Working paper/PM
2011:12

e-Health and Patient-Centered Care Processes in the United States of America

The objective of this report is to briefly describe e-health initiatives and patient-centered care processes in the United States and to identify the initiatives and stakeholders that should be included in a potential future, more detailed, study.

tillväxtanalys

Dnr: 2010/177
Swedish Agency For Growth Policy Analysis
Studentplan 3, SE-831 40 Östersund, Sweden
Telephone: +46 (0)10 447 44 00
Fax: +46 (0)10 447 44 01
E-mail info@growthanalysis.se
www.growthanalysis.se

For further information, please contact Sofie Björling or Martin Wikström
Telephone + 1 202 536 1587 or 010-447 44 73
E-mail sofie.bjorling@growthanalysis.se or martin.wikstrom@growthanalysis.se

Foreword

The objective of this report is to briefly describe e-health initiatives and patient-centered care processes in the United States and to identify the initiatives and stakeholders that should be included in a potential future, more detailed, study.

The study was initiated by Monica Winge, VINNOVA, and the Tokyo and Washington offices of the Swedish Agency for Growth Policy Analysis (Growth Analysis). A report named "e-Health and Patient-Centered Care Processes in Japan" was finished in June 2010.

In the United States, the term e-health is not used. Instead Health IT is the common term and will be used throughout this pre-study. Many countries have put Health IT high on their agenda. In the United States, where 80 % of physicians do not use any kind of digital records[1], a significant amount of federal funds is being invested in the area in order to improve the quality and efficiency of health care. The approach is "bottom-up" with numerous programs initiated all over the country with the purpose of developing patient-centered Health IT. There are also many organizations involved. The goal is that in the future all the systems that are being developed will be interoperable, which will be a challenge.

Health IT innovation attracts a lot of entrepreneurs and there are a large number of private companies involved. These will not be presented in this pre-study however, instead the most important federal and state initiatives and organisations involved are described.

The study was prepared by Sofie Björling, analyst and scientific attaché at the Washington DC office of the Swedish Agency for Growth Policy Analysis. Questions may be directed to Sofie Björling, sofie.bjorling@growthanalysis.se, +1 202 536 1587 or coordinator and analyst Martin Wikström, martin.wikstrom@growthanalysis.se, 010-447 4473.

Enrico Deiaco, Head of Department

Östersund, March, 2011

[1] *Report to the President: Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: the Path Forward. By the Executive Office of the President, the President´s Council of Advisors on Science and Technology (PCAST),December 2010, http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf*

Table of Content

Summary

American health care is the second most expensive in the world as part of GDP and is now facing big changes. In 2010, the Health Care Reform was signed, making health insurance by 2014 available to millions more Americans than today. The Health Information Technology for Economic and Clinical Health (HITECH) Act passed as part of the American Recovery and Reinvestment Act (ARRA) in 2009, and invests large sums of money in modernizing the health care system by promoting and expanding the use of HEALTH IT.

There are a large number of activities initiated by the HITECH act, mainly related to the development and usage of Electronic Health Records (EHRs). To the uninitiated some of the initiatives seem to overlap and in addition, numerous agencies and organisations are involved. The reason for this bottom-up approach instead of a top-down authoritarian approach is presumably the fear by many Americans of socialized medicine and the federal government taking too big of a role regarding health care. This in turn has led to the highly complicated structure of the health care system and the very different levels at which HEALTH IT is currently used in the United States, if at all. The needs are very different and the specific applications now being developed in different parts of the country will most likely differ significantly. The next step will be to connect and make all the HEALTH IT systems interoperable once they are up and running. This approach might seem ineffective when there is so much money invested at one time by the federal government. However, it is quite expected in a country where many want the federal government to be as little involved in their lives as possible. Many believe that the semantic web[2] will be used in order to extract data from the different systems.

All federal guidelines for Health IT in the United States have the patient in focus. The HEALTH IT solutions having been and being in the process of implementation in the country all appear to follow those directions. Clearly, Sweden should follow the progress of the numerous systems now being developed in America, particularly in the development of EHRs. This is an area where Sweden might be more advanced than the United States and there should be possibilities for Swedish companies and other stakeholders to partake in the large investments being made.

The HEALTH IT systems at Kaiser Permanente and the Veterans Health Administration are well developed and applicable to Sweden for many reasons: Their organisations are run more like a “landsting” than any other American health care organisation. They support approximately the same number of persons that live in Sweden; the Veterans Health Administration has patients all over the country and Kaiser Permanente has patients of all ages. It would therefore be of great interest for Sweden to study the HEALTH IT solutions in these two organizations in more detail.

Many activities on the state level are in progress in the United States. Swedish stakeholders should follow the development of the HEALTH IT systems in several different states, for example Rhode Island and Indiana.

[2] *The* Semantic Web *is a "web of data" that enables machines to understand the semantics, or meaning, of information on the World Wide Web, according to wikipedia: http://en.wikipedia.org/wiki/Semantic_Web*

It could be of interest to Sweden, where nurses traditionally have a strong position, that the role of nurses, their responsibilities and education are predicted to change significantly as a consequence of the increased need for care that the health care reform will bring. One could expect that there will be a shortage of nurses in the United States due to these changes. A future shortage of HEALTH IT professionals is anticipated in the United States due to the planned increase in HEALTH IT usage. The present drive by universities and colleges to support training and development of such professionals is in response to that scenario. Could HEALTH IT professionals and nurses become a Swedish export? Feasibility studies could be done in this area.

Swedish companies should be informed of the many possibilities of medical innovation in the United States, not only in HEALTH IT in general, but in e-prescription, data mining and analysis, care integration tools and decision support, specifically. The high level of funding currently being invested into HEALTH IT in the United States opens up many possibilities for a variety of stakeholders, including Swedish.

Sammanfattning

Amerikansk sjukvård är den näst dyraste i världen sett som andel av BNP och står nu inför stora förändringar. År 2010 klubbades sjukvårdsreformen, med innebörden att sjukförsäkring år 2014 kommer att bli tillgänglig för miljontals fler amerikaner än idag. The Health Information Technology for Economic and Clinical Health (HITECH)-lagen infördes som del av American Recovery and Reinvestment -lagstiftningen (ARRA) 2009 och innebär stora investeringar bl a i moderniseringen av sjukvårdssystemet genom att uppmuntra och utveckla användningen av e-hälsa.

Ett stort antal aktiviteter initierades av HITECH-lagen, främst inom utvecklingen och användningen av elektroniska patientjournaler. För den oinsatte verkar vissa av dessa överlappa med varandra och det finns mängder av myndigheter och organisationer involverade. Anledningen till detta "bottom-up"-tillvägagångssätt istället för ett auktoritärt "top-down" är troligen den rädsla många amerikaner känner inför socialiserad sjukvård och att regeringen ska ha en alltför stor roll inom vården. Detta har i sin tur bidragit till sjukvårdssystemets komplicerade struktur och de stora skillnaderna i användningen av e-hälsa, där det överhuvudtaget förekommer, runt om i landet. Behoven är väldigt olika och de e-hälsosystem som nu utvecklas på olika ställen i USA kommer förmodligen att skilja sig åt markant. Nästa steg blir att koppla ihop de olika e-hälsosystemen och få dem att kommunicera med varandra. Detta tillvägagångssätt kan verka ineffektivt när så mycket pengar investeras på en gång av den federala regeringen, men är att förvänta i ett land där många vill att den federala regeringen ska vara så lite involverad i deras liv som möjligt. Många tror att den semantiska webben[3] kommer att användas för att extrahera data from de olika systemen.

