems with our current systems. Many consider the technological health systems to be too complex. There are many login functions. Consumer technology is less complicated. Most healthcare professionals feel safe using private technology but not our systems.

Previously, we considered eHealth a technological question not an operational question. Healthcare professionals should be involved in the eHealth development process. This is not the case in Sweden.

SW: Did you hire external consultants in the eHealth development process?

PS: Yes. The operational needs were not the key focus in the eHealth development process. Some technological solutions may not consider the demand or how it will affect the work of the healthcare professionals. The healthcare professionals are the individual users of the systems. We must engage healthcare professionals in the development process. The systems affect their work. Healthcare professionals have the incentive to develop operating systems. The information technology department should not handle the eHealth development process. We must move focus from information technology to operations. This is essential to develop high quality and easy to use eHealth systems.

SW: Which patient groups benefit the most from eHealth?

PS: Older patients with chronic diseases who account for a large portion of healthcare delivery. When we focus on health promotion and prevention, eHealth will be beneficial to all. Others who benefit from eHealth are patients who suffer from rare diseases. Digitization enables the flow of information across countries. We can obtain information about patients who suffer from the same disease in other countries and increase the information about these rare diseases.

SW: Do countries in the European Union collaborate on eHealth?

PS: Some countries partly collaborate. Members of the European Union collaborate more closely. epSOS is one example of a collaboration project between member states. epSOS offers cross border healthcare to European citizens. epSOS aims to improve quality of care and patients safety when traveling

to another European country. epSOS enables patients to collect a prescription in one European country prescribed by a doctor in another European country.

There is some collaboration on a state level. The European Union Region Committee[9] works with collaboration related questions. Representatives from local governments, municipalities, and county councils serve on the committee. eHealth is a global phenomenon. Countries must agree on how to design and standardize the eHealth systems. We must collaborate more across countries so that individuals can be mobile.

SW: Thank you, Patrik, for sharing you thoughts on eHealth with ACCESS Health.

PS: Thank you, Sofia. Have a great day!

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[1] Tillsynsmyndigheten

[2] Datainspektionen

[3] Sveriges kommuner och landsting, SKL

[4] Inera, http://www.inera.se

[5] Välfärdsteknologi

[6] Min journal via nätet, http://www.lul.se/sv/Extranat/For_vardgivare/MOT-PATIENTEN/Sjukvard1/Journal-via-natet-min-journal-i-U-a-lan/

[7] Patientens egen rapportering, PER http://www.neuroreg.se/sv.html/motorneuronsjukdom-patientens-egen-registrering-per

[8] Nationell patientöversikt, NPÖ

[9] EUs regionkommitté

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ACCESS Health works to increase access to affordable health technologies that improve the quality of healthcare services and the functioning of health financing systems.

ACCESS Health Sweden studies eHealth technologies in Northern Europe. In this effort, we study the information infrastructure that underpins the healthcare systems. We study the design, history, context, and application of eHealth. eHealth is a term that encompasses a range of software applications in healthcare, such as patient record systems, prescription databases, and image exchanges. The ACCESS Health team has chosen to study the Estonian eHealth and eGovernance systems. Estonia has invested heavily since the early 1990s in building its eHealth infrastructure.

In Sweden, we study the Swedish eHealth system and the newly established eHealth Department, a new branch of the Swedish government. We also look at how regional healthcare systems apply national standards and implement eHealth services.

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