Samtliga federala riktlinjer inom e-hälsa i USA har patienten i fokus. De e-hälsoinitiativ som har, och håller på att utvecklas, verkar följa den logiken. Sverige borde följa utvecklingen av de många system som nu utvecklas i landet, särskilt utvecklingen av elektroniska patientjournaler. Detta är ett område där Sverige kommit längre än USA och det torde finnas möjligheter för svenska företag och andra aktörer att ta del av de stora investeringar som nu görs.

e-hälso-systemen vid Kaiser Permanente och Veterans Health Administration (f d militärers sjukvård) är väl utvecklade och tillämpbara på Sverige av flera anledningar: Deras organisationer sköts mer likt ett landsting än någon annan amerikansk sjukvårdsorganisation. De stödjer ungefär samma antal människor som bor i Sverige; Veterans Health Administration har patienter över hela landet och Kaiser Permanente har patienter i alla åldrar. Det skulle därför vara av stort intresse för Sverige att studera dessa två organisationers e-hälso-system.

Många aktiviteter på delstatsnivå pågår i USA. Svenska intressenter borde följa utvecklingen av e-hälso-systemen i flera olika stater, exempelvis i Rhode Island och Indiana.

[3] Enligt Wikipedia: Semantiska webben är ett begrepp myntat av World Wide Web Consortiums (W3Cs) chef Tim Berners-Lee, som också är skapare av världswebben (WWW). Begreppet beskriver metoder och teknik för att möjliggöra för maskiner att förstå innebörden eller "semantiken" i informationen på webben. http://sv.wikipedia.org/wiki/Semantiska_webben

Det kan vara av intresse för Sverige, där sjuksköterskor traditionellt har starka positioner, att deras roll, ansvarsområden och utbildning förväntas förändras markant till följd av det ökade behovet av vård som sjukvårdsreformen medför. Man kan förvänta sig att det kommer bli ont om sjuksköterskor i USA på grund av dessa förändringar. Amerikanerna förutser brist på e-hälsopersonal i framtiden på grund av den planerade ökade användningen av e-hälsosystem och följdaktligen investerar universitet och högskolor i träning och utbildning av relevant personal. Kan sjuksköterskor och e-hälsopersonal bli svenska exporter? Lämplighetsstudier borde göras inom området.

Svenska företag bör informeras om de många möjligheterna till medicinsk innovation i USA, inte bara generellt inom e-hälsa, utan inom e-recept, data mining/analys, verktyg för att integrera vård och klinisk data som kan användas som underlag till beslut. De stora summor som för närvarande satsas inom e-hälsa i USA öppnar många möjligheter för en mängd aktörer, inklusive svenska.

1 The Health Care System and its Reform

1.1 The Health Care System

Health care in the USA is more expensive than in any other country in the world except for East Timor (16% of GDP 2008, compared to Sweden´s 9.4%, according to OECD)[4]. The health care system in the United States differs from that in Sweden in many respects. The American system is insurance-based, which includes public financing as well. The system has been described in detail in the ITPS report of 2007[5] and will not be discussed at length in this pre-study. What should be noted, however, is that the system is a mixture of different health care solutions and ownerships, making it complicated to get an overview of the whole landscape. Most people below 64 years of age in the USA are insured privately (66.8%) while the second largest group has no insurance at all (16.6%). Almost as many individuals are insured through the federally funded program Medicaid (13.9%), according to the Center for Disease Control[6]. Nearly 50 million Americans have been without health insurance for at least part of 2010, according to Medline[7].

Medicaid is a joint federal and state program that offers families and individuals with low incomes and resources health insurance. Medicare is also a joint federal and state program, offering health insurance to individuals over 64 years old. Since Medicare and Medicaid are largely state and federal insurance programs, they have been the subject of several of the initiatives involving Health IT through the Centers for Medicare and Medicaid Services (CMS).

1.2 The Health Care Reform-- Affordable Care Act (PPACA)

The facts that health care is so expensive in the United States, that Americans on the average are not as healthy as one would expect given the investments made, and that so many lack or have insufficient health insurance, have led to calls for action. During the presidential campaign 2008, many candidates campaigned with promises of healthcare reform - Barack Obama was one of them.

*The **Patient Protection and Affordable Care Act (PPACA)***[8], was signed into law by President Barack Obama on March 23, 2010. The law includes many health-related provisions to take effect over the next four years, including expanding Medicaid eligibility. This means that an additional 32 million people will qualify for Medicaid starting 2014. It will no longer be allowed for insurance companies to deny coverage to people with pre-existing conditions. The law also subsidizes insurance premiums, gives incentives for businesses to provide health care benefits and provides support for medical research. The costs of these changes are paid by a variety of taxes, fees, and cost-saving measures. There will be a tax penalty for citizens who do not obtain health insurance (unless they are exempt due to low income or other reasons). It is estimated that the net effect will be a

[4] *http://www.oecd.org/topic/0,3699,en_2649_37407_1_1_1_1_37407,00.html*
[5] *Björn Falkenhall and Marcus Zackrisson "Sjukvårdssektorns tillväxtmöjligheter" ITPS A2007:012*
[6] *http://www.cdc.gov/nchs/data/hus/hus09.pdf#highlights*
[7] *http://www.nlm.nih.gov/medlineplus/news/fullstory_105337.html9*
[8] *http://www.healthcare.gov/law/introduction/index.html*

reduction in the federal deficit by $143 billion over the first decade and by $1.2 trillion in the second decade, when compared to current legislation. The cost of the first decade is estimated at $940 billion.

There will be approximately 20 million individuals who will not have any health insurance even after the implementation of the reform. Among these are persons who choose not to have an insurance and therefore will pay the tax penalty, illegal immigrants and legal residents with less than five years of residency.

Some parts of the reform were already implemented during 2010, for example: programs where persons with preexisting health problems get insurance coverage, helping employers get coverage to people on early retirement, payment of certain medications to Medicare patients, tax credits to small business to be able to provide coverage, allowing adult children up to age 26 to be part of the insurance of the parent, removing lifetime benefit caps, banning insurance companies from removing people from their insurance policy when they get sick, requiring new policies to include preventive services and the creation of a website http://HealthCare.gov, where people can get information on different health insurance providers and what they offer. [9]

The parts of the law that will affect most people: expansion of Medicaid, new insurance marketplaces in every state, tax subsidies for persons that work but get no insurance, guaranteed insurance access and the requirement that almost everyone buys coverage, will come into effect in 2014.[10]

Many Republicans campaigned in the midterm elections 2010 with the slogan "Repeal and Replace Obamacare" (as they call it) and won many votes doing so. As expected, on January 19 2011, the House of Representatives voted in favor of the proposal "Repealing the Job-Killing Health Care Law Act".[11] The Senate, however, voted against a repeal on February 4[12], since the Democrats are still in majority there. The act of repeal itself is full of symbolic value.

Meanwhile, 26 states have appealed the health care law, arguing that it is against the Constitution to force people to buy something, in this case health care insurance. In December 2010, a federal judge in Virginia ruled that the law indeed is unconstitutional, which immediately was challenged by the Obama administration.[13] On January 31, a federal judge in Florida made a similar ruling as the Virginia judge, giving the opponents to the law even more to hope for. Earlier, 22 other states had received the opposite ruling on their appeal. It is widely believed that this issue will be appealed all the way to the Supreme Court.[14]

Nurses´ roles, responsibilities and education should change significantly due to the increased need for care that the health care reform will bring, according to the Institute of Medicine.[15] This could be of great interest to Sweden, where nurses traditionally have a strong position.

[9] *http://www.healthcare.gov/law/introduction/index.html*
[10] *http://www.healthcare.gov/law/introduction/index.html*
[11] *Washington Post 110119*
[12] *Washington Post 110204*
[13] *Washington Post 101213*
[14] *Washington Post 110131*
[15] *http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12956*

2 Health IT Initiatives

It is commonly believed that IT has the potential of transforming health care. At least 1.5 million Americans are harmed each year due to medication errors according to an Institute of Medicine report.[16] It is widely thought that an efficient Health IT process would minimize such incidents, as well as helping patients become more involved in their own care.

However, this is not without controversy. On January 24, 2011, Medline reported a study[17] where a team from Stanford University had analyzed data from physicians´ offices and found no evidence that Electronic Health Records (EHRs), improved the quality of care, even when the system included support to the doctors in making decisions. These findings are in contrast to most previous studies but do not seem to have made a significant impact on the discussions.

The belief that Health IT could potentially open possibilities for new approaches seems to be without controversy, however. According to a recent report by Brookings Institute[18], Health IT is the way for personalized medicine to become a reality. According to the author, Darrell West, there are eight changes that should be made to enable personalized medicine: create "meaningful use" rules by the Office of the National Coordinator (which has already been done, see below); reduce isolation of health research from clinical practice; develop reasonable privacy rules; having differentiated codes for various molecular and genetic tests so that researchers can link genomic information to disease diagnostics and treatment; build data systems helping researchers compare, evaluate and update information; enable feedback loops so that new discoveries translates into treatment; deploy predict models in physicians practices and funding research projects demonstrating the value of health care innovation.

Sweden is one of the leading countries in the world in Health IT, according to the report "Health IT" by Daniel Castro, senior analyst at the Information Technology & Innovation Foundation (ITIF).[19] In the report, Mr Castro presents figures that show that all Swedish primary care physicians use EHRs as well as electronic prescribing, compared to 28% and 20% of American physicians. In Sweden 88% of hospitals use EHRs, compared to 8% in the United States. From these figures it is tempting to think that Sweden is far ahead of the United States in Health IT and that Sweden has nothing to learn from the United States. It should be noted, however, that Sweden has a very homogeneous health care system compared to the United States, as well as approximately 35 times fewer inhabitants. The Health IT report by Mr. Castro found that large countries with a diverse group of stakeholders appear to be at a disadvantage when deploying Health IT. Kaiser Permanente

[16] Institute of Medicine, Board on Health Care Services "Preventing Medication Errors", July 2006, National Academies Press, Washington, DC
< http://www.iom.edu/Reports/2006/Preventing-Medication-Errors-Quality-Chasm-Series.aspx >
[17] *Medline http://www.nlm.nih.gov/medlineplus/news/fullstory_108046.html*
[18] West, Darrell, "Enabling Personalized Medicine through Health Information Technology", Center for Technology Innovation at Brookings, January 28, 2011
http://www.brookings.edu/papers/2011/0128_personalized_medicine_west.aspx
[19] Castro, Daniel, "Explaining International IT Application Leadership: Health IT", ITIF, September 2009, *http://www.itif.org/files/2009-leadership-healthit.pdf*.

and Veterans Health Administration, two of the largest health care providers in the US with almost as many patients as Sweden has inhabitants, have fully integrated Health IT systems, which should be of great interest to Sweden and will be described in more detail below. According to Mr Castro´s report, one of the main barriers to the adoption of Health-IT in the United States is the asymmetrical relationship between the costs and benefits of adopting EHR systems. The return of an EHR system investment does not always justify the costs to the health care provider.

As stated in the e-health report of 2010[20], one of the goals of adopting Health IT is to put patients and citizens at the centre of the care chain. The only way that IT-applications may be fully exploited is when they cross boundaries, both organizational and technological. This report also states that Sweden has the strategy that the caregiver should "own" the data collected on the caretaker, and choose to make it available, while many other countries have the opposite view. This could affect the possibilities for exporting Swedish IT-solutions. This is in line with the Health Insurance Portability and Accountability Act (HIPAA) in the United States, which is described below.

The project EHR Impact[21], initiated by the Information Society and Media Directorate General (DG INFSO) at the European Commission and with the purpose of identifying the possibilities of Health IT, found that the most important prerequisites for high benefit are interoperability and high utilization. In the United States these two issues pose great challenges to its Health IT adaptation, since use of IT is still quite rare in the medical profession, and as the health care system at this time is not interoperable at all.

In comparison to the health care act, PPACA, Health IT seems to create no political controversy in the United States. Both Republican and Democratic presidents have acted on the topic and there seems to be an agreement that improving Health IT is a way towards cheaper and higher quality health care.

There is, however, concern about the security of the data that will be stored electronically. Who has access to the data? Where is the data stored and what happens if the provider ceases to exist?

2.1 Federal incentives, policies and activities

2.1.1 The Health Insurance Portability and Accountability Act (HIPAA)

The Health Insurance Portability and Accountability Act of 1996 (HIPAA)[22] Privacy and Security Rules included parts that deals with administrative simplification. It required the Department of Health and Human Services (HHS) to draft rules aimed at increasing the efficiency of the health care system by creating standards for the use and dissemination of health care information. HHS was required to adopt standards for certain electronic health transactions, including claims, enrollment, eligibility, payment, and coordination of benefits. These standards also had to address the security of electronic health information systems.

---

[20] Johannesson, Christina and Winge, Monica, "Hälsa genom e, e-hälsorapporten 2010", VINNOVA, mars 2011

[21] *www.ehr-impact.eu*

[22] *http://www.cms.gov/HIPAAGenInfo/Downloads/SummaryofAdministrativeSimplificationProvisions.pdf*

One important part of HIPAA is the Privacy Rule, where HHS in 2003 recommended privacy standards for health information. The HIPAA Privacy Rule regulates the use and disclosure of certain information held by "covered entities" (generally, health care clearinghouses, employer sponsored health plans, health insurers, and medical service providers that engage in certain transactions). It establishes regulations for the use and disclosure of such things as health status, provision of health care, or payment for health care that can be linked to an individual. This is interpreted rather broadly and includes any part of an individual's medical record or payment history. The rule aims at empowering the patient and to urge the producers of the Health IT systems to have the patient in focus.

The Privacy Rule[23]:

- gives patients more control over their health information;
- sets boundaries on the use and release of health records;
- establishes appropriate safeguards that the majority of health-care providers and others must achieve to protect the privacy of health information;
- holds violators accountable with civil and criminal penalties that can be imposed if they violate patients' privacy rights;
- strikes a balance when public health responsibilities support disclosure of certain forms of data;
- enables patients to make informed choices based on how individual health information may be used;
- enables patients to find out how their information may be used and what disclosures of their information have been made;
- generally limits release of information to the minimum reasonably needed for the purpose of the disclosure;
- generally gives patients the right to obtain a copy of their own health records and request corrections; and
- empowers individuals to control certain uses and disclosures of their health information.

Even though the aim of the rule is to empower the patient and to encourage the producers of the Health IT systems to have the patient in focus, it is important to remember that the owner of the information collected is not the patient, but the creator of that information. This is criticized sometimes in the United States, but is similar to the Swedish approach on the issue.

2.1.2 The executive order

Once the Privacy Rule was in place, President Bush gave the order in April 2004 “to provide leadership for the development and nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care.”[24]

The order included the establishment of the Office of the National Coordinator for Health Information Technology (ONC) within the Department of Health and Human Services. The ONC has the task of coordinating federal Health IT policies and programs as well as consulting with public and private stakeholder.

[23] http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm

[24] *Executive Order (EO) 13335, http://edocket.access.gpo.gov/2004/pdf/04-10024.pdf*

ONC's mission includes[25]:

- Promoting development of a nationwide Health IT infrastructure that allows for electronic use and exchange of information that:
    - Ensures secure and protected patient health information
    - Improves health care quality
    - Reduces health care costs
    - Informs medical decisions at the time/place of care
    - Includes meaningful public input in infrastructure development
    - Improves coordination of care and information among hospitals, labs, physicians, etc.
    - Improves public health activities and facilitates early identification/rapid response to public health emergencies
    - Facilitates health and clinical research
    - Promotes early detection, prevention, and management of chronic diseases
    - Promotes a more effective marketplace
    - Improves efforts to reduce health disparities
- Providing leadership in the development, recognition, and implementation of standards and the certification of Health IT products;
- Health IT policy coordination;
- Strategic planning for Health IT adoption and health information exchange; and
- Establishing governance for the Nationwide Health Information Network.

Progress to introduce standards was slow in the early stages of ONC´s existence, however, partly due to resistance of the Bush administration to too much federal involvement in the development of standards. Four years after its creation, the ONC released its strategic plan.

2.1.3 Federal Health IT Strategic Plan 2008-2012

In 2008 ONC released the "Federal Health IT Strategic Plan 2008-2012"[26] which included two main goals: Patient-focused Health Care and Population Health. Each goal contains the same four objectives, applied in different ways regarding the two goals.

Goal 1 Patient-Focused Health Care: Enable the transformation to higher quality, more cost-efficient, patient-focused health care through electronic health information access and use by care providers, and by patients and their designees.

- Objective 1.1 – Privacy and Security: Facilitate electronic exchange, access, and use of electronic health information while protecting the privacy and security of patients' health information
- Objective 1.2 – Interoperability: Enable the movement of electronic health information to where and when it is needed to support individual health and care needs
- Objective 1.3 – Adoption: Promote nationwide deployment of electronic health records and personal health records that put information to use in support of health and care
- Objective 1.4 – Collaborative Governance: Establish mechanisms for multi-stakeholder priority-setting and decision-making to guide development of the nation's Health IT infrastructure

[25] http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__onc/1200

[26] *(http://healthit.hhs.gov/portal/server.pt?open=512&objID=1211&parentname=CommunityPage&parentid=2&mode=2)*

Goal 2 Population Health: Enable the appropriate, authorized, and timely access and use of electronic health information to benefit public health, biomedical research, quality improvement, and emergency preparedness.

- Objective 2.1 – Privacy and Security: Advance privacy and security policies, principles, procedures, and protections for information access and use in population health
- Objective 2.2 – Interoperability: Enable the mobility of health information to support population-oriented uses
- Objective 2.3 – Adoption: Promote nationwide adoption of technologies and technical functions that will improve population and individual health
- Objective 2.4 – Collaborative Governance: Establish coordinated organizational processes supporting information use for population health

The Plan articulates 43 strategies that describe the work needed to achieve each objective. Each strategy is associated with a milestone against which progress can be assessed, and a set of illustrative actions to implement each strategy. As a group, the strategies are characterized by:

- Commitment to the engagement of multiple stakeholders across the public and private sectors;
- Concern for reliability, confidentiality, privacy, and security when exchanging, storing, and using electronic health information; and
- Focus on the consumer of health care as a critical participant in achieving the two overarching goals of the Strategic Plan, as described above.

The implementation of the plan was, however, hampered by the fact that there was no funding allocated to realize it.

2.1.4 Medicare Improvements for Patients and Providers Act (MIPPA)

Congress passed the Medicare Improvements for Patients and Providers Act (MIPPA)[27] in 2008. It mainly contained changes in reimbursement and coverage for Medicare, but it also set up a system to encourage e-prescribing, involving incentives and penalties.

2.1.5 The American Recovery and Reinvestment Act (ARRA)

President Obama signed the American Recovery and Reinvestment Act (ARRA)[28] in February 2009. This law was a response to the economic crisis, and has three goals:

- Save existing jobs and create new ones
- Invest in long-term growth and spur economic activity
- Create transparency and accountability in government spending

The funding for the law is $787 billion and includes up to $27 billion in Health IT spending through the Health Information Technology for Economic and Clinical Health (HITECH) Act passed as part of the ARRA. ARRA also legislatively mandated the ONC position as part of the HITECH Act.

[27] *http://www.ncpssm.org/news/archive/mippa_summary/*

[28] *http://www.recovery.gov/Pages/default.aspx*

The HITECH act has the goal of modernizing the health care system by promoting and expanding Health IT by 2014. By doing so, it is estimated that health costs for the federal government will be reduced by more than $12 billion during the coming 10 years. There is a large number of different activities initiated by the HITECH act and to the uninitiated some of them seem to overlap. The reason for this is most likely the highly complicated structure of the health care system. The different levels at which Health IT is currently used in the country, if at all, result in different needs and approaches. Therefore, the specific applications now developed in different parts of the country will most likely differ significantly and the challenge will be to try to connect and make interoperable all these Health IT systems once they are developed. This approach seems ineffective when there is so much federal money invested at one time and the government could show strong leadership, but is quite expected in a country where many fear that too much involvement by the federal government in the health care system is the first step to socialized medicine.

One initiative within the HITECH act that has received a lot of attention is the carrot-stick incentive program described below:

- **Medicare and Medicaid Electronic Health Records Incentive Programs**[29]

Starting in 2011, this program will provide incentives to eligible hospitals and professionals that adopt, implement, upgrade or demonstrate "meaningful use" of certified Electronic Health Records (EHRs). Professionals and hospitals with patients on Medicare may receive up to $44 000 and $2 million over five years, respectively. To get the maximum incentive payment the participation must begin by 2012. The doctors and hospitals that do not use EHRs in 2015 and later will receive a lower reimbursement by Medicare, i e a penalty. For doctors and hospitals with Medicaid patients the adoption of EHRs is voluntary, and may yield up to $63 750 in incentive payments. There is no penalty if there is no adaptation. As much as $27 billion may be expended in incentive payments over ten years. Since Medicare and Medicaid are two of few health care programs that the federal and state governments have the authority to influence, these incentive programs are powerful means with which the use of EHRs may be enforced.

However, since not all medical professionals have patients on Medicare and Medicaid, Dr. Rachel Nelson, Senior Advisor and Acting Division Director, Office of the Chief Scientist at the ONC, was asked in an interview[30] what incentives such professionals have to start using EHRs. For example, a pediatrician in an affluent suburb will not have Medicaid or Medicare patients, why should he/she buy an EHR-system? Dr Nelson explained that it is not really expected that all "old" doctors without incentives will start using EHRs, the focus is rather on the younger doctors. Some organizations, for example the American Pediatric Organizations, push their members to obtain EHRs and help them get discount on the purchase of Health IT-systems. It is commonly believed that physicians not using EHRs will be at a disadvantage if sued by patients and will risk loosing future malpractice law cases. Dr. Nelson therefore believes that this real threat facing American physicians is one factor that will be a driving force to make EHRs become the future common practice.

[29] http://www.cms.gov/EHRIncentivePrograms/

[30] *interview 101108 with Rachel Nelson, Senior Advisor and Acting Division Director, Office of the Chief Scientist at the Office of the National Coordinator*

The definition of meaningful use is a topic that has been discussed at length, and in July 2010 its definition was announced:[31]

- Use a computer or mobile device to make medication orders into the medical record of the patient.
- Implement drug-drug and drug-allergy interaction checks.
- Maintain up-to-date list of current and active diagnoses.
- Maintain active medication list.
- Maintain active medication allergy list.
- Record the following demographics: preferred language, gender, race, ethnicity and date of birth.
- Record and chart changes in: height, weight, blood pressure and BMI.
- Record smoking status for patients 13 years old or older.
- Report ambulatory clinical quality measures.
- Implement one clinical decision support rule relevant to a specialty or high clinical priority along with the ability to track compliance with that rule.
- Provide patients with an electronic copy of their health information upon request (including diagnostic test results, problem list, medication list and allergies) within four business days of the information being available.
- Provide clinical summaries for patients for each office visit.
- Capability to electronically exchange key clinical information among care providers and others authorized by the patient.
- Protect the created electronic health information through appropriate technical capabilities.
- Implement drug formulary checks.
- Incorporate clinical lab test results into EHR as structured data.
- Generate lists of patients with specific conditions in order to use for quality improvement, reduction of disparities, research or outreach.
- Send reminders to patients for preventive/follow-up care, depending on the preference of the patient.
- Identify patient-specific education resources using EHR technology and provide to patient.
- Perform medication reconciliation if a patient arrives from another setting of care or care provider.
- Provide a summary care record when a patient moves to another care setting or provider.
- Capability of submitting electronic data to immunization registries or information systems.
- Capability of submitting electronic syndromic surveillance data to public health agencies.

The main initiatives originating from the HITECH act at the ONC are the following[32]:

[31] *http://www.hhs.gov/news/press/2010pres/07/20100713a.html, https://www.cms.gov/EHRIncentivePrograms/Downloads/EP-MU-TOC-Core-and-MenuSet-Objectives.pdf*

[32] *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1487&parentname=CommunityPage&parentid=28&mode=2&in_hi_userid=11113&cached=true*

- **Beacon Health Information Technology Communities**[33]

This program gives funding to 17 selected communities in the United States that have already made advances in development of secure, private and accurate EHR systems. The communities were selected through an application process. The program will help the communities to strengthen their Health IT infrastructure in order to improve the quality of care and slow the growth of health care spending. The Beacon awardees will focus in quality, cost and population health.

- **State Health Information Exchange Cooperative Agreement Program**[34]

This grant program supports states, or entities formed by states, in establishing the capabilities of health information exchanges (HIEs) among providers of health care and hospitals.

- **Health IT Regional Extension Centers (RECs)**[35]

This program gives funding to 62 centers all over the country and enables health care practitioners to reach out to a local resource for technical assistance, guidance, and information on best practices. RECs are meant to address unique community requirements and to support and accelerate efforts to become meaningful users of electronic health records (EHRs). The RECs should help grow the emerging Health IT industry which is expected to support tens of thousands of jobs ranging from nurses and pharmacy technicians to IT technicians and trainers.

- **New Health IT Professionals**[36]

Many community colleges and research centers will receive funding to support training and development of more than 50,000 new Health IT professionals. All over the United States 70 community colleges are engaged in creating a six month training program for people with appropriate prior education and/or experience.

- **New Health IT Workforce Grants**

Three additional grant programs will support the training and development of the skilled workforce required to support broad adoption and use of Health IT. These programs are:

Curriculum Development Centers Program[37]: Grants to higher education institutions to support curriculum development to support Health IT.

---

33 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1805&parentname=CommunityPage&parentid=2&mode=2&cached=true*

34 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1488&parentname=CommunityPage&parentid=58&mode=2&in_hi_userid=11113&cached=true*

35 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1335&mode=2&cached=true*

36 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1804&parentname=CommunityPage&parentid=14&mode=2&in_hi_userid=11673&cached=true*

37 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1807&parentname=CommunityPage&parentid=13&mode=2&in_hi_userid=11673&cached=true*

Program of Assistance for University-Based Training[38]: Grants to quickly increase the availability of qualified individuals to serve in Health IT professional roles.

Competency Examination for Individuals Completing Non-Degree Training program[39]: Grants to higher education institutions to support their development of Health IT competency examinations.

- **Strategic Health IT Advanced Research Projects (SHARP)[40]**

SHARP projects will conduct focused research on solving current and future challenges that are barriers to adoption and meaningful use of Health IT within the areas of security of Health IT, patient-centered cognitive support, health care application and network platform architectures and secondary use of EHR data.

The examples above are a few of several programs originating from the HITECH act. There seems to be a risk of overwhelming and confusing the stakeholder and public with so many initiatives that to some extent are similar. To be more transparent, the HHS and ONC have created several web pages to inform stakeholders and the public about the programs and their progress. They recently opened http://www.hhs.gov/open/ to provide open access to data and information.

The HHS and ONC have also held several meetings with stakeholders and the public, informing them of initiatives and asking for comments. On December 14-15, 2010, for example, sessions were organized, including webcasts, providing an overview of ONCs programs, strategies and visions.[41] Furthermore, the public was invited to submit comments on personal health records, either via the web, e-mail, or during the Personal Health Record roundtable, December 3, 2010.[42]

2.1.6 PCAST report to the President on Health IT

In December 2010, the President´s Council of Advisors on Science and Technology (PCAST), issued the report "Realizing the full potential of health information technology to improve healthcare for Americans: the path forward".[43] The report made the conclusions that HHS efforts have laid a foundation for progress in the adoption of EHR but that there needs to be an accelerated progress towards exchange of health information. National decisions should be made soon to establish a "universal exchange language" to allow data to be shared across institutions in a safe manner. These required capabilities are technically feasible and the ONC should move rapidly to ensure their development. The Centers for Medicare and Medicaid Services should modernize its IT platform to make this possible.

---

38 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1808&parentname=CommunityPage&parentid=15&mode=2&in_hi_userid=11673&cached=true*

39 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1809&parentname=CommunityPage&parentid=16&mode=2&in_hi_userid=11673&cached=true*

40 *http://healthit.hhs.gov/portal/server.pt?open=512&objID=1806&parentname=CommunityPage&parentid=17&mode=2&in_hi_userid=11673&cached=true*

41 *http://healthit.hhs.gov/portal/server.pt?open=512&mode=2&objID=3334*

42 *http://www.e-healthcaremarketing.com/archives/5155*.

43 *http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf*

2.1.7 Nationwide Health Information Network (NHIN)

In order to provide a secure, nationwide, interoperable health information infrastructure that will connect providers, consumers, and others involved in supporting health and healthcare, the Nationwide Health Information Network (NHIN) is being developed within HHS.[44] The goal is that this infrastructure will enable health information to follow the consumer, be available for clinical decision making, and support appropriate use of healthcare information beyond direct patient care so as to improve health. The NHIN is planned to be a "network of networks", which will connect diverse entities that need to exchange health information in order to promote a more effective marketplace, greater competition, and increased choice through accessibility to accurate information on healthcare costs, quality, and outcomes. These entities could be state and regional health information exchanges (HIEs), integrated delivery systems, health plans that provide care, personally controlled health records, federal agencies, and other networks as well as the systems to which they, in turn, connect.

2.1.8 National Institute of Standards and Technology (NIST)

The ARRA law calls for ONC to collaborate with NIST, the National Institute of Standards and Technology[45], to encourage a more widespread adoption of interoperable health information technologies. The goal is to develop a program for the voluntary certification of health information technology that is in compliance with applicable certification criteria to meet defined meaningful use requirements. In collaboration with ONC, NIST is developing the necessary functional and conformance testing requirements, test cases, and test tools in support of the Health IT certification program.[46]

NIST has developed a Health IT standards and testing website jointly with vendors, implementers and organizations which will give information and access to methods to use when testing if a Health IT system meets the meaningful use requirements and standards.

2.1.9 Agency for Healthcare Research and Quality (AHRQ)

The Agency for Healthcare Research and Quality, AHRQ,[47] is an agency within the HHS with the mission to improve the quality, safety, efficiency and effectiveness of American health care. AHRQ has activities in Health IT with the goals of improving health care decision making and quality and safety of medication management as well as supporting patient-centered care.

AHRQ has invested $300 million in contracts and grants to promote access to and encourage the adoption of Health IT. The funds have been allocated to communities, hospitals, providers and health care systems in almost every state with the goals of helping clinicians to provide higher quality, safer health care; putting the patient at the center of health care; stimulating implementation of health care especially in rural and underserved areas; identifying successful approaches and barriers to the implementation of Health IT and evaluating costs and benefits of Health IT in order to make a business case.

---

[44] *http://www.hhs.gov/healthit/healthnetwork/background/*
[45] *http://www.nist.gov/index.html*
[46] *http://healthcare.nist.gov /*
[47] *http://healthit.ahrq.gov/portal/server.pt/community/about/562*

AHRQ supports research in[48]: Clinical Decisions Support, Computerized Disease Registries, Consumer Health IT Applications, Electronic Medical Record Systems, Electronic Prescribing, Health IT in Small and Rural Communities, Health Information Exchange and Telehealth.

2.1.10 The National Institutes of Health (NIH)

The National Institutes of Health (NIH)[49] supports medical research in the United States and elsewhere. NIH is via its international office, the Fogarty International Center for Advanced Study in the Health Sciences, engaged in research and activities regarding Mobile health. Mobile health, or mHealth, uses mobile technologies as tools and platforms for health research and healthcare delivery.[50]

2.1.11 The National Coordination Office for Networking and Information Technology Research and Development (NITRD)

The National Coordination Office for Networking and Information Technology Research and Development (NITRD),[51] is an organization decided upon by Congress in 1991, designed to be a mechanism for coordination of federal networking and IT research as well as development investments. Fourteen federal agencies are members of NITRD, and several other federal organizations participate in NITRD activities.

George O. Strawn and Mark A. Luker, NITRD President and vice President, respectively, described[52] that NITRD has working groups in many areas. One of them is a Health IT steering group that coordinates programs, budgets and policy recommendations for Health IT Research and Development (R&D). The group identifies and integrates requirements, establishes priorities, share program information and R&D activities, conducts joint program planning and develops joint strategies for Health IT R&D programs among the agencies participating in the steering group.

When asked if there was any activity in Health-IT on the federal level during the years between President Bush´s Executive Order in 2004 and ARRA in 2009, Dr. Strawn answered no, because there was no funding allocated. He believes that the way to make Health IT data interoperable is through the semantic web.

2.2 Other stakeholders

Not only are there a large number programs initiated, there are also many organizations and agencies involved. The most relevant are presented below:

---

48 *http://healthit.ahrq.gov/portal/server.pt/community/ahrq_national_resource_center_for_health_it/650*

49 *http://nih.gov/*

50 *http://www.fic.nih.gov/news/publications/global_health_matters/2010/1210_mhealth.htm*

51 *http://www.nitrd.gov/*

52 *interview with George O. Strawn and Mark A. Luker, National Coordination Office for Networking and Information Technology Research and Development (NITRD), President and vice President, respectively, 110104*

2.2.1 The Certification Commission for Health Information Technology (CCHIT)

The Certification Commission for Health Information Technology (CCHIT)[53] is an independent, nonprofit organization with the public mission of accelerating the adoption of robust, interoperable health information technology. The Commission has been certifying EHR technology since 2006.

2.2.2 Healthcare Information and Management Systems (HIMMS)

Healthcare Information and Management Systems (HIMSS),[54] is a non profit organization that has a mission to provide global leadership for the optimal use of Health IT and management systems for the betterment of healthcare. HIMSS and its related organizations have offices all over the United States, in Brussels, in Singapore and in Leipzig. HIMSS represents more than 30,000 individual members, mostly within health care, as well as governmental and non profit organizations. HIMSS has over 470 corporate members and more than 85 non profit organizations. HIMSS represents 50 chapters across the United States, Canada, and India. The chapters serve a valuable role in bringing healthcare system professionals together in a local forum. HIMSS also organizes meetings and conferences in order to discuss the issues of Health IT.

2.2.3 The Information Technology & Innovation Foundation (ITIF)

The fact that the United States uses a bottom-up approach, in which each HIE will develop its own solution first, followed by the issue of making the different solutions interoperable, is according to Daniel Castro,[55] senior analyst at the Information Technology & Innovation Foundation (ITIF), not a good approach to the problem. The country has, so far, been lacking national leadership, but he hopes that this will change now when the ONC has the funds required.

When asked in what areas he believes that Swedish know-how in Health IT could be utilized in the United States he answered that the two countries are similar in many ways, and that there should there be many possibilities for collaborations. Mr. Castro believes that knowledge in e-prescribing is a topic that Sweden should be able to share with the United States. When asked which states he would suggest that Sweden should look closer at, he recommends Indiana.

2.3 State activities

2.3.1 State Health Information Exchange Cooperative Agreement Program

Health information exchanges (HIEs),[56] have been created to provide the capability of moving clinical information among disparate health care information systems toward

[53] *http://www.cchit.org/*

[54] http://www.himss.org/ASP/aboutHimssHome.asp

[55] *Daniel Castro, senior analyst at the Information Technology & Innovation Foundation, ITIF, interview 100927*

[56] http://healthit.hhs.gov/portal/server.pt?open=512&objID=1488&mode=2

national interoperability. Their goal is to facilitate access to and retrieval of clinical data in order to provide safer, timely, efficient, effective, equitable patient-centered care. It will also assist in analysis of population health.

The ONC funds state HIE programs. Each state, territory and district has its own HIE, which builds on existing efforts to advance relevant regional and state-level initiatives.

In an interview with Dr. Rachel Nelson, Senior Advisor and Acting Division Director, Office of the Chief Scientist at the ONC,[57] she explained that the states may use the HIE funding for policy development, hiring staff to understand requirements and to interact with neighbouring states. Each state was required to apply for funding, although some of them may have done so reluctantly. ONC has interoperability standards for the systems and one of the conditions to be entitled to a grant was that the states committed to a system that use the standards in the regulation so that data can be moved between states. They do not envision one single location where the data is stored, but it should be reachable everywhere. The aim is interoperability for the whole country, so that an EHR can be reached all over the United States. The ONC has been discussing a joint project with the European Union (EU) in which EHRs could be transferred between the United States and Europe, to be used if you are a tourist in need of medical care. The United States and EU are working on a non-binding memorandum of understanding (MoU) in this area.

Since the United States does not issue personal identification numbers, one of the challenges is how to work without these to identify patients securely, according to Dr. Nelson. Furthermore, social security numbers may not be used as identifiers since they are reissued after an individual´s death. In the pilots the ONC has performed they used probabilistic matching of several parameters, for example, drivers licence number, name, birthday, social security number, place of birth etc, in order to identify patients. Dr. Nelson says that it will be interesting to see what solutions the different providers of Health IT systems will innovate.

Dr. Nelson does not believe that the biggest challenge is to get nationwide interoperable EHRs to work - the biggest challenge will be to get people, including physicians as well as other professionals, to believe in and use the systems. In addition the trust of patients must be obtained. When asked which states she would suggest that Sweden should look closer at to learn more about its Helath-IT solutions, she recommended Rhode Island.

2.3.2 Rhode Island

Rhode Island Quality Institute (RIQI),[58] is the only organization nationally that has won all three of the major ARRA awards (Beacon, Regional Extension Centers and Health Information Exchanges). The state started discussing the issue of health care and IT already in 2001, and it is the first state to electronically link physicians to most of its pharmacies.

The Rhode Island Regional Extension Center (REC) helps Rhode Island providers of health care with subsidies, tools, services, and guidance to implement or optimize EHRs.

---

[57] *interview with Rachel Nelson, Senior Advisor and Acting Division Director, Office of the Chief Scientist at the ONC, 101117*

[58] http://www.riqi.org/matriarch/default.asp

The Rhode Island Health Information Exchange (HIE) has formed a consortium of partners, users and health care providers. They test different scenarios through partners that volunteer their data and systems, in order to determine the most effective way to achieve transfer of information electronically. The goal is to develop a system that consumers of health care may use in a similar way as they manage finances or book flights on the web, in order to empower the patient. They work with a consumer advisory and legal and policy committees to develop standards and guidelines that define how patients will control access to their health information. This way they make sure that the consumer perspective is represented at every level and step of the development of the HIE.

The state's HIE network, Currentcare, allows the interchange of important health data between physicians.[59]

The fact that Rhode Island is a small state, the geographically smallest in the United States and with a little more than one million inhabitants, is a contributing factor to its advances in Health IT. However, strong leadership and involvement by many parts of the society might be the most important factor when investigating the reason for the success of Rhode Island. Already in 2001 the then Attorney General invited many stakeholders to discuss the health care system in the state and this discussion has led to an advanced Health IT system. [60] It would be of interest to study the systems developed in Rhode Island more closely.

2.3.3 Indiana

The Indiana Health Information Exchange (IHIE),[61] is a non-profit organization formed by institutes, hospitals, local and state health departments and health care and community organizations. It connects over 80 hospitals, long-term care facilities and other healthcare providers in Indiana. It is the largest HIE in the country and serves more than ten million patients and over 19,000 physicians. It was formed 2004 and has also received a Beacon community award by the ONC.

IHIE has come a long way in order to provide information in a secure, standardized and electronic format, enabling information to follow the patient and its solutions should be of interest for Sweden to study further.

The organization also assembles this health data for providers to help them achieve improved health outcomes for their patients, with a specific focus on cancer screenings, diabetes care, heart health, asthma care, well-child visits and other care interventions.[62]

[59] *http://www.riqi.org/matriarch/default.asp*

[60] *http://www.riqi.org/matriarch/MultiPiecePage.asp_Q_PageID_E_3_A_PageName_E_InsideRIQI*

[61] *http://www.ihie.com/*

[62] *http://www.ihie.com/*

3 Examples of existing Health IT systems

3.1 The Veterans Health Administration (VHA)

The US Department of Veterans Affairs provides patient care and federal benefits to military veterans. The patient care is performed through the Veterans Health Administration (VHA). This system resembles Swedish health care in many ways. The major differences are that most patients are older and mostly male (no children, 20 % female), sicker (war veterans) and poorer (if one makes more than $26 000/year one is ineligible for care) than the average demographic population of a country. The population is therefore not representative in relation to a national population structure. However, the similarities with Sweden are that the number of patients at VHA is approximately seven million and are spread all over the country. Patients will also often stay in the VHA system for life after being enrolled, instead of transferring to Medicare when reaching retirement age.

VHA has many hospitals, most of them in the vicinity of a research university where some VHA physicians are faculty as well. VHA contracts with local health care clinics in rural areas where there are no VHA hospitals. Since veterans receive large discounts on medicine, there are specific VHA pharmacies. Dr. Neil C Evans, Head of Informatics & Co-Chief of Primary Care, described[63] how VHA had a very bad reputation some years ago, but that it now outperforms the private sector in almost every section of care. VHA monitors satisfaction of their patients which has improved dramatically the past years. He attributes this enormous change in quality of care to Health IT.

Dr. Evans explained that by 1999 100% of VHA activities were totally digitized with electronic health records (EHRs), subscription of medicines etc, all connected to the same system. The system has improved ever since. Dr. Evans explained and demonstrated some of its capabilities:

- Administrating medication using bar codes and wrist codes for patients.
- Alerting the physician if a patient does not go to the VHA pharmacy to obtain his/her prescribed medication. This is possible since there are specific VHA pharmacies connected to the Health IT system.
- Providing only the choice of the types and amounts of a medication that is appropriate for that specific patient, depending on for example age, size and other medications that are taken, when prescribing medication.
- Enabling a patient to perform home measurement and send the results over the telephone. A nurse follows up and reacts if there is a problem.
- Enabling a patient to correspond via e-mail to his/her caregiver, and summoning the patient via e-mail to tests and check-ups.
- Displaying every test and its results in the EHR, independently on which specialist has ordered it.

[63] *Neil C Evans, Head of Informatics & Co-Chief of Primary Care, Veterans Health Administration, interview 100930*

- Alerting the physician if a patient needs some kind of test performed and if it has not been done.
- Displaying graphs of many parameters, such as blood pressure, weight, cholesterol level, in order to see trends and if certain treatments influence the parameters.
- Enabling a physician to compare his patients with those of other physicians, to see which treatment works etc. The physician may also monitor how he/she is performing compared to other physicians, if check-ups are not on time, prescription drugs not obtained etc. This competitive approach is a way to keep performance levels high, according to Dr. Evans.
- Giving patients access to their EHRs with a simple click on the VHA website, in order feel ownership of and be more engaged in their own health.

According to Dr. Evans, the VHA Health IT system is looked upon as being the start of a common IT solution for the country and collaborations with the health care system of the Department of Defense and others are under way. It seems obvious that this system should be studied in more detail by Swedish stakeholders.

3.2 The Department of Defense (DoD)

The Department of Defense (DoD), provides health care to active military personnel through the military health system (MHS). The Health IT system at MHS will not be described herein, but it should be noted that MHS has developed many applications within Medical Mission Support, i.e. support for deployed military medical personnel. One of these applications is called Theater Medical Information Program,[64] where medical personnel on the battle-field have access to clinical care documentation of an injured soldier as well as being able to track medical supplies and equipment. The goal is to make these systems portable in order to be accessible on the battle-field.

3.3 Kaiser Permanente (KP)

A health maintenance organization (HMO) in the United States is a type of managed care organization that provides a form of health care coverage that is fulfilled through hospitals, doctors, and other providers with which the HMO has a contract. Kaiser Permanente (KP)[65] is one of the United States´ largest not-for-profit HMOs, serving more than 8.6 million members. Most of these (6.5 million) live in California, Oregon or Washington, the rest are scattered in a few other states. The organization comprises Kaiser Foundation Health Plan which is the insurance part of the organization, Kaiser Foundation with subsidiaries including its hospitals, and the Permanente Medical Groups which includes KPs medical staff. KP has 35 hospitals, 454 medical offices, 15 129 physicians and over 164 000 employees. HMOs seem more prone to doing work in preventive care than regular insurance companies, which do not appear to see any financial benefit of such activities. KP runs many preventive care activities.[66]

Mr. Fish Brown, the Director of Federal Relations at KP, explains[67] that most insurance companies are positive to the health care reform. There are, however, huge challenges of

[64] *http://www.health.mil/About_MHS/Health_Care_in_the_MHS/Innovations.aspx*
[65] *https://members.kaiserpermanente.org/kpweb/aboutus.do*
[66] *https://www.kaiserpermanente.org/*
[67] *Fish Brown, Director of Federal Relations at Kaiser Permanente, interview 101116*

interoperability of all the different Health IT systems that are now being developed around the country. He wishes that the Government would provide more guidelines to enable interoperability. KP is discussing this issue with the Veterans Health administration, since they share several patients, i e patients belonging to both organizations, and it would be of great value to be able to share EHRs. KP is also talking to the ONC about standards etc.

Mr. Brown describes how KP in 2004 decided to invest billions of dollars into Health IT. The system is called HealthConnect and in March 2010 it was implemented in all of KPs hospitals and medical offices. KP HealthConnect coordinates patient care between the physician's office, the hospital, radiology, the laboratory, the pharmacy, etc. It includes bedside documentation, clinical decision support and bar-coding for medication administration. It creates "fora" between physicians, so that they may discuss treatments and best practices with each other. The different medical professionals have access only to the parts of the EHRs that are relevant to them, and the persons working in the billing department are not able to see any of the medical information. The system is created so that future information sharing may be incorporated.

Anna-Lisa Silvestre[68] explains that all KP members have access to portions of their KP HealthConnect record via the web, including the ability to securely e-mail their doctors and view most lab test results online. In 2010, members exchanged over ten million secure e-mails with their doctors and securely viewed over 25 million lab test results online. Ms Silvestre describes how family members may become proxy members of a patient in order to e-mail the relative´s physicians and take part of laboratory results and other health related information.

KP HealthConnect is the largest private deployment of an electronic health record in the world, according to their website[69]. With the exception of a few government-deployed systems (the Departments of Defense and Veterans Health Administration), there are few models for a health care information technology (IT) project this broad in scope.

KP resembles Swedish health care in many ways. It has patients of all ages and both genders that are somewhat geographically spread-out and it takes responsibility for all of the patients´ care, including preventive care. It should be one of the organizations to study more closely in the future.

[68] *Anna-Lisa Silvestre, vice President Internet Services Group, Kaiser Permanente. Presentation at OECD-NSF Workshop: Building a Smarter Health and Wellness Future, 15-16 February 2011 http://www.oecd.org/document/4/0,3746,en_2649_34223_46766340_1_1_1_1,00.html?rssChId=34223*

[69] *http://xnet.kp.org/newscenter/aboutkp/healthconnect/index.html*

4 Medical Innovation

In conjunction with all the funds put into health care and Health IT in the US today, it is an excellent time to be an innovator within these areas, according to Aneesh Chopra, U.S. Chief Technology Officer, Assistant to the President and Associate Director for Technology, Office of Science & Technology Policy at the White House. He points out that especially in the fields of data mining and analysis, care integration tools and decision support are innovations needed.[70]

An example of such innovation is Galileo Analytics, a newly started company in the Maryland suburbs of Washington DC. Galileo has developed a suite of health data analytics and visualization tools that significantly increase the speed and flexibility for probing large sets of longitudinal clinical data. The Galileo tools can be applied to any clinical database, but Galileo founders Simon Fitall and Anna McCollister-Slipp are focusing on the provision of de-identified data from aggregated sources of EHRs. The founders explained[71] that Galileo's proprietary tools can probe vast databases of complex information within minutes to hours, providing researchers real-time access to richly detailed clinical data and enabling the visualization of clusters of related elements within that data.

[70] *Presentation at the meeting "Medical Innovation at the Crossroads: Choosing the Path Ahead". January 12, 2011.*
[71] *Simon Fitall and Anna McCollister-Slipp, Galileo founders, interview101206*

5 Implications for Sweden and for future studies

All federal guidelines for Health IT in the US have the patient in focus. The Health IT solutions already in use and being implemented seem to follow this direction. Sweden should follow the numerous initiatives currently initiated and running in the United States, particularly the development of Electronic Health Records (EHRs). This is an area where Sweden might be more advanced than the United States in many aspects. There should be possibilities for Swedish companies and other stakeholders to partake in the large investments being made.

The Health IT solutions at Kaiser Permanente and the Veterans Health Administration are applicable to Sweden since they support approximately the same number of persons that Sweden has inhabitants. However, the Veterans Health Administration has patients all over the country, while Kaiser Permanente is geographically limited. Kaiser Permanente has patients of all ages, while Veterans Health Administration covers no children. It would be of great interest for Sweden to study the Health IT solutions in these two organizations.

Many activities on the state level are in progress in the United States. Swedish stakeholders should follow the development of the Health IT systems in several different states, for example in Rhode Island and Indiana.

It could be of interest to Sweden, where nurses traditionally have a strong position, that the role of nurses, their responsibilities and education are predicted to change significantly due to the increased need for care that the health care reform will bring. One could also expect that there will be a shortage of nurses in the United States due to these changes. A shortage of Health IT professionals in the United States in the future due to the planned increased usage of Health IT is anticipated, thus the drive by universities and colleges to support training and development of such professionals. Could Health IT professionals and nurses become a Swedish export? Feasibility studies should be done in this area.

Swedish companies should be informed of the many possibilities of medical innovation in the United States, not only in Health IT in general, but in e-prescription, data mining and analysis, care integration tools and decision support, specifically. The high level of funding currently being invested into Health IT in the United States opens up many possibilities for a variety of stakeholders, including Swedish.

6 References (interviews and publications)

Brown, Fish, Director of Federal Relations at Kaiser Permanente, interview 101116

Castro, Daniel, "Explaining International IT Application Leadership: Health IT", ITIF, September 2009, http://www.itif.org/files/2009-leadership-healthit.pdf

Castro, Daniel, senior analyst at the Information Technology & Innovation Foundation, ITIF, interview 100927

Evans, Neil C, Head of Informatics & Co-Chief of Primary Care, Veterans Health Administration, interview 100930

Executive Office of the President, the President´s Council of Advisors on Science and Technology (PCAST), "Report to the President: Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: the Path Forward", December 2010, http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf

Falkenhall, Björn and Zackrisson, Marcus, "Sjukvårdssektorns tillväxtmöjligheter" ITPS A2007:012

Fitall, Simon and McCollister-Slipp, Anna, Galileo founders, interview 101206

Institute of Medicine, Board on Health Care Services "Preventing Medication Errors", July 2006, National Academies Press, Washington, DC

http://www.iom.edu/Reports/2006/Preventing-Medication-Errors-Quality-Chasm-Series.aspx

Johannesson, Christina and Winge, Monica, "Hälsa genom e, e-hälsorapporten 2010", VINNOVA, mars 2011.

Nelson, Rachel, Senior Advisor and Acting Division Director, Office of the Chief Scientist at the Office of the National Coordinator, interview 101108

Strawn, George O. and Luker, Mark A., National Coordination Office for Networking and Information Technology Research and Development (NITRD), President and vice President, respectively, interview 110104

West, Darrell, "Enabling Personalized Medicine through Health Information Technology", Center for Technology Innovation at Brookings, January 28, 2011 http://www.brookings.edu/papers/2011/0128_personalized_medicine_west.aspx

www.tillvaxtanalys.se

Tillväxtanalys, myndigheten för tillväxtpolitiska utvärderingar och analyser, är en gränsöverskridande organisation med 60 anställda. Huvudkontoret ligger i Östersund och vi har verksamhet i Stockholm, Brasilia, Bryssel, New Delhi, Peking, Tokyo och Washington.

Tillväxtanalys ansvarar för tillväxtpolitiska utvärderingar och analyser och därigenom medverkar vi till:

- stärkt svensk konkurrenskraft och skapande av förutsättningar för fler jobb i fler och växande företag
- utvecklingskraft i alla delar av landet med stärkt lokal och regional konkurrenskraft, hållbar tillväxt och hållbar regional utveckling

Utgångspunkten är att forma en politik där tillväxt och hållbar utveckling går hand i hand. Huvuduppdraget preciseras i instruktionen och i regleringsbrevet. Där framgår bland annat att myndigheten ska:

- arbeta med omvärldsbevakning och policyspaning och sprida kunskap om trender och tillväxtpolitik
- genomföra analyser och utvärderingar som bidrar till att riva tillväxthinder
- göra systemutvärderingar som underlättar prioritering och effektivisering av tillväxtpolitikens inriktning och utformning
- svara för produktion, utveckling och spridning av officiell statistik, fakta från databaser och tillgänglighetsanalyser

Om Working paper/PM-serien: Exempel på publikationer i serien är metodresonemang, delrapporter och underlagsrapporter.

Övriga serier:
Rapportserien – Tillväxtanalys huvudsakliga kanal för publikationer.
Statistikserien – löpande statistikproduktion.
Svar Direkt – uppdrag som ska redovisas med kort varsel.

Tillväxtanalys Studentplan 3, 831 40 Östersund
Telefon: 010 447 44 00 | info@tillvaxtanalys.se | www.tillvaxtanalys.se